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Exploring family involvement in cancer consultations and decision-making

THE UNIVERSITY OF SYDNEY

A thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

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Certification of originality

I hereby certify that the work submitted in this thesis is the result of original research and has not been submitted for a higher degree to any other university or institution.

I also certify that this thesis has been written by me. Any assistance I have received in my research work and the preparation of the thesis has been acknowledged.

Signed:

Rebekah C Laidsaar-Powell
Publications, presentations, and awards relating to this thesis

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Symposia


Presentations


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List of abbreviations

AIHW: Australian Institute for Health and Welfare
BCNA: Breast Cancer Network Australia
CALD: Culturally and Linguistically Diverse
CCAT-PF: Cancer Communication Assessment Tool for Patients and Families
CDT: Classical Decision Theory
DM: Decision-Making
FM: Family Member
GEE: Generalised estimated equations
GP: General Practitioner
HP: Health Professional
IPA: Interpretive Phenomenological Analysis
NBCC & NCII: National Breast Cancer Centre and National Cancer Control Initiative
NCI: National Cancer Institute
NHMRC: National Health and Medical Research Council
NHS: National Health Service
NSW: New South Wales
OR: Odds Ratio
QoL: Quality of Life
RIAS: Rotor Interaction Analysis System
SPSS: Statistical Package for the Social Sciences
TRIO: Triadic Oncology
UK: United Kingdom
US: United States
VIC: Victoria
WHO: World Health Organisation
Abstract

Introduction

Family members often attend cancer consultations with patients and may provide emotional support, contribute information, and may be involved in treatment decision-making both inside and outside the cancer consultation. However, research into medical communication and decision-making has focused almost exclusively on the physician-patient dyad and there is currently limited extant research, theory, and practical strategies which attempt to understand and accommodate family involvement in consultations and decisions. This thesis aimed to systematically review the existing evidence base, and to explore oncology health professional, patient, and family attitudes towards, experiences of, and actual behaviours in triadic (physician-patient-family) cancer consultations. On the basis of this work, this thesis aimed to propose an initial conceptual framework explaining family involvement in decision-making and draft practical consultation strategies for physicians.

Method

A systematic review of 52 triadic consultation communication/decision-making papers was conducted (Chapter 2). Interviews with health professionals (10 oncology nurses, 11 oncologists) examined their attitudes and experiences toward family involvement in consultations and decisions (Chapter 3). Interviews with 30 patients and 34 family members aimed to examine attitudes and experiences of family involvement in cancer consultations and decisions (Chapter 4). A new triadic interaction analysis coding system capturing the behaviours of family members and family-relevant behaviours of patients and physicians was developed and applied to the transcripts of 72 audiotaped initial cancer consultations (Chapter 5). On the basis of the above, an initial conceptual framework of triadic decision-making was developed and iteratively reviewed by the candidate and supervisors (Chapter 6). Finally, strategies proposed in previous publications and throughout this thesis were synthesised and reviewed to form draft strategies for oncology clinicians (Chapter 7).

Results

Systematic review (Chapter 2) results highlighted that the majority of reviewed studies provided descriptive evidence about the characteristics of triadic consultations and accompanied patients or focused qualitatively on preferences for family involvement. Few studies examined deeper concepts such as the nature and impact of family on decision-making, health professional attitudes and practices towards family, family behaviours within actual consultations, and factors influencing the level of family involvement in consultations and decisions.
Qualitative study (Chapter 3; Chapter 4) results highlighted that health professionals, patients, and family members typically held positive attitudes towards family involvement, and highlighted an array of family behaviours and roles both inside (e.g. information gathering and provision, emotional support, patient advocacy) and outside of the consultation (e.g. pre-consultation preparation support, family liaison, decision-making sounding board). Whilst appreciating family involvement and noting the impact of cancer on the family, most health professionals, patients, and family members believed the patient should remain the priority within the consultation and retain authority over decisions. Interviews and consultation analyses (Chapter 5) highlighted that family involvement in decision-making appears to rest on a spectrum from passive to dominant and is dynamic, varying across decision-making stages, across the illness experience, and between different triads. A number of factors may impact on the extent of family involvement such as patient and family demographics, clinical characteristics, and culture. In light of these results, an initial conceptual framework was proposed (Chapter 6), using a triangle to graphically represent the complex triadic dynamics.

Participants in the qualitative studies also reported challenges such as conflicting patient-family treatment wishes, role confusion, and physician blocking behaviours towards the family. Some family members reported unmet information and supportive care needs. Whilst health professionals stated that they utilise many strategies to manage family involvement, consultation analyses revealed that health professionals regularly interrupted family members, rarely initiated interaction with them or provided support, and never clarified patient or family involvement preferences. Given these results, practical strategies for health professionals to prepare for family involvement, establish and negotiate family involvement, facilitate family inclusion and support, and manage the common triadic consultation challenges were proposed (Chapter 7).

**Conclusion**

This thesis improves our understanding of patient, family, and health professional experiences of, and actual behaviours within, cancer consultations involving family. It highlights the dynamic and multifaceted nature of family involvement in decision-making and raises a number of conceptual, ethical, legal, practical, and systemic issues regarding the accommodation of family in consultations and decisions. Continued iterative revision and evaluation of the proposed conceptual framework and consultation strategies will follow completion of this thesis.
Chapter 1:
Introduction
1.1 The impact of cancer on patients and family members

1.1.1 What is cancer?

Cancer is a diverse group of more than 100 different but related diseases. Cancer occurs when some of the body’s cells become abnormal and multiply out of control. These cells may invade and damage the surrounding tissues, and in some cases may break away from the primary site and metastasise in other parts of the body. Whilst some cancers are non-invasive (benign) and rarely life threatening, other cancers are invasive (malignant) and if the cancer is not controlled it can result in significant illness burden and death (AIHW, 2014).

1.1.2 Rates of cancer in Australia

In Australia, cancer is a major cause of illness, and has a significant impact on individuals, their family members, and the health-care system. Despite an overall decline in cancer mortality and an increase in cancer survival, it remains the leading cause of both disease burden and death in Australia, and the incidence of cancer is rising. Each year over 120,000 new cases of cancer are diagnosed, with this number expected to rise to 150,000 in 2020 (AIHW, 2014). One in two Australian men and one in three Australian women will be diagnosed with cancer by the age of 85. Cancer accounts for more than 43,000 deaths annually (AIHW, 2014). Despite it being the leading cause of death, improvements in early detection and treatments have led to an increase in the overall 5-year survival rate among Australians diagnosed with cancer from 47% in 1982-1987 to 66% in 2006-2010 (AIHW, 2014). More Australian households have a family member who has been diagnosed with cancer than ever before. Indeed, prevalence data suggests that there are almost 800,000 people in Australia who have been previously diagnosed with cancer (Cancer Australia, 2014). These rates, proportionate to population size, are comparable to other Western nations such as the UK (Office For National Statistics, 2012), US (U.S. Cancer Statistics Working Group, 2014), and Canada (Statistics Canada, 2012). Cancer is increasingly being viewed as a chronic disease, requiring long term management and care (Cancer Council Australia and Clinical Oncological Society of Australia, 2010).

The most common cancers diagnosed in Australia in 2012 (excluding non-melanoma skin cancer) were prostate cancer, followed by colorectal cancer, breast cancer, melanoma of the skin, and lung cancer. The cancers causing most deaths were lung cancer, followed by colorectal cancer, prostate cancer, breast cancer, and pancreatic cancer (AIHW, 2014).
Cancer is an international health problem, with current World Health Organisation (WHO) figures highlighting that worldwide approximately 14 million new cases of cancer are diagnosed each year, with 8.2 million cancer related deaths in 2012. The number of new cases worldwide is expected to rise by 70% over the next two decades (World Health Organization, 2014).

1.1.3 The clinical course of cancer

The severity and trajectory of cancer is widely variable and determined by the type of cancer and stage of the disease (see Figure 1.1). Some individuals diagnosed with early-stage cancers may experience relatively low-moderate levels of disruption and impairment. These patients will likely experience one episode of treatment for cancer (albeit possibly multi-modal) leading to rehabilitation and long-term survival. For others, such as those diagnosed with late-stage or highly invasive cancers, greater levels of distress, disruption, and demands may be placed on the patient and their family. For these patients, the clinical course may be short, moving rapidly from diagnosis to palliative care and death. Alternatively, the clinical course may be a long and exhausting experience, with individuals undergoing repeated episodes of recurrence and treatment (Veach, 2002).

Cancer treatments vary according to the type and stage of the cancer; the main treatments include surgery, chemotherapy, radiation therapy, targeted cancer therapies and/or hormone therapy. A range of side effects may occur with each of these treatments (U.S. Cancer Statistics Working Group, 2014). Unique physical and psychosocial difficulties may occur for patients and their family members during each phase of the disease and/or specific treatments (Veach, 2002).

Figure 1.1: Nature of cancer trajectory (Veach, 2002)
1.1.4 The impact of cancer on patients

Cancer patients may experience physical, psychological, social, and practical concerns as a result of their illness. Some physical concerns experienced by cancer patients include pain, nausea, vomiting, fatigue, bowel and urinary problems, impaired sexual function, nutritional deficiencies, respiratory difficulties, and reduced overall wellbeing (National Breast Cancer Centre and National Cancer Control Initiative, 2003). Some cancer treatments, such as surgery, may result in changes to the body, such as loss of a breast following mastectomy, a colostomy after removal of the bowel, or lymphedema (swelling usually in the arms or legs) after the removal of affected lymph nodes (U.S. Cancer Statistics Working Group, 2014). Additionally, altered libido and sexual function may be a consequence of cancer treatment (Schover, 2005).

Apart from physical consequences, cancer patients may also experience reduced psychological wellbeing. Although negative emotional reactions to the cancer experience are almost universal, substantial proportions of patients will experience clinically significant levels of psychological distress at some stage in their cancer journey. A study of over 10,000 cancer patients with varying disease characteristics found that, across cancer types, 42% of patients had clinical or subclinical levels of anxiety and 29% of patients had clinical or subclinical levels of depression. Levels of distress varied according to cancer type, point within the cancer trajectory, age, and gender (Linden, Vodermaier, MacKenzie, & Greig, 2012). Cancer patients may have a number of unmet needs throughout their illness experience. Sanson-Fisher et al. (2000) found that the greatest unmet needs for cancer patients were psychological in nature, including fears about cancer spread and concerns about the worries of those close to the patient. Certain subgroups of patients reported greater unmet needs, including patients not in remission, younger patients, and female patients.

Whilst distress is common during the more acute stages of the cancer trajectory, psychological concerns may persist into the survivorship phase for some patients. Common emotional and psychological concerns include changes in self-concept and body image and fear of cancer recurrence (Stanton, 2006). Some patients may also experience reduced cognitive functioning, such as problems with memory and concentration (Boykoff, Moieni, & Subramanian, 2009).

Overall, cancer patients and survivors appear to have a lower quality of life (QoL) when compared to the general population. For example, L. Jansen et al. (2011) found that some colorectal cancer patients experienced restrictions in domains such as, social, emotional, and cognitive and role functioning, and specific health problems like bowel dysfunction, fatigue, and insomnia. Compared
to healthy controls, more colorectal cancer survivors experienced clinically relevant detriments in QoL, even 10 years after diagnosis.

1.1.5 The impact of cancer on family members

Cancer places a significant burden not only on the patient, but also on those individuals around the patient, most notably, the patient’s family. This thesis adopts the Institute for Patient and Family Centred Care’s broad definition of family which acknowledges family as two or more persons who are related in any way—biologically (e.g. parents, siblings, children), legally (e.g. spouses, de facto partners, adoptive families), or emotionally (e.g. friends, neighbours). The Institute for Patient and Family Centred Care notes that patients and families define their families (Johnson, Abraham, & Shelton, 2009).

From diagnosis, patients usually turn to their family for support. Family members often accompany patients to cancer consultations, with studies highlighting that between 64-86% of cancer consultations include a family member (Eggly et al., 2006; Street & Gordon, 2008). During these consultations, family members may provide emotional, practical, and informational support, act as a patient advocate, and may be involved in the medical decision-making process (Ellingson, 2002).

Many family members provide physical, informational, and/or emotional support to the patient inside and/or outside of consultations, and are therefore classified as informal caregivers (Franks & Stephens, 1992; Laizner, Yost, Barg, & McCorkle, 1993). Shorter hospital stays and greater rates of survival have shifted the care of cancer patients to the home, and consequently family members have become the “central plank of service provision” (Allen, 2000) (p. 150). The role of family members is multi-faceted and may include assisting the patient with medical tasks (e.g. dressing wounds, taking medications) and daily living activities (e.g. hygiene, dressing), performing practical tasks (e.g. shopping, cleaning, cooking, transport), and may also include financial assistance. In addition, family members usually provide significant emotional support to the patient (Franks & Stephens, 1992; Laizner et al., 1993).

Family members may be expected to undertake all of these roles whilst remaining strong and emotionally centred. However they may feel unprepared and overwhelmed by their new and sometimes unexpected roles as caregivers, have inadequate knowledge, and may receive little guidance and support from the oncology team (Burridge, Winch, & Clavarino, 2007). Family caregivers often neglect their own health care needs in order to assist their family member (Jepson,
McCorkle, Adler, Nuamah, & Lusk, 1999; Schulz & Beach, 1999). This can result in deterioration of their mental and physical health and a decline in their quality of life, while reducing their capacity to support the patient. Indeed, illness and death in family caregivers occurs at a significantly higher rate than in the general population. The physical impact of caring can include high blood pressure, tiredness, stress, burnout and physical injury as well as poorer overall health compared to the general population, and reduced life expectancy (Wilkinson, 2010). A population-based cohort study found that caregiver strain increased mortality risk by 63% within 5 years (Schulz & Beach, 1999).

Apart from the impact on physical health, family members of cancer patients can also experience reduced psychological wellbeing, marked by elevated rates of anxiety, depression and distress and poor quality of life (Girgis, Johnson, Aoun, & Currow, 2006). Meta-analyses have shown that levels of anxiety and depression in family caregivers are equal to, or even greater than those of the patient (Hodges, Humphris, & Macfarlane, 2005). Up to 62% of family caregivers of advanced cancer patients have been found to experience distress or depressive symptoms at a level suggesting clinical depression (Dumont et al., 2006). Depressive symptoms are particularly prevalent among younger family caregivers, spouses of the patient, and family caregivers who blame the patient for the cancer (Siminoff, Wilson-Genderson, & Baker, 2010). Apart from the threatened loss of a family member, and the strain of providing physical and emotional support, reduced opportunities for social and leisure activities and decreased employment opportunities and income can also affect family wellbeing (Girgis et al., 2006). Family caregivers also tend to have greater unmet psychological needs than patients, reflecting their generally overlooked and under-supported position within the medical system (Soothill et al., 2001). Specifically, Sklenarova et al. (2015) found that family caregivers were significantly more distressed and anxious than patients either in active treatment or follow-up, and that 43.6% of family caregivers reported ten or more needs on the Supportive Care Needs Survey for Partners and Caregivers that were unmet. Some of the most common unmet needs were addressing fears about the patient’s physical or mental deterioration, managing their own fear of cancer recurrence, working through feelings about death and dying, and accessing information about treatments. Additionally a review by McCarthy (2011) identified that family members of cancer patients have a number of information needs (e.g. prognosis, cancer treatments, sexuality, pain management, inheritance of cancer) and often seek this information from health professionals when accompanying the patient to consultations. However, several studies in McCarthy’s (2011) review reported negative family member experiences in trying to access information such as feeling ignored, disrespected, and receiving inadequate or conflicting
information and explanations from health professionals.

More Australians than ever before are living with a diagnosis of cancer, and thus increasing numbers of family members are assuming the often demanding caregiving and supportive role. Given the difficulties family members can face, and the physical and psychological toll caring for a patient can take, research that attempts to understand and subsequently improve the experiences of family members of cancer patients is vital (Olson, 2009).

1.2 Communication and decision-making in the cancer setting

1.2.1 Medical consultations and communication

Despite the impact of cancer on the family, there is limited acknowledgement of, and support for, family members within medical consultations. Medical consultations are an important component of the overall health care delivery system, particularly within the cancer context, as they are a time for the physician, patient (and potentially family) to communicate about symptoms, diagnoses, and treatments. It is an opportunity for information to be obtained, questions to be asked, concerns to be communicated, skills to be learned, and management strategies to be shared. Consultations are a time to build trusting relationships between patients, physicians (and family members) and discuss psychosocial issues, such as the emotional impact of a life threatening illness and dealing with uncertainty whilst maintaining hope (Epstein & Street, 2007). Effective communication is crucial to the success of this interaction (Taylor, 2009). A large amount of research attention has been devoted to describing what occurs during medical consultations, and consequently to the development of models to describe what should occur in a consultation (i.e. aspirational models) to optimise patient outcomes. However, medical communication theory and research published to date have almost exclusively had a dyadic (physician-patient) focus, which represents an incomplete understanding of the modern medical encounter, given that family members are regularly present and actively involved in these interactions (e.g. Eggly et al., 2006; Ellingson, 2002; Street & Gordon, 2008).

Currently, the most prominent and endorsed approach to medical care and communication is patient-centred care. Over the past few decades, patient-centred care has been increasingly advocated in medicine, replacing a paternalistic approach to medical care where the physician assumed a position of authority (Taylor, 2009). Epstein et al. (2005) suggested that the term patient centredness describes a moral philosophy of core values such as: i) considering patients’ needs, perspectives, and experiences; ii) offering patients opportunities to participate in their care;
and iii) enhancing partnership and understanding between the patient and physician. The patient-centred approach is widely accepted as the preferred or 'gold standard' approach to medical care and consultations (Kramer et al., 2014). Whilst family members have been highlighted as an important part of the patient-centred framework among seminal papers (e.g. Gerteis, 1993) and some recent publications have specified that patient-centred care involves the accommodation and engagement of the family (e.g. Australian Commission on Safety and Quality in Health Care, 2011), the vast majority of studies examining patient-centred care focus on the dyadic physician-patient relationship (Kitson, Marshall, Bassett, & Zeitz, 2013).

Given the involvement of family in the cancer process and the impact it can have on them, some researchers, such as Johnson et al. (2009), have proposed an approach called 'person- (or patient) and family-centred care'. Within this approach, patients and families are recognised, supported and encouraged as essential members of the health care team. The patient's family members are considered to be active partners in care, rather than 'visitors' in the healthcare setting. Partnerships with families within medical care are considered to be essential because for the patient, the family is the constant link across different settings (Johnson et al., 2009). However, uptake of this approach has been limited and the dyadic physician-patient relationship remains the focus of most medical communication research and interventions.

1.2.2 Medical decision-making in the cancer context

A particularly important component of many cancer consultations is medical decision-making. Making (and living with the outcomes of) decisions about tests, medications, treatments, or health behaviours are likely to have a significant impact on the patient and their family (American Cancer Society, 2015). Decisions in the cancer context may be particularly difficult and complex due to a variety of factors discussed below.

Optimal cancer treatment depends on medical factors such as the cancer type, site and stage, the availability of evidence-based treatments, as well as an individual’s general health and personal preferences. Around the time of diagnosis, decisions regarding specific tests may need to be made (e.g. whether to have certain diagnostic procedures such as a biopsy, endoscopy, or lumbar puncture). At the time of initial treatment, decisions regarding which specific treatment (e.g. radiation vs. surgery), combination of treatments (e.g. chemotherapy plus hormone treatment, or chemotherapy alone), order of treatments (e.g. surgery before or after chemotherapy), or the option not to receive treatment, may need to be considered. If the disease reoccurs or metastasises,
decisions may need to be made regarding how aggressively the cancer will be treated or managed. If the cancer is incurable, patients (and their families) may face decisions such as continuing or ceasing treatment, and whether and how to use palliative care services. For each of these decisions, a number of factors may be considered such as the benefits, risks, or side effects of treatment, the patient’s (and potentially family’s) quality of life, and the patient’s (and potentially family’s) preferences, values and goals (e.g. American Cancer Society, 2015; Cancer Council Australia, 2014).

The growing focus on involving and partnering with patients in their medical care over the past 20 years has increased the participation of patients (and often their family members) in the cancer decision-making process (Hook, 2006). However, at the same time, cancer treatment decision-making has become increasingly complex due to a variety of medical advances such as the availability of multiple effective therapies and new treatments which may control but not cure advanced cancer; therefore, choosing treatment may require balancing medical risks and benefits of multiple treatment options that may interact (Hunink & Glasziou, 2001). In addition, as more factors such as patient values, preferences, quality of life, and lifestyle are accounted for, medical decision-making has become increasingly more patient-centred, but also potentially more complex and uncertain (Stacey, Paquet, & Samant, 2010).

1.2.3 Conceptual approaches to medical decision-making

Given the significance and complexity of medical decision-making, particularly for individuals with serious illnesses such as cancer, theoretical models dedicated to explaining and/or prescribing various approaches to decision-making have been proposed (Makoul & Clayman, 2006). Currently, the most prominent approaches to treatment decision-making range on a spectrum from the paternalistic (physician-led) through to informed (patient-led) approaches. The most widely advocated model, shared decision-making, sits in the middle of the spectrum (e.g. Charles, Gafni, & Whelan, 1997, 1999).

Paternalistic decision-making: In this approach, the physician is seen as directing the medical encounter, and utilising their skills to diagnose and treat the patient, acting as a ‘guardian’ of the patient’s best interests (Emanuel & Emanuel, 1992). The physician may give the patient selected information and encourage the patient to agree with and consent to the physician’s recommendations (Charles et al., 1997). The paternalistic approach is now viewed by many as inappropriate in many decision-making contexts, particularly in light of current societal views toward healthcare promoting patient empowerment and engagement. The extent to which
physicians utilise this approach in practice is widely variable, depending in part on the physician's style, and also the situation (e.g. it may be the only feasible and appropriate model in an emergency situation)(Charles et al., 1997).

**Informed (independent) decision-making:** In this approach, the patient decides upon the treatment option after the physician provides information about the benefits, risks, and alternative treatment options (Wirtz, Cribb, & Barber, 2006). The physician's role is limited to communicating scientific and technical information, and the patient is then able to make decisions based on the medical knowledge of their physician and their own preferences and values. In this approach, the physician's treatment preferences do not enter into the decision-making process (Charles et al., 1997). However, patient preferences for decision-making involvement vary widely, and whilst some patients may feel empowered to make their own treatment decisions within this approach, others may feel abandoned by their physician (Quill & Brody, 1996).

**Shared decision-making:** The shared decision-making approach is positioned in between the paternalistic and informed approaches (Makoul & Clayman, 2006). To date, no individual shared decision-making model has been accepted as the gold-standard definition, as there are several similar but distinct shared decision-making models. However, a central tenet of all shared decision-making models is that patients and physicians have different but equally valuable perspectives and roles within the medical encounter (Makoul & Clayman, 2006). Charles et al.'s (1997) is the most widely cited shared decision-making model (according to the Web of Science citation tracker the 1997 paper has received 1030 citations, and the 1999 paper has received 692 citations to date). The Charles et al. (1997; 1999) model breaks shared decision-making into three core stages: i) information exchange, ii) deliberation, iii) decision. In information exchange the physician informs the patient of all relevant information about available treatment options (e.g. benefits and risks) whilst the patient provides information about their preferences, values, beliefs, social context, and knowledge about the illness/treatment. The deliberation stage refers to the process of expressing and discussing treatment preferences in an interactive process. The final stage is choosing a treatment to implement, or the decision, where both parties work towards reaching an agreement and action plan to follow.

Shared decision-making has been described as the pinnacle of patient-centred care (Barry & Edgman-Levitan, 2012), and research indicates that it may be preferable over other decision-making models where one party has greater power and control (Gattellari, Butow, & Tattersall,
The interest in shared decision-making has grown rapidly over the past 15 years; in fact so much that a number of journals have published special issues heralding a “paradigm shift” in healthcare delivery (Moumjid, Gafni, Bremond, & Carrere, 2007; Wirtz et al., 2006).

Shared decision-making models have generally been designed to describe and/or prescribe a specific conception of good clinical practice (Wirtz et al., 2006). However, it is widely acknowledged that shared decision-making models may be difficult to achieve in practice for both physician and patient (Charles, Whelan, & Gafni, 1999; Elwyn, Edwards, Gwyn, & Grol, 1999; Wirtz et al., 2006). Coulter (1997) reported that criticisms include that many patients do not want to participate in decisions, that revealing uncertainties inherent in medical care could be harmful, and that discussing the potential risks and benefits of all treatment options is not feasible. Gravel, Légaré, and Graham (2006) reported some of the barriers towards implementing shared decision-making which include that it is time-consuming and difficult to implement in clinical practice, and that it may not be applicable in many clinical settings. However, Légaré and Thompson-Leduc (2014) recently argued that many of the common criticisms and barriers to shared decision-making should be considered myths, as evidence is continuing to build in support of shared decision-making.

Whilst shared decision-making is now widely accepted as a marker of quality clinical practice, the conceptualisation and approach to shared decision-making is undergoing a shift, from individual to relational and from linear to nonlinear (Epstein & Street, 2011). To better understand this shift, it is important to first understand the cognitive underpinnings of decision-making theory.

1.2.4 Cognitive theories of decision-making

Underpinning the theoretical approaches to medical decision-making are cognitive theories of decision-making. To date, decision-making has largely been conceptualised as an individual and independent process, however Epstein (2013) argued that a clearer and more accurate picture of decision-making can be gained by also considering the influence of others through the ‘shared mind’.

Epstein (2013) explained that historically, most theoretical decision-making perspectives focus on the individual, and are usually grounded in either micro- (value analytic thinking such as classical decision-making and expected utility theory) or macro- (intuitive thinking such as naturalistic decision-making) cognitive approaches. Classical Decision Theory (CDT) is a well-known value analytic approach which focuses on how individuals identify alternatives and quantify the
costs/benefits of alternative actions. According to CDT, medical decisions involve calculating and evaluating the probability of a potential event and the expected utility of the outcome (McNutt, 1989). However, CDT explanations may lack external validity as individuals rarely make decisions by identifying all possible courses of action and calculating the probabilities and expected utility of options (Epstein, 2013). Additionally, CDT may not fit well in chaotic worlds, uncontrolled environments, or critical situations (Chapman & Sonnenberg, 2003). Growing criticism of CDT led to a reframing of thinking, and naturalistic decision-making was developed. The naturalistic approach posits that individuals use past experiences to categorise situations, and these are typically associated with a particular course of action. The focus of naturalistic decision-making is on making an acceptable (not necessarily optimal) decision and often relies on both intuitive and analytical strategies (Klein, 2008).

A major limitation of both value analytic and naturalistic explanations is that they carry an embedded implication that decisions are made by individuals. However, research shows that patients include family members, friends, and clinicians in the decision-making process (e.g. Stiggelbout et al., 2007). Epstein (2013) asserted that it is important to recognise that social networks and contextual factors that affect decisions, and acknowledge that problem recognition, deliberation, and decision-making may be the result of cognitive processes that include more than one individual.

Epstein and Peters (2009) proposed the term ‘shared mind’ which refers to the idea that cognitive and affective schemas can be distributed across two or more people. In an ideal situation, ‘shared mind’ is where the physician and patient collaborate and achieve an understanding of the situation, each other’s perspectives, and are able to reach agreement on the treatment decision to implement. Epstein and Street (2011) further clarified the central tenets of the ‘shared mind’-focused decision processes which are: i) decisions are made within social networks; ii) autonomy depends on and emerges through communication and trusting relationships; iii) preferences are constructed as a result of interactions; and iv) patients use the full range of human experience to inform decisions—logic, affect, intuition, relationships. The ‘shared mind’ conceptualisation of decision-making is gaining widespread support among many leading shared decision-making researchers (Elwyn et al., 2014).
1.2.5 Recent collaborative theories of decision-making

Medical decision-making is undergoing a conceptual shift. Many of the earlier shared decision-making frameworks (e.g. Charles et al., 1997; Elwyn, Edwards, Kinnersley, & Grol, 2000; Towle & Godolphin, 1999) were based on individual cognition and decision-making, and depicted a linear decision process progressing stepwise from providing information, to identifying choices, deliberating, and then agreeing on an action plan (Epstein & Gramling, 2013). However, a ‘shared mind’ understanding proposes a shift in the conceptualisation of decision-making from independent to connected, from isolated to interpersonal, and from linear to dynamic. Epstein and Street (2011) proposed that the three processes involved in decision-making (information, deliberation, decision), can be reconceptualised through a shared mind lens, with greater focus on shared knowledge and collaborative cognition. This new understanding represents an exciting opportunity for greater integration of family into decision-making theory. Krieger (2014) noted that “the theoretical move...to ‘shared mind’ conceptualisations of decision-making holds tremendous promise for understanding the process through which family members become involved in treatment decision-making” (p284).

A newly proposed model of medical decision-making by Elwyn et al. (2014) represents additional progress towards conceptual accommodation of family members. Elwyn et al. (2014) state that most theoretical frameworks have viewed decision-making as a circumscribed activity, done by an individual patient as if in isolation. However, theories have not fully considered the contribution of interpersonal work, i.e. that patients turn to others, such as clinicians, family members and friends for help and support in decision-making. Elwyn et al. (2014) posits five propositions underpinning the ‘collaborative deliberation’ model which recognise the value of collaboration between individuals, rather than an individualistic approach by the patient. They also acknowledge that decision-making is typically a messy and uncertain process. Elwyn et al. (2014) argues that the theoretical underpinning of health care communication needs more attention, and we need a conceptual model that considers collaborative effort.

Another recently proposed collaborative theory of decision-making is Légaré et al.’s (2011) Inter-professional Shared Decision-Making model (IP-SDM). The IP-SDM model expands on the traditional dyadic patient-physician model to capture the influence of factors at the micro level (individuals), as well as the influence of systemic factors at both the meso level (health care teams within organisations) and the macro level (broader policies and social contexts). Within the model, various individuals are acknowledged such as the inter-professional team (e.g. doctor, nurse,
pharmacist) as well as family members. An important underlying assumption of the IP-SDM framework is that family members are important participants involved in the decision-making process, and their preferences may not necessarily align with those of the patient.

While Epstein and Street’s (2011) shared mind, Elwyn et al.’s (2014) collaborative deliberation model, and Légaré et al.’s (2011) IP-SDM model recognise and accommodate the influence of others (including family), clear delineation of family roles and dynamics within the decision-making process remain unexplained.

1.2.6 Calls for integrating family into decision-making theory and research

There appears to be room to conceptually accommodate family members into decision-making theory, and a need to do so. Charles et al. (1997) acknowledged that “limiting the conceptualization of shared decision-making to a physician-patient dyad may not, in many cases, reflect the current realities of clinical practice, where other participants may well be involved. It misses altogether the important role that the patient’s friends or family may play and the case of incompetent or seriously ill patients who require third parties to act on their behalf. There is almost no discussion in the shared decision-making literature on the implications of these situations for conceptualization and measurement of shared decision-making” (p685).

In Siminoff and Step’s (2005) communication model of shared decision-making, there was a call for research to “account for the dynamics of decision-making with patient advocates and caregivers. The addition of caregivers, other physicians, or family members can significantly alter the flow of information and relational perceptions (pS104)”.

Epstein and Street (2011) acknowledged the importance of family, and the need to accommodate them more in decision-making research. They stated “in high-stress high-stakes situations, individuals can bolster each others’ thinking compensating for deficits in each others’ ability to process information and solve problems... Patients whose cognition is compromised by fatigue, information overload, and emotional distress thus ask family members to help with recall and sort through complex information and choices; collaboration might also reduce patients’ anxiety and help them process information more effectively. Yet, family members’ contributions to decision-making are frequently ignored in clinical consultations and in research on decision-making” (p457).
More recently, Clayman and Morris (2013) echoed this call in their editorial stating "only by acknowledging and better understanding the role of the companion will researchers be able to develop a 360 degree understanding of decision-making" (p2).

Family involvement—where family members assume the role of companions (and often carers) to patients both within and outside of consultations—is becoming increasingly crucial as the delivery of healthcare moves from the inpatient to outpatient environment (Johnson et al., 2009). In addition to an increasing interest in the conceptual accommodation of family members in medical decision-making, ethical and legal approaches are also increasingly emphasising the importance of family involvement in medical care, as discussed below.

1.3 Ethical, legal, and professional approaches to family involvement

1.3.1 Ethical approaches to family involvement in medical care

Western medicine has traditionally been underpinned by an individualistic ethical approach to patient autonomy. The ethic of individual autonomy highlights that patients should be allowed, enabled, and empowered to make decisions about their healthcare autonomously—free from controlling influences. Individual autonomy is associated with confidentiality, privacy, and truth telling (Entwistle, Carter, Cribb, & McCaffery, 2010), and these concepts are ingrained in Western bioethics, law, and clinical practice (Kerridge, Lowe, & Stewart, 2013).

Initially, bioethicists and philosophers focused their attention on enhancing the patient’s independence in relation to the controlling influence of physicians, rather than family members (Saunders, 1994). However, Ho (2008) argues that although the primary focus has been on minimising professional coercion in medical decisions, there has also been a steady ethical concern about family’s involvement in decision-making and the potential for coercion. Blustein (1993) wrote an essay about the rights of the family when competent adults face medical decisions and posited that the locus of decision-making authority should remain with the patient, and that family involvement in decisions may not result in a mutual accommodation of interests, but rather an erosion of patient autonomy and subordination of patient interests. However, despite advocating for patient autonomy, Blustein (1993) also recognised the important role family can play in enhancing the patient’s autonomy and assisting them in their decision-making, and believed that physicians have a duty to encourage and facilitate conversation between patients and their family members.
Additionally, ethical guidance endorsed by the American College of Physicians (Mitnick, Leffler, Hood, American College of Physicians Ethics, & Committee, 2010) also calls for respect of patient autonomy. Whilst respect for, and acknowledgement of, family members appears throughout the ethical guidance, Mitnick et al.'s (2010) main focus is on preserving patient autonomy. For example the guidance states “clinical encounters should be patient-centered, allowing for maximum appropriate patient autonomy and participation in decision-making” (p256).

However, the current conceptualisation of individual autonomy has been questioned by a number of ethicists. For example, Entwistle et al. (2010) proposed that the focus on individual patient autonomy may be detrimental to patients who need support and assistance when making decisions, such as patients who lack confidence, are confused about what option to select, or have conflicting priorities. These patients may feel abandoned rather than autonomous.

Whilst individual patient autonomy has been advocated in legal, professional and ethical guidelines, recent ethical publications have proposed that relational autonomy may be a more appropriate conceptualisation. Relational autonomy differs from individual autonomy in that it acknowledges that individuals are located within, and influenced by, interpersonal relationships and a broader social context. Relational autonomy recognises that humans are social beings and that trusting relationships and personal knowledge enhance autonomy by helping patients to process complex decisions that might otherwise overwhelm the cognitive capacity of a single individual (Epstein & Street, 2011). Implicit within relational autonomy is the notion that decision-making is a collaborative process (which may include family members) and that this style of decision-making may be ethically appropriate and beneficial for the patient (Gilbar, 2011). This approach is gaining increasing support, with recent publications by leading medical decision-making researchers Epstein and Street (2011) and Elwyn and colleagues (2014) supporting a relational understanding of medical decision-making. However, as noted by Epstein and Gramling (2013), family involvement is not simple, as it can either enhance or diminish a patient’s autonomy. When preferences are shaped by coercive or controlling relationships, they have the potential to reduce patient autonomy, however when socially constructed preferences are shaped by trusting relationships, they may enhance patient autonomy.

Despite the potential negatives of family involvement, numerous bioethicists and philosophers have published supporting the family's important rights in the decision-making process, to varying degrees. Hardwig (1990) and Ho (2008) argued that the family deserves to have an influential role
in the decision-making process, as they are often affected by the decision. However, the views of Hardwig (1990) and Ho (2008) have been met with opposition from some legal and ethical researchers such as Gilbar (2011), who believed that this level of accommodation of family influence may see the patient’s wishes and preferences overridden too easily by the needs of the family.

Other ethicists have proposed more moderate approaches to family involvement, such as Lindemann Nelson (1992) who argued that whilst families should be taken seriously in the medical setting, the patient has a greater stake in the decision than any other person, and it is the patient’s body which is ultimately affected. Lindemann Nelson (1992) did not support situations where the family’s interests outweighed those of the patient. Levine and Zuckerman (2000) also proposed a more moderate and flexible approach, advocating recognition of individual roles and interests, negotiation, accommodation, and the formation of partnerships within the physician, patient and family triad. While physicians have an obligation to respect patient interests and preferences, Levine and Zuckerman (2000) argue that family wellbeing and interests are also important, and there is no simple formula to determine the primacy of interests. Gilbar (2011) proposed that different ethical approaches may be appropriate in different situations and suggested that a delicate balance between individual autonomy and family involvement needs to be struck, whereby decision-making is a social process which involves the family, but also that the patient has the right to make decisions about their own life.

Gilbar (2011) noted that despite the fact that a relational ethic is becoming increasingly recognised, law and professional guidelines continue to treat family members with a degree of suspicion.

1.3.2 Legal and professional approaches to family involvement in medical care

In Australia, the authority of the patient is legally protected, and there are several situations where the law and/or professional medical guidelines limit or prohibit the involvement of family. Whilst this thesis will focus predominantly on the Australian context, similar legal principles advocating for patient autonomy are found in other Western countries such as the UK (Gilbar, 2011) and USA (Blanchard, 2007).

Some family members may request that medical information, such as diagnosis or prognosis, not be disclosed to the patient (often with the intention to protect the patient from distress). However, in Australia, a culture of disclosure of diagnosis is widely endorsed and practiced on the basis of
medical ethics and patient autonomy (Butow & Baile, 2012). The Australian Charter of Healthcare Rights (Australian Commission on Safety and Quality in Health Care, 2011) states that all patients have a right to be informed about services, treatment, options and costs in a clear and open way.

Additionally, the privacy and confidentiality of the patient is protected by legislation (e.g. New South Wales Government, 2002), and professional medical guidelines reflect this legal position. The NSW Health publication ‘Patient Information and Privacy: A guide for Carers and Family’ (NSW Health, 2012) states that “Health staff can give information to family members about the patient if the patient (or someone authorised to act for them) has given permission for this to happen. If a patient does not give permission, information cannot be given except in special circumstances” (p2). These special circumstances include situations where the patient is unable to give permission for staff to share information due to injury, illness, or impairment (e.g. if the patient is unconscious or has dementia), in emergency situations, and in some cases concerning disclosure of genetic information.

Additionally, Australian law requires that patients must give consent for medical procedures. For consent to be legally valid it must be informed, specific, freely given, timely, and the person should have the capacity to consent (Kerridge et al., 2013). Most relevant to family involvement in decision-making is the requirement for consent to be freely given by the patient. Kerridge et al. (2013) noted that illness may leave patients prone to undue influences from family members, who may persuade or coerce the patient. To ensure valid informed consent is obtained, Kerridge et al. (2013) notes that health professionals need to be aware of any undue influence from the family. A clear example of the pre-eminence of the patient is the NSW Health Guidelines for end of life care and decision-making (NSW Health, 2005) which states that “the wishes of the adult patient with decision-making capacity are paramount. If the patient’s expressed wishes regarding active treatment or refusal of treatment prior to loss of decision-making capacity are known, then these wishes prevail over the wishes of the family. Disagreements between the patient and his or her family may arise if the family is not properly informed by the treating team about the directions given by the patient, and every effort should be made to communicate this information to the family” (p9).

An issue relevant to family involvement in the consent process is the ethical and professional shift towards shared decision-making. Although Australian law does not require physicians to practice shared decision-making, there has been a general ethical and professional shift towards two way (patient-physician) interactions during the consent process (i.e. shared decision-making). The
Australian Healthcare Charter of Healthcare Rights (Australian Commission on Safety and Quality in Healthcare, 2008) states that patients have “a right to be included in decisions and choices about my [their] care” (p1). The National Health and Medical Research Council (2015) state that “shared decision-making should be incorporated into routine clinical practice in Australia when discussing medical decisions with a patient”. Despite the fact that family members often assume an integral role in assisting the patient’s informed decision-making, family are not readily acknowledged in the promotion and endorsement of shared decision-making in Australian professional guidelines. This stands in contrast to the US legislation which states that health programs should “facilitate collaborative processes between patients, caregivers, and clinicians that engage the patient and caregiver in decision-making” (299b–36) (United States Government, 2010). However, recent developments in Australian legislation, such as the Carer Recognition Act (Commonwealth Government of Australia, 2010), may help to better acknowledge and accommodate family members involved in the healthcare system.

Over the past five years, there has been increasing recognition of family members in policy and legislation. The Carer Recognition Act includes a number of provisions for the inclusion of carers in medical consultations and medical decisions, such as: “i) The views and needs of carers and the views, needs and best interests of the persons for whom they care must be taken into account in the assessment, planning, delivery and review of services provided to persons who are cared for; ii) Carers' choices in their caring role should be supported and recognised, including the recognition of carers in the assessment, planning, delivery and review of services that impact on carers and their role as carers; iii) Carers’ unique knowledge and experience should be acknowledged and recognised” (Commonwealth Government of Australia, 2010).

Despite the important recognition that these Acts provide, Section 9 of the Carers Recognition Act states that “Nothing in this Act: (a) operates to create in any person any legal rights not in existence before the enactment of this Act, or (b) affects the validity, or provides grounds for review, of any judicial or administrative act or omission and (2) If a public sector agency is required by another law to consider particular matters, or to comply with particular requirements, in the exercise of its functions, nothing in this Act is to be taken to require the agency to act inconsistently with that law”. (Commonwealth Government of Australia, 2010). Therefore, this legislation may have limited impact. For example, although the Carer Recognition Act states that the views and needs of carers must be taken into account, this may be in conflict with and outweighed by the laws and professional guidelines governing disclosure, confidentiality, patient autonomy and consent. It
remains unclear how greater consideration of, and engagement with, family should be implemented in clinical practice when health professionals are restricted by the current legal and professional climate of individual patient autonomy and confidentiality.

A review of empirical research below will examine how various stakeholders view family involvement in consultations, and what impact family members have on the medical decision-making process.

1.4 Family involvement in medical consultations and decisions: Empirical research and conceptual frameworks

1.4.1 Empirical research on family involvement in cancer consultations and decisions

The focus of medical communication and decision-making literature has almost exclusively focused on the physician-patient dyad, leaving the role and impact of family members relatively unaccounted for. It is clear that family members often accompany patients to cancer consultations, assume a variety of roles, and may engage in an array of helpful and/or challenging behaviours (Eggly et al., 2006; Ellingson, 2002; Speice et al., 2000; Street & Gordon, 2008). Their involvement can lead to benefits, such as improved quality and quantity of information exchanged (Hubbard, Illingworth, Rowa-Dewar, Forbat, & Kearney, 2010; Kimberlin, Brushwood, Allen, Radson, & Wilson, 2004) and improved patient recall of information (J. Jansen et al., 2010). However, their involvement may also result in challenges such as a sense of intrusion on the physician-patient relationship, family conflict, or undue influence over decisions (Siminoff, 2013).

A systematic review of the literature on this issue is reported in Chapter 3. Therefore, a brief summary only is provided below.

The limited number of studies conducted to date indicates that the various stakeholders (i.e. patient, family member, physician) hold relatively favourable attitudes towards family involvement in cancer consultations. Patients appear to appreciate the various forms of support (e.g. informational, emotional, decision-making) their family members provide (Speice et al., 2000). Similarly, family members appear to appreciate the opportunity to be involved and are pleased to help both the patient and physician (Morris & Thomas, 2001). However, some family members have reported negative experiences such as being made to feel superfluous or unwelcome by physicians (Morris & Thomas, 2001; Sinfield, Baker, Agarwal, & Tarrant, 2008). Two qualitative studies of
oncology health professionals’ views found that they also appeared to hold favourable attitudes towards family involvement, however some health professionals reported that triadic (physician-patient-family) consultations held inherent challenges which needed to be overcome such as disruptive family dynamics, argumentative family members, and conflicting patient-family treatment wishes (Beisecker & Moore, 1994; Speice et al., 2000). Many aspects of family involvement in cancer consultations, such as the perceived benefits, challenges, and strategies to facilitate positive family involvement remain relatively unexplored.

To date, the majority of studies in this evidence base have focused on qualitative accounts of family involvement, and there has been limited objective analysis of cancer consultations to elucidate the nature of triadic consultations. Of the studies which have examined audio-or video-taped consultations, most have compared dyadic and triadic consultations focusing on behaviours common to both contexts (e.g. patient question asking, physician provision of information) (Eggly et al., 2011; Eggly et al., 2006), and only a limited number have analysed the roles and behaviours of family members (Clayman, Roter, Wissow, & Bandeen-Roche, 2005; Street & Gordon, 2008). There is a paucity of research examining the specific behaviours of family members and the family-relevant behaviours of physicians and patients in cancer consultations.

There is also relatively little known about the involvement of family in the medical decision-making process. To date, most relevant studies have quantitatively examined two aspects: i) the preferences of patients and family members towards family involvement in decision-making, and ii) the actual experiences of family involvement in the decision-making process. Studies examining decision-making preferences found that between 49-84% of cancer patients wanted their family member to actively participate in the decision-making process (Gilbar & Gilbar, 2009; Gonçalves et al., 2005; Pardon et al., 2010; Schäfer et al., 2006) and one study which examined the actual rates of family involvement in decisions found that 67% of patients reported that this preference was satisfied (Schäfer et al., 2006). One study which examined family members’ preferences found that 54% of family members felt they should have a say in the decision (Schäfer et al., 2006), whilst actual rates of family involvement in decision-making were higher, ranging from between 60-80% (Schäfer et al., 2006; Srirangam et al., 2003). Collectively, these studies indicate that a substantial proportion of patients and family members want family to be involved in decision-making.

Only six studies have qualitatively examined the nature of family involvement in cancer treatment decision-making (U. Boehmer & Clark, 2001; Hilton, 1994; Hubbard et al., 2010; Öhlén, Balneaves,
Bottorff, & Brazier, 2006; Reust & Mattingly, 1996; Zhang & Siminoff, 2003). Hilton (1994) and Ohlen et al. (2006) interviewed cancer patients and their family members and reported that family involvement in decision-making can range from passive to active, and may be influenced by demographic, relationship, and disease factors. Reust and Mattingly (1996) and Hubbard et al. (2010) identified a number of common family member behaviours (e.g. informational support, advocacy, sounding board) during the cancer treatment decision-making process. Collectively, these studies indicate that family involvement in decision-making is widely variable; the family members role in decision-making may range on a spectrum from passive to directive, they can be involved across the various stages of decision-making, and their involvement can be influenced or mediated by a number of patient and/or family member characteristics. Zhang and Siminoff’s (2003) study indicates that the patient and family are not always aligned with their preferences, and disagreements and mismatched needs and wishes for treatment decisions can occur.

However, these studies have a number of limitations. Hilton’s (1994) study reported combined patient and family dyad views, therefore the separate attitudes and experiences of patients and family members remained unexplained. Studies by Reust and Mattingly (1996) and Öhlén et al. (2006) focused on the dyadic patient-family relationship, and did not explain or account for the involvement of the physician in the decision-making process. Boehmer and Clark’s (2001) study was a secondary analysis of focus groups and included only seven patients. Hubbard et al.’s (2010) study, although novel in exploring the influence of family across the various stages of decision-making (e.g. information exchange, deliberation) did not detail the variety and complexity of family member behaviours. Zhang and Siminoff’s (2003) study focused on patients with advanced lung cancer (>80% of patients had a life expectancy of less than 2 years), thus the decision-making dynamics of this group may be very different from other cancer patients and their families with different treatment goals and prognoses. Much remains unknown about how family are involved in the decision-making process.

Therefore:

Based on the previous literature, an initial aim for this thesis was to systematically review the evidence base, including both quantitative and qualitative studies, related to triadic (physician-patient-family) communication and decision-making across all medical contexts with adult patients (e.g. cancer, primary care, diabetes).
An additional aim was to comprehensively explore the attitudes of patients, family members, and health professionals, particularly the benefits and challenges of family involvement in consultations, and the nature of and attitudes towards family involvement in decision-making.

It is also clear that there is a paucity of studies which have examined what actually happens in cancer consultations. Therefore, an aim of this thesis was to examine the behaviours of family members and family-relevant behaviours of physicians and patients in audiotaped cancer consultations.

1.4.2 Conceptual frameworks explaining family involvement in cancer consultations and decisions

As discussed throughout this introduction, there is currently limited conceptual explanation of the nature of family involvement in medical consultations or decision-making. To date, relevant conceptual explanations have focused on either: i) describing typologies of family involvement; ii) explaining coalitions which form in the triad; or iii) proposing process models to explain factors affecting triadic interactions.

Before examining the conceptual publications proposed to date, a number of key terms require definition. Carpiano and Daley (2006) highlighted that a conceptual framework is a broad theoretical explanation of a phenomena, which identifies a set of variables and the relations among them- but does not provide explanations for outcomes. A theory, usually nested within a framework, explains a more dense and logically coherent set of relationships, including direction and hypotheses, and makes specific assumptions that are necessary to diagnose a phenomenon, explain its processes, and predict outcomes. Models are typically narrower in focus than frameworks and theories, and are developed and used to make specific assumptions about a limited set of parameters and variables. They may be presented graphically to highlight proposed linkages between constructs. Finally, a typology is a system of classification of conceptual constructs that breaks down an overarching concept into component dimensions and types (Bailey, 1994; Collier, LaPorte, & Seawright, 2012). Based on these definitions, several of the below are most likely to be either typologies (U. Boehmer & Clark, 2001; Gilbar, 2011; Goldsmith, Wittenberg, Platt, Iannarino, & Reno, 2015; Hilton, 1994; Krieger, 2014; Öhlén et al., 2006; Rosow, 1981) or models (Dalton, 2003; Wolff & Roter, 2011).

Four publications have described typologies of family involvement in communication or decision-making. Four of these are conceptual categorisations based on qualitative analyses of interviews with patients and family members (Gilbar, 2011; Goldsmith et al., 2015; Hilton, 1994; Öhlén et al.,
2006), and one is conceptual typologies based on a theoretical and empirical review (Krieger, 2014). Hilton’s (1994) typologies rest on a spectrum from minimally to extensively involved (deference to physician; minimal exploration; joint engagement; deliberative examination) and highlighted that the decision-making style assumed is influenced by the nature and perception of the situation, and patient, couple, family, and physician factors. Similarly, Öhlén et al. (2006) proposed a spectrum of typologies of family involvement in decisions ranging from passive through to directive (creating a safe space for the patient to make a decision; becoming a team-collaborative decision-making; moving the patient towards a decision; making the decision for the patient). Öhlén et al. (2006) noted that as circumstances changed, new information and experiences were gained, and relationship dynamics shifted, the family involvement style shifted. Gilbar (2011) also proposed that family involvement fell on a spectrum from minimal to substantial (minimal influence; moderate influence; substantial influence), and noted that irrespective of typology, family were usually heavily involved in the provision of informational support. Goldsmith et al. (2015) proposed that family caregivers can fall into one of four typologies of family communication: Lone, Partner, Carrier, and Manager, and asserted that clinical staff should identify the family communication type and tailor their approach to the family accordingly. However Goldsmith et al.’s (2015) typologies focus less on styles of family involvement in consultation communication and medical decision-making, but on more general family-patient communication and care patterns. Collectively, the above typologies indicate that family involvement in communication and decision-making varies widely on a spectrum from minimal to active, that several factors may affect the style of family involvement, and that it may be beneficial if health professionals’ adapt their approach to the family based on the family’s style of involvement. To date, there has been no synthesis of typologies proposed across studies.

Krieger (2014) proposed that alignment or misalignment of patient and family preferences for autonomy or interdependence may result in five different typologies. Three typologies describe situations where patient and family involvement preferences are aligned (independent, collaborative, delegated), and two typologies describe situations where patient and family preferences are misaligned (isolated, demanding). Krieger (2014) proposed that aligned patient-family preferences would lead to greater satisfaction and adjustment, and misaligned preferences would lead to lower satisfaction and higher distress. Whilst Krieger’s (2014) paper reconceptualised decision-making typologies by accounting for the alignment/misalignment of preferences, a limitation is that the behaviours and impact of the physician were not accounted for.
Whilst each of the above typologies provides valuable insight into the nature of family involvement in decision-making, they have not adequately acknowledged or built upon previous empirical or theoretical work and do not capture the complex interactions and dynamics of all three participants (physician-patient-family) in the triadic decision-making process.

Two publications have described typologies of coalition formation within triadic encounters. These papers (U. Boehmer & Clark, 2001; Rosow, 1981) provide insight into how the presence of a third person can negatively or positively impact upon interactions, and how several different coalitions can form in a triadic encounter. Rosow's (1981) paper observed that a variety of coalitions may form in medical encounters with elderly patients and their children (patient and caregiver versus doctor; doctor and caregiver versus patient; and doctor and patient versus caregiver). U. Boehmer and Clark (2001) similarly observed typologies of coalitions forming in cancer treatment decision-making. These include patient-doctor and patient-family coalitions. Whilst providing important explanation of triadic dynamics, these coalition papers do not specifically explain the behaviours of family members within a consultation.

Two triadic process models have been proposed (Dalton, 2003; Wolff & Roter, 2011) which attempt to explain the factors affecting triadic interactions and the consequences of these interactions. Dalton (2003) proposed the theory of collaborative decision-making which describes interactions between patients, families and nurses when making healthcare decisions. It asserts that the pro- or anti- collaborative attitudes of the patient, family and nurse can affect collaboration, decision-making and coalition formation, and the level of three-way collaboration can affect patient, family and nurse outcomes such as autonomy and satisfaction. Collaboration and outcomes are proposed to be affected by contextual factors such as the personality, knowledge, and attitudes of each individual. However, Dalton's (2003) theory derivation process was not based on widely recognised models of decision-making, and addresses decision-making predominantly within home-care situations for the elderly. It does not address decision-making for life-threatening illnesses such as cancer, nor explores the influence of the physician on such interactions. More recently Wolff and Roter (2011) proposed the Family Involvement in Interpersonal Health Care Processes model, which depicts the interaction pathways between patients, families, and health professionals. It acknowledges the important impact patient, family, and physician factors have on the dynamics of the triad, and how the triadic consultation may impact on patient outcomes (e.g. satisfaction, knowledge, and adherence) and also the quality of health care.
For the current project, the categorisation of family members according to a typology or ‘spectrum’ appears to more closely align with the exploratory and descriptive aims of this thesis, in comparison to the process models of Dalton (2003) and Wolff and Roter (2011), which are more predictive and explanatory. However, each of the aforementioned decision-making models (Elwyn et al., 2014; Epstein & Street, 2011; Legare et al., 2008) typologies (U. Boehmer & Clark, 2001; Gilbar, 2011; Goldsmith et al., 2015; Hilton, 1994; Krieger, 2014; Öhlén et al., 2006; Rosow, 1981) and conceptual frameworks (Dalton, 2003; Wolff & Roter, 2011) will provide a valuable theoretical foundation throughout the thesis, will assist in interpretation of study findings (Chapters 3-5), and will inform a newly proposed conceptual framework (Chapter 6) of family involvement.

To date, no broad framework has been developed to provide an overall explanation of the nature and scope of family involvement in decision-making. Development of such a framework is needed to provide direction for future research and theory.

**Therefore:**

*Based on the empirical and theoretical literature proposed to date, and the empirical research conducted throughout this thesis, an aim of this thesis was to propose a preliminary conceptual framework of family involvement in decision-making capturing the nature and complexity of their involvement.*

### 1.5 Strategies to manage and enhance family involvement in medical consultations and decisions

As previously highlighted, patient-centred care and shared decision-making are now established as gold standard components of quality healthcare (Barry & Edgman-Levitan, 2012; Kramer et al., 2014). A plethora of studies have examined interventions to improve dyadic physician-patient communication and shared decision-making, including decision aids, question prompt lists, communication skills training programs, and clinical strategies documents (Berkhof, van Rijssen, Schellart, Anema, & van der Beek, 2011; Kinnersley et al., 2008; Stacey et al., 2011). However there is a dearth of interventions designed to facilitate positive communication or decision-making during triadic consultations. More specifically, there is limited guidance (e.g. clinical strategies) provided to health professionals for how to manage and enhance family involvement, particularly when important treatment decisions need to be made. Given that previous research highlights that some family members report negative experiences in triadic consultations such as feeling superfluous or unwelcome (Morris & Thomas, 2001), and physicians experience a range of
challenges such as disruptive family dynamics and conflicting patient-family treatment wishes (Speice et al., 2000), strategies and interventions targeting physicians, patients, and/or family members may help to facilitate positive communication in these complex interactions.

A number of relevant interventions have recently been developed to assess and/or improve patient and family member communication. Siminoff, Zyzanski, Rose, and Zhang (2008) developed the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF), which measures the level and types of communication concordance and discordance and decision-making dynamics between patients and caregivers and has the potential to act as a tool to assess family risk for communication problems. Additionally, Wolff et al. (2014) developed a pre-consultation information preference and role clarification checklist, which aims to assist the patient and family member to clarify and discuss their needs prior to the consultation. Whilst both interventions show promising initial results, they primarily focus on the patient-family dyad rather than the health professional's communication with the family member, which has been found to be suboptimal (Morris & Thomas, 2001; Sinfield et al., 2008). To date, only a limited number of publications have focused on communication strategies for health professionals when family are present, each of which remain untested.

Speice et al.’s (2000) study was one of the first to propose clinical strategies for when family members are present in cancer consultations. Speice et al. (2000) suggested that health professionals might benefit from completing a self-assessment of their own attitudes and behaviours towards family members, and also recommended the routine integration of a family meeting at the start of care to provide a forum to discuss patient and family needs and to help guide family members on how to best support the patient. Speice et al. (2000) also proposed that health professionals ask role clarifying questions to patients and family members to help ascertain preferences for family involvement. No evaluation of these strategies has been conducted.

Lang et al. (2002) identified a number of skills to respectfully and efficiently involve family members in primary care consultations. Lang et al. (2002) proposed ‘core’ family interviewing skills which should be used in routine consultations when the family member communicates effectively and when minimal differences exist between the family member, patient, and physician. These core skills include: i) greeting and building rapport; ii) identifying each person’s agenda; iii) checking each person’s perspective; iv) allowing each person to speak; v) recognising and acknowledging feelings; vi) avoiding taking sides; vii) respecting patient privacy and maintaining
confidentiality; viii) interviewing the patient alone; and ix) evaluating agreement with the plan. Lang et al. (2002) then proposed that advanced interviewing skills are useful in situations where the family exhibits ineffective communication or when there is conflict or intense emotion. These skills include: i) guiding communication; ii) managing conflict; iii) reaching common ground; and iv) considering referral for family therapy. However, there is minimal empirical evidence provided for each of the strategies and it is unclear how each of the strategies was developed.

Based on a review of the literature, Burkhalter and Bromberg (2003) made recommendations for oncology health professional-led family conferences and noted that the basic elements of family conferences could be incorporated into consultations. Burkhalter and Bromberg (2003) recommended that health professionals privately address with the patient what information should be shared, and with whom. During family conferences and consultations, strategies for health professionals include: i) listen for what family members know about the illness and what concerns them most; ii) observe how the family interacts; iii) educate family about the illness, treatment options, and prognosis; iv) make referrals to assist the family, such as support groups; and v) ask family to identify a spokesperson to the oncology team.

Mitnick et al.’s (2010) paper, endorsed by the American College of Physicians and ten other professional societies, offered ethical guidance to physicians in managing family involvement across a variety of medical settings. Mitnick et al.’s (2010) recommendations were predominantly focused on protecting the patient’s autonomy (e.g. “Clinical encounters should be patient-centered, allowing for maximum appropriate patient autonomy and participation in decision-making”; “The physician should routinely assess the patient’s wishes regarding the nature and degree of caregiver participation in the clinical encounter and strive to provide the patient’s desired level of privacy”) (p. 256). However, Mitnick et al. (2010) also recommended that respect for, and acknowledgement of, family is also important (e.g. “Physicians should routinely validate the family caregiver’s role and be sensitive to specific commitments the caregiver may have made regarding how he or she will manage the patient’s care”) (p. 257).

Overall the strategies developed to date have a number of limitations. The strategies by Speice et al. (2000), Lang et al. (2002), and Mitnick et al. (2010) are based on very limited empirical evidence. For example, Wolff and Roter’s (2010) letter to the editor regarding the strategies developed by Mitnick et al. (2010) highlights the omission of many studies of central relevance and suggests that the recommendations made by Mitnick et al. (2010) would be strengthened if they acknowledged
the existing evidence base. The strategies proposed to date do not clearly acknowledge the legal, professional, and ethical frameworks underpinning family involvement in consultations and decisions, are not theory-driven or theory-informed, and do not include any practical strategies for managing or enhancing family involvement in the decision-making process. Finally, despite the challenges reported by health professionals when conducting triadic consultations, current interventions have not clearly acknowledged strategies to overcome common concerns which arise when family are involved.

**Therefore:**

*A final aim of this thesis was to propose a range of draft clinical strategies to guide physicians to manage challenging situations and enhance positive family involvement in triadic consultations and decision-making, informed by the evidence base.*
1.6 Project overview and aims

The over-arching aim of this thesis was to comprehensively explore the involvement of family in cancer consultations and decision-making. Five aims were articulated:

1. To systematically review and synthesise the literature on the involvement of family in consultations and decision-making across all medical settings
2. To understand patient, family, and health professional attitudes towards, and experiences of, family involvement in cancer consultations and decision-making
3. To describe actual behaviours of physicians, patients and family members in triadic cancer consultations
4. To develop a draft conceptual framework capturing the nature of family involvement in decision-making
5. To propose draft strategies for oncology physicians that could be used to enhance communication and decision-making in cancer consultations involving family members

Development of a comprehensive conceptual framework and clinical strategies document were beyond the scope of this project. The candidate aimed for this thesis to culminate in the proposal of draft versions of these publications, which will be taken forward through expert review and consensus after completion of this thesis, as part of the candidate’s postdoctoral position.

The aims of the thesis were addressed in five steps:

1. First a systematic review was conducted. As the literature on triadic cancer consultations was sparse, the review was expanded to all medical settings which included cognitively competent adult patients and a family member. It also included both quantitative and qualitative studies to ensure sufficient scope and depth of information was captured. The systematic review is detailed in Chapter 2.
2. Second, semi-structured interviews were conducted with oncology health professionals, cancer patients, and family members of cancer patients. These interviews aimed to capture experiences of family involvement in cancer consultations and decision-making, the perceived benefits and challenges of family involvement, and any strategies which may enhance triadic consultations. The interviews with oncology health professionals are detailed in Chapter 3, and the interviews with cancer patients and family members are detailed in Chapter 4.
3. Third, the behaviours of physicians, patients, and family members in audio-taped triadic cancer consultations were analysed through application of a purpose designed triadic
interaction analysis coding-frame in Chapter 5. These consultation analyses were conducted to capture the actual behaviours of participants, particularly during the treatment decision-making process.

4. A draft conceptual framework capturing the nature of family involvement in decision-making is proposed in Chapter 6.

5. Draft strategies to guide physicians in managing challenging situations and enhancing positive family involvement in triadic consultations and decision-making are proposed in Chapter 7. These strategies are based on existing literature and the empirical and theoretical findings of this thesis.

A final discussion of the findings, acknowledgement of the strengths and limitations of the project, and proposals for future directions can be found in Chapter 8.
Chapter 2:
Systematic review of physician-patient-family communication and decision-making
2.1 Introduction

The following chapter aims to systematically review the triadic (physician-patient-family) consultation and decision-making evidence base. Given the limited number of cancer-relevant studies published to date, it was decided to expand the review to all medical consultations with cognitively competent adult patients and family members to obtain a more comprehensive and general view of how family members can be involved in medical consultations and decisions.

To date, literature on medical communication has primarily focused on the physician-patient relationship, leaving the influence of family members relatively unexplored. Despite this, a diverse, albeit disjointed, literature base has begun to highlight the important role family member’s play during medical consultations.

Family members often accompany patients into the consultation, provide emotional, informational, or practical support (Wolff & Roter, 2008), and participate in medical decision-making (Clayman et al., 2005). They can change the dynamics of the consultation, influence the patient’s relationship with the physician, and increase the complexity of the encounter (Beisecker & Moore, 1994). To date, there has been little translation of research findings into guidance for physicians regarding how best to conduct consultations when a family member is present. A number of articles have suggested practical strategies, however these remain untested, or lack grounding in the literature base (Burkhalter & Bromberg, 2003; Lang et al., 2002; Mitnick et al., 2010; Speice et al., 2000).

Further, there has been little synthesis of information in this area, potentially due to: diverse disciplines investigating the topic (e.g. medicine, linguistics, sociology, psychology), the range of consultations under investigation (e.g. geriatrics, oncology, diabetes, primary care) and the wide variation in terminologies used to describe the topic area (e.g. carer, companion, family, relative, third-person, kin, significant other). The need for such synthesis is reflected in the recent publication by Wolff and Roter (2011) of their meta-analytic review of provider-patient-family consultations. Wolff and Roter (2011) provided an overview of some of the characteristics and impacts of patient accompaniment. As Wolff and Roter (2011) conducted a meta-analysis, they were restricted to include only quantitative studies (n=17), and limited the meta analysis to routine medical visits. Therefore, a wealth of relevant qualitative and quantitative studies remains unexamined.

Qualitative studies can provide depth of information and increased understanding of attitudes and behaviours. Since there are a number of relevant qualitative studies in this area, the current review
aimed to take a broader perspective on the triadic literature. In addition, our broader inclusion criteria enabled discussion of several areas unexplored by Wolff and Roter (2011), including: i) the roles of family members, ii) the attitudes of each party toward family involvement, and iii) preferences toward, and dynamics of, triadic medical decision-making. The current review provides a more exhaustive and detailed analysis of the physician-patient-family literature base, with inclusion of 52 quantitative and qualitative studies across a range of illness types (primary care, oncology, diabetes, cardiovascular disease, palliative care) and severities (routine visit, newly diagnosed, seriously ill, end-of-life).

The aim of the systematic review was to assess available studies that examine the nature of triadic (physician-adult patient-adult family member) communication and decision-making within all medical encounters. The scope of this review was restricted to studies describing cognitively competent adult patients with an adult family member.

2.2 Methods

2.2.1 Search strategy

A search of relevant databases (i.e. PsycINFO, MEDLINE, CINAHL, EMBASE, SCOPUS, Sociological Abstracts, Proquest Social Science Journals) was conducted. Search results were limited to articles published from 1950 to July 2011. Due to the varied nature of keywords in this field, a comprehensive list of search terms was developed (see Box 2.1). The returned search results were screened for irrelevant articles, review papers, and duplicates. An eligibility checklist was developed (see Box 2.2) to guide the selection of appropriate studies. Decisions regarding inclusion/exclusion were first made by the candidate and then verified by two supervisors. Common reasons relevant studies did not satisfy the inclusion criteria included: i) a focus on nurse communication (e.g. J. Jansen et al., 2010; Lewis, Pearson, Corcoran-Perry, & Narayan, 1997), ii) patient-family communication/decision-making without the involvement of the physician or a focus on the consultation environment (e.g. Öhlén et al., 2006; Zhang & Siminoff, 2003), or iii) physician-family communication without the involvement of the patient (e.g. Meeker & Jezewski, 2005). Reference lists of included articles, and any studies which have cited these, were subsequently searched for relevant articles.
Box 2.1: List of search terms

(Triad* or companion or relative or famil* or third person or family involvement or carer or caregiver or husband or wife or spouse or accompan* or significant other*)

AND

(Consultation or medical encounter or medical visit or medical setting or physician or doctor)

AND

(Illness or disease or chronic or cancer or heart or diabetes or general practi* or oncolog*)

AND

(Communicat* or decision* or decision making or collaborat* or coalition)

NOT

(Pediatric* or Alzheimer* or dementia)

Box 2.2: Eligibility criteria for inclusion/exclusion in systematic review

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<th>Types of studies:</th>
<th>Quantitative or qualitative (primary and secondary analyses of data sets) studies including:</th>
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<td>- Interviews/focus groups</td>
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<td>- Surveys</td>
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<td>- Consultation audit-studies (audio- or video-taped consultations, consultation observation)</td>
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<td>*Exclusion: Review papers, editorials, commentary/discussion papers, papers published in languages other than English, papers not available in full text</td>
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<th>Types of participants:</th>
<th>Triadic communication/decision-making must have included one of the following participants:</th>
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<td>- Adult patients (&gt;18 years)</td>
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<td>*Exclusion: Studies where patients not able to fully engage in the consultation (e.g. patients with dementia, minors, unconscious patients)</td>
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<td>- Adult family members involved in the consultation (including spouse, family, friends)</td>
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<td>*Exclusion: Studies where the family/companion had a unique responsibility (e.g. paid caregiver, proxy)</td>
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<td>- Physicians</td>
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<td>*Exclusion: Studies which only examined triadic communication with a nurse, or allied health professional (e.g. psychologist)</td>
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| Types of settings: | Any type of medical setting (including but not limited to: oncology, general practice, geriatrics, rehabilitation, diabetes) |

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<th>Types of communication:</th>
<th>Any form of physician-patient-family communication and/or decision-making</th>
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<td>*Exclusion: Studies which examined communication between only two members of the triad (e.g. patient-family communication outside of the consultation)</td>
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2.2.2 Data extraction

Both inductive and deductive data extraction techniques were utilised. All studies were initially analysed inductively to determine broad themes describing the literature base. Specifically, the candidate assessed each study and recorded the main aims and findings. Similar findings were grouped according to topic area and a preliminary list of themes was developed. The candidate and two supervisors engaged in iterative discussions about organisation of findings, after which the final five themes were decided. Deductive data extraction techniques were subsequently used to re-examine each study and extract data using a standard format (design, method, sample, measures, results and summary). Data was extracted by a research assistant and cross checked for accuracy by the candidate.

2.2.3 Quality assessment

The quality of included studies was based on the standardised Qualsyst assessment tool (Kmet, Lee, & Cook, 2004). Qualsyst consists of two separate scoring systems to evaluate study quality; a quantitative scale and a qualitative scale (see Box 2.3 and Box 2.4). This assessment tool was selected because it included an extensive manual for quality scoring with definitions and detailed instructions. A research assistant assessed the quality of all studies and the candidate assessed 50% of the studies. Cohen's Kappa, used to determine inter-rater reliability, was 0.61 between the two raters; indicating substantial agreement according to the Landis and Koch (1977) standards for interpretation. Agreement was defined as the proportion of items where both raters gave the same score (e.g. 0, 1, or 2). Disagreement was defined as the proportion of items where both raters did not reach the same score (e.g. a score of 1 from research assistant, a score of 2 from candidate). Any identified discrepancies were resolved through iterative discussions. Each study was allocated a final score, which, as defined by Lee, Packer, Tang, and Girdler (2008), was used to define the quality of the study as: limited (<50%), adequate (50-70%), good (71-80%), or strong (score of >80%). The quality of included studies is also reported in the summary tables, with endnotes to clarify which aspects of each study scored a rating of partial (not fully addressed) or no (not evident or inappropriate). For full definitions and instructions for quality scoring, see Kmet et al. (2004).
**Box 2.3: Checklist for assessing the quality of quantitative studies (Kmet et al., 2004)**

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**Box 2.4: Checklist for assessing the quality of qualitative studies (Kmet et al., 2004)**

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2.3 Results

The search strategy produced 8,409 references, most of which were not specifically relevant to the current topic but broadly related to illness and/or medical consultations. After deletion of duplicates and detailed assessment for eligibility, 52 studies were included (See Figure 2.1).

**Identification**

- 8,409 studies identified through database searching and additional searches
- 8,183 irrelevant studies and duplicates removed

**Screening**

- 226 abstracts screened
- 164 studies excluded

**Eligibility**

- 62 full-text articles assessed for eligibility
- 10 studies excluded

**Included**

- 52 studies included

*Figure 2.1: Flow diagram of study selection*

Examination of selected studies revealed five primary themes which were used to guide organisation of review findings. Theme 1, **patient, family, and consultation characteristics**, discusses the features of triadic consultations, characteristics of accompanied vs. unaccompanied patients or consultations, and characteristics of family members (see Table 1, Appendix A). Theme 2, **family member roles**, highlights the overall categories of a family member’s role in the consultation and the main reasons for their attendance at a consultation. Studies which coded the presence/absence of discrete family behaviours (e.g. *family member prompts patient to ask question*) were not included in this theme (see Table 2, Appendix A). Theme 3, **attitudes of patients, family members, and physicians toward family involvement**, explores each parties’ opinions and experiences of triadic communication (see Table 3, Appendix A). Theme 4, **attitudes towards, and patterns of, triadic decision-making**, highlights studies exploring medical decisions within triadic consultations (see Table 4, Appendix A). Finally, theme 5, **impact of family involvement on patient and provider ratings**, is a summary of the positive and negative changes/consequences, reported by patients or healthcare providers, as a result of family involvement.
participation (e.g. patient satisfaction, patient understanding of information, family conflict, physician overburden) (see Table 5, Appendix A). Findings relevant to each primary theme are described in detail within summary tables, with as much relevant information included as possible (some studies did not report information such as response rates or statistical values). Tables are summarised in text using summary statements. Wherever discrepant results were found, the candidate attempted to look further into the data to uncover any characteristics which explained the findings. Studies that addressed more than one of the five themes are listed in each relevant table and include the measures, and results specific to the theme. Studies included in Tables 1, 2, and 5 of Appendix A are organised under the sub-categories of quantitative, qualitative, or mixed methods. Studies included in Tables 3 and 4 of Appendix A are organised under sub-categories of attitudes of patients, family members, physicians, or 2+ members of the triad. Within each sub-category, studies are ordered according to their quality rating (highest to lowest). All tables are displayed in Appendix A.

2.3.1 Theme 1: Patient, family, and consultation characteristics

Twenty eight studies examined the characteristics of triadic consultations, including the nature of triadic consultations (e.g. length of visit), characteristics of accompanied vs. unaccompanied patients, and characteristics of family members attending consultations (see Table 1, Appendix A). The majority of studies were of good to strong quality (>70% in quality ratings) and used quantitative methods; with thirteen of the studies involving analyses of audio- or video-tapes of actual medical encounters (Baker, Yoels, Clair, & Allman, 1997; Beisecker, 1988, 1989; Clayman et al., 2005; Eggly et al., 2011; Eggly et al., 2006; Greene, Majerovitz, Adelman, & Rizzo, 1994; Ishikawa, Hashimoto, et al., 2005; Ishikawa, Roter, Yamazaki, Hashimoto, & Yano, 2006; Ishikawa, Roter, Yamazaki, & Takayama, 2005; Labrecque, Blanchard, Ruckdeschel, & Blanchard, 1991; Shields et al., 2005; Street & Gordon, 2008). There were little differences between the quantitative and qualitative results for this theme. The nine studies that reported accompaniment rates highlighted variation according to patient population. Adult patients who attended primary care or outpatient clinics had the lowest accompaniment rate (16-25%) (Beisecker, 1988; Botelho, Lue, & Fiscella, 1996; Brown, Brett, Stewart, & Marshall, 1998; Schilling et al., 2002), this rate increased in older patients (aged > 60 years) who visited a primary care, geriatric or outpatient clinic (36-57%) (Beisecker, 1988; Glasser, Prohaska, & Gravdal, 2001; Glasser, Prohaska, & Roska, 1992; Ishikawa, Hashimoto, et al., 2005; Prohaska & Glasser, 1996). Within cancer consultations, 64% of patients were accompanied in one study (Street & Gordon, 2008), and the accompaniment rate increased to
86% in a study of cancer consultations where ‘bad news’ was disclosed (Eggly et al., 2006). The majority of studies (17 out of 28) included in this theme sampled both accompanied and unaccompanied patients to enable comparison of dyadic versus triadic consultations (Beisecker, 1989; Botelho et al., 1996; Brown et al., 1998; Eggly et al., 2011; Glasser et al., 2001; Glasser et al., 1992; Greene et al., 1994; Ishikawa, Hashimoto, et al., 2005; Ishikawa, Roter, et al., 2005; Labrecque et al., 1991; Prohaska & Glasser, 1996; Rosland, Piette, Choi, & Heisler, 2011; Schilling et al., 2002; Shields et al., 2005; Silliman, Bhatti, Khan, Dukes, & Sullivan, 1996; Street & Gordon, 2008; Wolff & Roter, 2008) (see sections 2.3.1.1 and 2.3.1.2), whilst the remaining 11 studies explored the characteristics of only triadic consultations, without the comparison component (Baker et al., 1997; Barone, Yoels, & Clair, 1999; Beisecker, 1988; Beisecker, Brecheisen, Ashworth, & Hayes, 1997; Beisecker & Moore, 1994; Clayman et al., 2005; Eggly et al., 2006; Ishikawa et al., 2006; Main, Holcomb, Dickinson, & Crabtree, 2001; Petronio, Sargent, Andea, Reganis, & Cichocki, 2004; Srirangam et al., 2003) (included only in section 2.3.1.3).

2.3.1.1 Demographic characteristics of unaccompanied versus accompanied patients

The demographic characteristics of accompanied patients appeared to differ from unaccompanied patients. Although inconsistent, quantitative results indicated that accompanied patients were more likely to be older, female, less educated, and in worse physical health. Specifically, six studies found that accompanied patients were older than unaccompanied patients (Beisecker, 1989; Brown et al., 1998; Ishikawa, Hashimoto, et al., 2005; Schilling et al., 2002; Silliman et al., 1996; Wolff & Roter, 2008); while five found no difference in age (Eggly et al., 2011; Glasser et al., 2001; Labrecque et al., 1991; Prohaska & Glasser, 1996; Street & Gordon, 2008). Upon examining these differences, it appears that illness severity may partially explain this discrepancy as three of the five studies which found no difference in age were conducted with cancer patients, whereas all of the studies which found differences in accompaniment rate by age were in geriatric or primary care settings. Two studies found that accompanied patients were more likely to be female (Glasser et al., 2001; Prohaska & Glasser, 1996) and three studies found no difference in sex (Eggly et al., 2011; Ishikawa, Roter, et al., 2005; Labrecque et al., 1991). The two studies indicating higher female patient accompaniment were amongst elderly patients in a primary care setting, whereas two of the three studies finding no differences in sex were amongst cancer patients.

Five studies found that, compared to their unaccompanied counterparts, accompanied patients were less educated (Botelho et al., 1996; Ishikawa, Hashimoto, et al., 2005; Prohaska & Glasser, 1996; Schilling et al., 2002; Wolff & Roter, 2008); however three studies found no difference in
education level (Eggy et al., 2011; Glasser et al., 2001; Street & Gordon, 2008). All of the studies which indicated a difference were conducted in routine, primary care visits; whereas two of the three studies which found no difference in accompaniment status were cancer consultations. Six studies found that accompanied patients were more likely to be in worse physical health or have a poorer functional status (Greene et al., 1994; Ishikawa, Hashimoto, et al., 2005; Labrecque et al., 1991; Schilling et al., 2002; Silliman et al., 1996; Wolff & Roter, 2008), whilst one study found no difference in patient health status (Street & Gordon, 2008). Five of the six studies which found a significant difference were conducted in a primary care setting; whilst the study which found no significant difference was conducted amongst lung cancer patients. Three studies found no significant difference between accompanied and unaccompanied patients in their psychological status (Greene et al., 1994; Ishikawa, Roter, et al., 2005; Street & Gordon, 2008); however one study found that accompanied patients reported more symptoms of depression (Glasser et al., 2001). However, the three studies which found no difference utilised global measures of psychological functioning (SF-8, SF-12, Functional Status Questionnaire), whilst the study which found greater depressive symptoms in accompanied patients used the more specific Durham GRECC Scale to measure depression. More consistent measurement of psychological outcomes is needed before conclusions can be drawn.

Amongst the majority of demographic characteristics, it appears that most of the studies which found no significant difference were conducted in the oncology setting. Therefore family members of cancer patients may be more likely to attend the consultation irrespective of patient’s demographic characteristics or functional status. Conversely, in more routine medical visits such as primary care or geriatric appointments, it appears that patients with reduced competence or greater need (e.g. older, less educated, poorer health) were more likely to be accompanied.

2.3.1.2 Communication patterns in dyadic versus triadic consultations

There were mostly no significant differences in the communication patterns of dyadic versus triadic consultations. Four studies found no difference in consultation length between unaccompanied and accompanied visits (Beisecker, 1989; Greene et al., 1994; Ishikawa, Hashimoto, et al., 2005; Street & Gordon, 2008), and another found no differences in number of words spoken or speech turns taken (Shields et al., 2005). However, one study of oncology outpatients found that the duration of accompanied visits was, on average, three minutes longer (Labrecque et al., 1991). Whilst one study found that physicians engaged in less partnership building and positive talk when family members were present (Ishikawa, Roter, et al., 2005), other studies found no differences in physician
communication, which included: physician control of conversation or use of facilitative communication (Street & Gordon, 2008); number of physician raised topics; and physician responsiveness (information giving and supportiveness) (Greene et al., 1994). It is unclear why there are some discrepancies in communication, and it appears unrelated to consultation context or illness severity. The experience of the physician may influence communication patterns; however most studies failed to report on the experience levels and psychosocial orientation of participating physicians.

Findings related to patient involvement also varied. Patients in accompanied consultations were less involved than those in unaccompanied consultations in two studies conducted in geriatric and primary care settings (Greene et al., 1994; Ishikawa, Hashimoto, et al., 2005) but not in another study conducted in an oncology setting (Eggly et al., 2011). Accompanied patients in the primary care setting raised fewer topics, engaged less in joint decision-making, and were rated as less expressive and assertive compared to unaccompanied patients (Greene et al., 1994). Geriatric patient contribution to the medical dialogue and number of words spoken by the patient was lower when a family member was present (Ishikawa, Hashimoto, et al., 2005). Conversely, a recent study amongst cancer patients and their family members found that presence of family did not significantly decrease the total frequency of patient questions (Eggly et al., 2011). Compared to accompanied patients, unaccompanied patients were found to express more negative feelings (Street & Gordon, 2008); and were more likely to understand their medical problems (Prohaska & Glasser, 1996). Most of the studies assessing communication patterns applied interaction analysis coding frames to consultation audio-tapes (Eggly et al., 2011; Greene et al., 1994; Ishikawa, Hashimoto, et al., 2005; Ishikawa, Roter, et al., 2005; Street & Gordon, 2008). However, several different coding frames were used (e.g. RIAS, MDIA, K-ISAS) making comparisons between studies difficult.

It appears that the illness severity/consultation context may also influence patient involvement levels. Studies conducted within the geriatric and primary care settings indicate that some accompanied patients may be less actively involved in the consultation than their unaccompanied counterparts. This is unsurprising given that accompanied patients tend to be older, less educated, and in poorer health; and these factors may contribute to their overall low activity levels within the consultation. However, patients accompanied to cancer consultations appear to be actively engaged in the consultation; suggesting that family may attend consultations for serious illnesses irrespective of the patient’s ability to actively engage in the consultation.
2.3.1.3 Behaviour of family members in triadic consultations

The behaviour of family and their influence on the communication in the consultation was less clear. One study showed that in 41% of consultations, family members were more verbally active than geriatric patients (Ishikawa et al., 2006). Similarly, in a study which examined ‘bad news’ oncology interactions, family members asked more questions than patients (Eggly et al., 2006). However, within some accompanied consultations, lung cancer patients were more active and assertive than their family (Street & Gordon, 2008); geriatric patients instigated laughter more than family (Baker et al., 1997), and older primary care patients raised more issues than their family member (Shields et al., 2005). Illness severity and patient functioning do not appear to be influencing the direction of results. The inconclusive findings regarding the behaviour of family members and their influence on consultation communication warrants further inquiry.

In ten studies within Theme 1 the most common family member was the spouse (Beisecker et al., 1997; Clayman et al., 2005; Eggly et al., 2011; Glasser et al., 2001; Ishikawa et al., 2006; Labrecque et al., 1991; Main et al., 2001; Prohaska & Glasser, 1996; Schilling et al., 2002; Wolff & Roter, 2008), with six studies reporting that an adult child was the second most common (Eggly et al., 2011; Glasser et al., 2001; Ishikawa et al., 2006; Labrecque et al., 1991; Main et al., 2001; Wolff & Roter, 2008).

2.3.2 Theme 2: Family member roles

Fifteen studies defined overall categories of family member roles or explored the main reasons for their attendance at a consultation. Twelve of these studies were conducted in the USA (see Table 2, Appendix A). Nine studies were quantitative (Brown et al., 1998; Glasser et al., 2001; Ishikawa et al., 2006; Ishikawa, Roter, et al., 2005; Prohaska & Glasser, 1996; Schilling et al., 2002; Silliman et al., 1996; Street & Gordon, 2008; Wolff & Roter, 2008), four were qualitative (Beisecker & Moore, 1994; Ellingson, 2002; Petronio et al., 2004; Speice et al., 2000), and two studies used mixed methods (Beisecker, 1989; Beisecker et al., 1997). Within this theme, the quantitative results mainly provided frequencies of each family role; whereas the qualitative studies gave greater depth and context to these results, explaining that roles may vary within the consultation and throughout the illness trajectory, and that family members may be unsure of which role to assume. The majority of studies were of good to strong quality (> 70% in quality ratings). Seven studies were conducted in the primary care and/or geriatric setting and included older adults only (>60 years old) (Beisecker, 1989; Glasser et al., 2001; Ishikawa et al., 2006; Ishikawa, Roter, et al., 2005; Prohaska & Glasser, 1996; Silliman et al., 1996; Wolff & Roter, 2008); whilst two additional studies
were conducted in the primary care setting, but included adult participants of all ages (Brown et al., 1998; Schilling et al., 2002). Five studies involved cancer consultations (Beisecker et al., 1997; Beisecker & Moore, 1994; Ellingson, 2002; Speice et al., 2000; Street & Gordon, 2008), and one study examined the role of family members at any clinical visit (Petronio et al., 2004). Twelve studies assessed patient/family/physician perspectives of family roles which used questionnaires or interviews (Beisecker et al., 1997; Beisecker & Moore, 1994; Brown et al., 1998; Glasser et al., 2001; Ishikawa et al., 2006; Ishikawa, Roter, et al., 2005; Petronio et al., 2004; Prohaska & Glasser, 1996; Schilling et al., 2002; Silliman et al., 1996; Speice et al., 2000; Wolff & Roter, 2008) and three used direct observation of consultations by researchers or analysis of consultation audio-recordings (Beisecker, 1989; Ellingson, 2002; Street & Gordon, 2008).

The most commonly reported roles of family members were to provide: **logistical assistance** (transportation and physical assistance) (Beisecker et al., 1997; Glasser et al., 2001; Prohaska & Glasser, 1996; Schilling et al., 2002; Wolff & Roter, 2008); **informational support** (clarified patient history, remembered information, ensured patient understanding) (Beisecker et al., 1997; Glasser et al., 2001; Prohaska & Glasser, 1996; Schilling et al., 2002; Silliman et al., 1996; Speice et al., 2000; Wolff & Roter, 2008); **emotional support** (Comforted patients, provided companionship, provided non-verbal support) (Beisecker et al., 1997; Beisecker & Moore, 1994; Glasser et al., 2001; Prohaska & Glasser, 1996; Schilling et al., 2002; Speice et al., 2000; Wolff & Roter, 2008); and **some family members addressed their own needs** (e.g. expressed own concerns to physician) (Schilling et al., 2002; Silliman et al., 1996). The primary role of family members of patients with chronic illnesses (e.g. diabetes, cancer) appeared to be emotional and informational support, whereas the family of geriatric or older primary care patients often provided logistical assistance and informational support. Physicians identified the main role of the family member as emotional or informational support (Beisecker & Moore, 1994; Brown et al., 1998; Schilling et al., 2002).

Ellingson (2002) identified the following eight family roles through direct observations: i) memory aid; ii) emotional support; iii) transcriber; iv) aid in decision-making; v) elaborator; vi) advocate; vii) interpreter; and viii) company provider. Street and Gordon (2008) found that most family members adopted a passive observer role (49%), a minority were moderately involved partners (18%) and a third of family members were highly active advocates/surrogates (33%). Although family members primarily supported the patient, they also indirectly supported the physician by recalling essential information about the patient and re-explaining and recalling information for the patient after the consultation (Street & Gordon, 2008). Family roles appear to vary greatly, which
may be partially explained by perceived patient needs; however other factors such as personality and relationship dynamics may also influence involvement and roles.

2.3.3 Theme 3: Attitudes of patients, family members, and physicians toward family involvement

Sixteen studies examined attitudes toward triadic communication by those participating in the consultations (see Table 3, Appendix A). There were six quantitative studies (Botelho et al., 1996; Brown et al., 1998; Glasser et al., 2001; Ishikawa et al., 2006; Repetto, Piselli, Raffaele, & Locatelli, 2009; Schilling et al., 2002), nine qualitative studies (Barone et al., 1999; Beisecker & Moore, 1994; Ellingson, 2002; Huang, Butow, Meiser, & Goldstein, 1999; Kimberlin et al., 2004; Morris & Thomas, 2001; Petronio et al., 2004; Sinfield et al., 2008; Speice et al., 2000), and one mixed-methods study (Beisecker et al., 1997). Within this theme, the inclusion of nine qualitative studies provided insight into participants’ emotions toward family involvement and the reasons behind their involvement preferences and attitudes.

Studies were divided into attitudes of: i) patients only; ii) family members only; iii) physicians only; and iv) two or more members of the triad. Quality ratings of the studies varied widely from adequate to strong (64% - 100%). Most studies were from an oncology setting (Beisecker et al., 1997; Beisecker & Moore, 1994; Ellingson, 2002; Huang et al., 1999; Kimberlin et al., 2004; Morris & Thomas, 2001; Repetto et al., 2009; Sinfield et al., 2008; Speice et al., 2000), four studies from primary care (Botelho et al., 1996; Brown et al., 1998; Glasser et al., 2001; Schilling et al., 2002), two geriatric studies (Barone et al., 1999; Ishikawa et al., 2006), and one study examined family members’ attitudes and experiences in any type of consultation (Petronio et al., 2004).

2.3.3.1 Patient attitudes

Studies that examined patients’ preferences highlighted that patients generally preferred family involvement in the consultation (Beisecker et al., 1997; Huang et al., 1999; Kimberlin et al., 2004; Repetto et al., 2009; Speice et al., 2000), although they believed that they should be the one who decides whether their family member attends (Beisecker et al., 1997). Cancer patients appreciated family involvement as a source of support, assistance with decision-making and communication with the physician. They also appreciated the informational support provided by family members, including asking questions, gathering information, taking notes, and recalling details. Additionally, they appreciated the efforts that their physicians made to involve family; for example, by inviting family members into the consultation and getting to know them (Speice et al., 2000). Cancer
patients identified that family members were most involved in consultations at the beginning of treatment, when test results were discussed, and decisions had to be made (Beisecker et al., 1997). Two studies revealed that between 16-30% of patients who attended a primary care consultation alone wished that they had a family member to accompany them (Botelho et al., 1996; Schilling et al., 2002).

### 2.3.3.2 Family member attitudes

Similarly, studies that examined family attitudes were mostly from an oncology setting. Family members of oncology patients thought that it was important that they were involved in the consultation (Kimberlin et al., 2004; Morris & Thomas, 2001; Sinfield et al., 2008) and did not view attending medical visits with the patient as a burden (Kimberlin et al., 2004; Petronio et al., 2004). However, family members felt that they needed to be invited into the consultation by the patient (Morris & Thomas, 2001). Family members perceived that they were helpful in the consultation and believed they helped both the patient and physician in the ensuring provision of the best possible medical care (Beisecker et al., 1997; Petronio et al., 2004). Some family members acknowledged that they also protected the patient by providing information and advice to the physician (Huang et al., 1999). Despite their perceived helpfulness in the consultation, some family members reported some negative experiences such as being actively excluded by healthcare professionals or feeling superfluous in the consultation (Morris & Thomas, 2001).

### 2.3.3.3 Attitudes of patient-family pairs

Three studies examined the preferences of matched patient-family pairs (Beisecker et al., 1997; Glasser et al., 2001; Ishikawa et al., 2006). A study among geriatric patients found that they expected family to be more indirectly involved (supporting, remembering information, facilitating communication) rather than directly involved (asking questions, providing information); whereas family members expected to play a more active role (Ishikawa et al., 2006). A study of matched cancer patient-family pairs revealed that while both patients and family members found family involvement helpful, family members’ perception of their helpfulness and involvement was greater than the views of patients (Beisecker et al., 1997). Mirroring these findings, one study found that although 70% of patients and family members agreed that accompaniment was important, family were more likely to rate the importance of accompaniment higher (Glasser et al., 2001). These findings suggest potential mismatch of expectations or confusion about what role to assume within the patient-family relationship.
2.3.3.4 Physician attitudes

Overall, physicians appreciated the family member's input, and thought they were helpful in gathering and sharing information regarding medical history, medications used, and symptoms experienced (Barone et al., 1999; Beisecker & Moore, 1994). Some oncologists acknowledged that including a family member added increased complexity to the consultation (Beisecker & Moore, 1994). To improve patient assessment, some geriatricians preferred that patients answer the questions themselves (Barone et al., 1999). Geriatricians stated that sometimes they viewed the family's presence as an indication that the patient was incapable of answering questions (Barone et al., 1999).

2.3.4 Theme 4: Attitudes towards, and patterns of, triadic decision-making

Twenty studies examined the attitudes towards, and patterns of, triadic medical decision-making (see Table 4, Appendix A). The quality of studies varied considerably, five studies scored <65%. Most studies (14 out of 15 studies) that examined participant's attitudes employed quantitative methodology, whereas three out of five studies that examined decision-making patterns of triads employed qualitative methodology. Twelve studies were from an oncology setting (U. Boehmer & Clark, 2001; Davison et al., 2002; Gilbar & Gilbar, 2009; Gonçalves et al., 2005; Hilton, 1994; Hubbard et al., 2010; Pardon et al., 2010; Philip, Gold, Schwarz, & Komesaroff, 2009; Schäfer et al., 2006; Shepherd, Tattersall, & Butow, 2008; Srirangam et al., 2003; Stiggelbout et al., 2007), two studies from primary care and/or geriatrics (Clayman et al., 2005; Shields et al., 2005), and six studies included patients of other disease types (Gabbay et al., 2005; Heyland et al., 2006; Ito, Tanida, & Turale, 2010; Nolan et al., 2005; Petronio et al., 2004; Sekimoto et al., 2004).

2.3.4.1 Patient attitudes

Most patients wanted their family member to be involved in the decision-making process; however, the extent of preferred family involvement varied. In three studies of patients with various illness severities (primary care, diabetes, and acutely ill hospitalised patients), approximately one third of patients preferred that all parties in the consultation have equal say in the decision-making process (i.e. shared triadic decision-making) (Heyland et al., 2006; Ito et al., 2010; Sekimoto et al., 2004); whereas approximately one third of patients expressed a desire to make the decision themselves after consulting with their physician and family member (Ito et al., 2010). Another third of patients preferred that the physician be the main decision-maker (Gonçalves et al., 2005; Nolan et al., 2005). Factors associated with wanting greater family involvement in decision-making were having a
partner and poorer physical functioning (Pardon et al., 2010). In a study of diabetes patients given one of three hypothetical decision-making vignettes (cancer, pneumonia, or gangrene diagnosis), substantially more 'cancer' patients wished for family involvement in decision-making than 'gangrene' or 'pneumonia' patients. Therefore, illness severity may also play a part in patient preferences for family involvement in decision-making (Sekimoto et al., 2004). Little else is known about factors influencing patient preferences for family involvement in decision-making.

### 2.3.4.2 Family member attitudes

Between 55-60% of family members of cancer patients surveyed prior to decision-making stated a preference to be involved in the decision-making process (Davison et al., 2002; Schäfer et al., 2006); whilst retrospective studies indicated that between 60-88% of family members of cancer patients indicated that they were actively involved in the decision-making process (Schäfer et al., 2006; Srirangam et al., 2003). Therefore, the majority of cancer patient family members desire involvement, and are subsequently involved in the decision-making process. Despite their involvement, some family members (40%) reported that they deliberately avoided influencing the patient’s final decision (Srirangam et al., 2003); whilst some felt uncomfortable participating in decision-making as they had not anticipated this as a role (Petronio et al., 2004). Therefore, an important minority of family members may be reluctantly involved in the decision-making process.

### 2.3.4.3 Physician attitudes

In two studies conducted in the oncology setting, physicians believed that family involvement in decision-making is important and were generally supportive of their involvement (Gabbay et al., 2005; Shepherd et al., 2008). One study found that 69% of oncology physicians agreed that family members encouraged patient involvement and reflection on treatment decisions (Shepherd et al., 2008). In another study, Japanese- and US-based medical residents perceived the involvement of family in medical encounters to be very important (Gabbay et al., 2005). However, physicians also identified challenges of family involvement, such as family domination as a barrier in the decision-making process (Shepherd et al., 2008).

### 2.3.4.4 Patterns of decision-making

Only five studies to date have assessed the patterns of triadic decision-making within medical encounters, each with a different approach (U. Boehmer & Clark, 2001; Clayman et al., 2005; Hilton, 1994; Hubbard et al., 2010; Shields et al., 2005). A study which analysed audio-taped geriatric consultations found that half of all patients were active decision-makers, compared to a quarter of
family members (Clayman et al., 2005). Spouses and adult children of patients were more likely to be active in decision-making than other relatives or friends. Three qualitative studies have identified a spectrum of the decision-making roles and patterns that family members assumed within cancer consultations (U. Boehmer & Clark, 2001; Hilton, 1994; Hubbard et al., 2010). In a study of cancer patient family members, roles ranged from more passive facilitators of discussions and stimulating thinking, to active roles such as directing the flow of information and discussion about decisions. The influence of the family was dependent on the patient’s information processing ability, the family member’s skill in anticipating the needs of the patient, and the perception of what treatment choices were available (Hubbard et al., 2010). Further, family and patient activity ranged from minimal participation through to extensive active participation in decision-making. Involvement patterns appeared to be influenced by pre-diagnosis communication of the patient and family, patient/family age and education, and complexity of the decision (Hilton, 1994). Family members were also found to influence the decision-making process outside of the consultation, acting as sound-boards for the patient and stimulating thinking about the decision ‘behind the scenes’ at home (Hubbard et al., 2010). Measurement of decision-making patterns was diverse, with some studies using observational coding frames (e.g. RIAS, MPCC, RPAD), whilst others included patients’ qualitative accounts of decision-making patterns. Standardised assessment of triadic decision-making patterns is needed before comparisons between studies or populations can be made.

2.3.5 Theme 5: Impact of family involvement on patient and provider ratings

Seventeen studies examined the impact of family involvement on consultations (see Table 5, Appendix A). This theme explored both the positive and negative consequences resulting from family participation. There were ten quantitative studies (Glasser et al., 2001; Greene et al., 1994; Ishikawa, Hashimoto, et al., 2005; Labrecque et al., 1991; Prohaska & Glasser, 1996; Repetto et al., 2009; Rosland et al., 2011; Shields et al., 2005; Street & Gordon, 2008; Wolff & Roter, 2008), six qualitative studies (Barone et al., 1999; Beisecker & Moore, 1994; Coe & Prendergast, 1985; Hubbard et al., 2010; Kimberlin et al., 2004; Speice et al., 2000), and one mixed methods study (Beisecker et al., 1997). The majority of studies were of good to strong quality, scoring > 70%. Most studies were conducted in the USA. Eight studies were from an oncology setting (Beisecker et al., 1997; Beisecker & Moore, 1994; Hubbard et al., 2010; Kimberlin et al., 2004; Labrecque et al., 1991; Repetto et al., 2009; Speice et al., 2000; Street & Gordon, 2008), eight from primary care and/or geriatrics (Barone et al., 1999; Coe & Prendergast, 1985; Glasser et al., 2001; Greene et al., 1994;
Patient’s satisfaction with the medical visit and with the care provided by physicians was one of the most commonly measured outcomes of family involvement, via the use of items adapted from various questionnaires. Six studies that measured satisfaction yielded inconsistent results. Three studies from various medical settings (geriatrics, primary care, oncology) found no differences between accompanied and unaccompanied patients (Greene et al., 1994; Labrecque et al., 1991; Shields et al., 2005), whereas three studies reported significant effects (Rosland et al., 2011; Street & Gordon, 2008; Wolff & Roter, 2008). In a study involving a large community sample of older individuals, those patients accompanied to medical visits were more satisfied with their physician’s technical skills, information provision, and interpersonal skills than unaccompanied patients, after controlling for socio-demographic and health differences (Wolff & Roter, 2008). Another study showed that cardiovascular/diabetes patients were more satisfied with their physician’s care when their family members were actively involved (Rosland et al., 2011). It is unclear why these satisfaction results are discrepant; however each study used a different measure of satisfaction which may have influenced the results. Additionally, few studies have examined satisfaction in sufficient depth to uncover whether patient satisfaction may vary depending on particular types or levels of family involvement. One study of cancer patients which did explore this concept found that when patients and family members had similar levels of participation in the consultation, patients were less satisfied with the encounter than patients with either more passive or more active family members (Street & Gordon, 2008). One suggestion is that family members who are in some way complementary to the patient may increase patient satisfaction, rather than all family members leading to increased satisfaction.

The majority of patients reported positive consequences of family involvement in consultations. Patients reported that family members helped increase their understanding (Rosland et al., 2011) and helped improve the quantity and quality of information exchanged in consultations (Hubbard et al., 2010; Kimberlin et al., 2004). Changes reported by patients when a family member was present were an increase in the total number of questions asked, and feeling more comfortable during consultations (Beisecker et al., 1997). Some patients found it easier to discuss difficult topics at the consultation when accompanied (Rosland et al., 2011); and most physicians in one study thought family members positively influenced the information exchanged in consultations (e.g. family assisted patients by encouraging or prompting them to ask more questions) (Beisecker &
Moore, 1994). They reported that the family member’s presence allowed physicians to obtain more information (Beisecker & Moore, 1994), and to improve their understanding of the patient’s concerns (Rosland et al., 2011).

However, some unfavourable consequences were also reported. Patients stated that involvement of family could create disagreements between the patient and the family; and that both physicians and family members sometimes shared too much information in the consultation (Rosland et al., 2011). Physicians also raised concerns such as family involvement taking time away from discussing important issues with patients; and some physicians reported feeling overburdened when family participated (Rosland et al., 2011). Some physicians found it difficult when patients and family members purposely concealed information from one another (Speice et al., 2000). They also believed that the presence of a family member might prevent patients from discussing sensitive issues (Barone et al., 1999).

2.4 Discussion and conclusion

2.4.1 Discussion

The current review has demonstrated that a diverse literature base exists within the field of triadic consultations. The majority of reviewed studies provided descriptive evidence about the characteristics of triadic consultations and accompanied patients/family members, or focused on participant preferences for family involvement. However, studies were restricted by the lack of relevant theory describing triadic consultations. Currently, there are few applicable theories to assist in depicting triadic interactions; however some recent studies have proposed preliminary process models, which highlight factors influencing triadic interactions and potential outcomes, which may be useful for future research (Dalton, 2003; Wolff & Roter, 2011). One such process model is the *Family Involvement in Interpersonal Health Care Processes* framework proposed by Wolff and Roter (2011); whereby the interaction pathways between patients, families, and health professionals are depicted, and the influence of family on interpersonal processes and outcomes of medical consultations are discussed. Continued development and utilisation of comprehensive triadic theoretical frameworks, particularly one that explains triadic dynamics, may provide guidance and direction for future research, allowing for greater integration and progress within this diverse research area.

Many of the studies included in the review have neglected deeper concepts such as factors influencing the level of family involvement, qualitative recounts of attitudes and experiences, and
the impact of family members on treatment decision-making. To date, very few studies have examined the impact of patient-family relationship quality and dynamics on consultation interactions or the characteristics of patients who do not desire accompaniment. Aside from satisfaction, few studies have examined other potential effects of family involvement within consultations (e.g. quality of decision-making, family wellbeing). A particular challenge of this literature base was the variability in the terms used to describe a ‘third person’; for example, ‘carers’ may behave in a different way to ‘loved ones’. To date, no studies have identified the characteristics and behaviours of different types of third parties (e.g. spouse vs. adult child).

Overall, existing studies indicated that family members regularly attend consultations and assume a variety of roles within the consultation. Upon further examination, it appears that increased patient need may mediate accompaniment rates, involvement levels, and family roles. Patients attending geriatric or primary care consultations were more likely to be accompanied and less likely to be actively involved in the consultation if they were older, less educated, or more unwell, therefore potentially possessing lower capacity and increased need. Studies indicated that for patients attending specialist consultations for a life threatening illness (e.g. cancer), demographic characteristics did not appear to influence accompaniment or involvement levels; however the overall family attendance rate was high (64-86%) indicating that for serious illness, patients may be in need of family support for different reasons. Family roles appear to shed light on this pattern, with family members engaging in more logistical support for geriatric/primary care patients, whilst providing greater emotional support for cancer patients. Informational support appeared to be provided irrespective of illness severity/type, however further research to tease apart the different types of informational support (e.g. asking questions, recalling information, ensuring patient understanding) that a family member provides is warranted.

Within the consultation, both patients and physicians generally preferred family involvement and appreciated the support family members provide. Patients particularly found the informational support family provided to be useful, such as asking questions, taking notes, and recalling information; especially during important discussions and treatment decision-making. Hubbard et al. (2010) suggested that the informational support provided by family members can be particularly useful for patients who are passive within consultations, but who might discuss information about treatment with their family outside of consultations. Physicians also appreciated the informational assistance provided by family members, but some physicians preferred giving the
patient the opportunity to answer for themselves to assist patient assessment. Family members should potentially be made aware of what behaviours patients and physicians find most helpful.

Studies also revealed that family involvement can lead to positive consequences. Patient visit satisfaction within triadic consultations was equal to or higher than dyadic consultation satisfaction, despite the results indicating that accompanied patients were often older, in poorer physical health, and less educated. Additionally, family involvement was associated with improved patient understanding, improved quality and quantity of information exchanged, and an increased patient perception of comfort and freedom of expression inside the consultation. Future research should aim to develop strategies which increase these beneficial behaviours and outcomes.

However, various challenges were also evident in triadic consultations, including confusion about what role the family member should assume, family conflict, physicians or family members over-sharing information, and difficulty discussing sensitive issues. Explicit clarification and agreement of preferred family involvement levels and roles by the physician upon commencement of the consultation may overcome some of these challenges. Additionally, physicians perceived dominating or demanding family members to be particularly challenging. Future research needs to explore strategies to best manage difficult family members whilst ensuring consultation objectives are still achieved. Within the communication and decision-making literature, it appears that most patients have the desire to retain control of who attends the consultation, what information is conveyed, and how decisions are made. Family members and physicians should be made aware of, and respect, the patient’s wishes regarding the extent to which family members influence the consultation and decision-making process.

Patients and physicians generally supported family involvement in decision-making; however mediating factors such as pre-existing patient-family relationship dynamics, physical functioning, and illness severity may affect involvement levels. Patients’ preferences for the level of family involvement in decision-making varied from passive to active. However, some family members did not anticipate active involvement in decision-making, and were uneasy about influencing the final decision. There is a need for further research and theory to clarify how family are specifically involved in the decision-making process, what influence they have on the final decision, and deeper understanding of the varying preferences and experiences of patients/family members/physicians regarding family involvement in decisions.
Overall, it appears that a family member’s position within the consultation is variable, and can range from ‘active partner’ or ‘welcome guest’ to ‘intruder’; and this involvement may be perceived differently by the patient, family, and physician. Therefore, it may be helpful for physicians to ascertain from the patient and/or family why the family member has accompanied the patient to the consultation.

Although quality of the reviewed studies was variable (50-100% on the Qualsyst quality assessment tool), the majority (36 studies) were rated as strong (i.e. >80%). Common limitations identified in the quantitative studies were inappropriate sampling strategies, inadequate description of participant characteristics, and inadequate control of confounding variables (e.g. health status, age). Many of the quantitative studies were restricted by the lack of validated triadic measures and coding frames and many questionnaire items lacked specificity (e.g. asking patients to rate family ‘helpfulness’). Future measures should be validated and include items which clarify the specific behaviours of family members in consultations and which of these behaviours are most helpful to the patient. Additionally, not all studies used the same measures, nor did they measure the same outcomes, therefore comparison between studies was made difficult. Consistent usage of validated measures specifically designed for triadic consultations would enable greater comparison of findings across studies and populations. Furthermore, six quantitative studies were secondary analyses of previous data sets (Baker et al., 1997; Beisecker, 1989; Clayman et al., 2005; Eggly et al., 2011; Eggly et al., 2006; Greene et al., 1994); therefore the methods used to collect initial data may not be ideal for the current (triadic) research question. Among the 14 included qualitative studies, some of the common limitations identified in the quality ratings included inappropriate sampling strategies, unclear description of data collection methods, and limited use of verification procedures (e.g. inter-rater reliability or external audits).

The included literature was biased toward western cultures (44/52 studies), with over half of the studies conducted in the US. However, studies examining triadic decision-making were more culturally diverse (including Portugal, Germany, Israel, and Japan). To date, only one study has explored cross cultural differences regarding family involvement in consultations (Gabbay et al., 2005). Literature was also skewed towards the disciplines of primary care, geriatrics, and oncology, with only five studies examining other illnesses (e.g. diabetes, heart failure). Since attitudes toward family involvement and behaviours of participants in triadic consultations are likely to vary depending on illness type and severity (Sekimoto et al., 2004) further research into other medical settings is warranted.
Some of the trends we observed in the literature can be compared to the findings of the Wolff and Roter (2011) meta-analysis. Our review indicated that patients may be more likely to be accompanied if they were older, more unwell, less educated, and female, and this was mirrored in the meta-analysis. Surprisingly, four out of five studies in our review found no difference in consultation length between dyadic and triadic consultations, however when the data was pooled in the meta-analysis, Wolff and Roter (2011) found that accompanied visits were approximately 20% longer. Both reviews found that although overall physician behaviour did not vary considerably across dyadic and triadic consultations, a few studies indicated that some physicians became less patient-centred when a family member was present. While Wolff and Roter's (2011) meta-analysis allowed greater synthesis of quantitative results within the setting of routine medical visits, our wider eligibility criteria, including qualitative studies, enabled a deeper exploration of the variation in roles, attitudes, and behaviours within triads, as well as a deeper understanding of the experiences and preferences of each party in a variety of medical settings and in medical decision-making.

2.4.2 Limitations

Although the candidate searched systematically and thoroughly for eligible studies, this is not a well-indexed field of research, therefore it is possible that some relevant studies were not included in this review. Additionally, database searches were limited to studies written in English, therefore some studies from non-English speaking cultures may not have been included. Finally, this review is unable to provide comment on triadic communication in consultations which involved other health professionals (e.g. nurses, psychologists), or on decision-making discussions between the patient and family member outside of the consultation, as these topics were beyond the scope of the current review.

2.4.3 Conclusion

Despite the diverse literature base identified in this review, there are numerous gaps in our understanding of triadic consultations. Research is particularly needed in settings other than primary care and geriatrics; and across a range of cultures. Qualitative exploration of participant attitudes and experiences may also help to provide a deeper understanding of this topic area. Similarly, qualitative insight into the attitudes towards and facilitators/barriers/nature of triadic medical decision-making is also warranted. In addition, a clearer understanding of how the specific needs and characteristics of patients influence family involvement levels is needed. The
development of triadic theoretical frameworks, validated measures, and a specific triadic coding frame which captures family behaviours and family relevant behaviours of patients and physicians may also improve the overall quality of the research area. Finally, based on the limited translation of findings to clinical practice, future studies should identify and evaluate strategies to enhance triadic interactions such as strategies to facilitate positive family involvement and manage any challenging family member behaviours, particularly during the medical decision-making process.

2.4.4 Practice Implications

Family members are often perceived as helpful within consultations and their presence can result in perceived benefits such as increased patient comfort and understanding, and improved quality and quantity of information discussed. The role a family member assumes appears to be based on patient need, and includes logistical, informational and emotional support. Informational support is valued by the majority of patients and physicians, with behaviours such as note taking, question asking, and recalling of information often deemed very helpful. However, there are also challenges of family involvement such as family conflict or confusion about the family's role. Clarification and agreement of preferences and roles by the physician upon commencement of the consultation is one suggested strategy to ensure family members understand patient needs and preferences, whilst also minimising some of these challenges (Speice et al., 2000). Additionally, studies indicate that the majority of patients desire to retain control over which family members attend, what information is conveyed, and how decisions are made within the consultation. Physicians should be aware of patient preferences regarding family involvement.

Some patients also expressed discomfort sharing sensitive information (e.g. sexuality, depression) in front of family; therefore physicians could ask family members to leave during physical examinations, providing patients with a private opportunity to discuss any sensitive information (Ellingson, 2002). Health professionals should also be aware that family members are often involved in the decision-making conversations, inside and outside the consultation; therefore actively engaging with family inside the consultation during decision-making discussions may provide physicians with a greater awareness of the extent and type of influence family may have on the treatment decision.

Literature highlights that physician practices may remain unchanged, or become less patient centred, when family members are present; and in some studies, family reported unfavourable physician practices (e.g. blocking behaviours). Some preliminary suggestions from the literature to
overcome unfavourable practices include: i) physicians completing a self-assessment, providing opportunities to reflect upon their practices and attitudes towards family members in consultations; ii) physicians welcoming family and learning their name (Speice et al., 2000); and iii) acknowledging and involving family throughout the consultation (Morris & Thomas, 2001). Some of the above preliminary strategies are summarised in Box 2.5, and many of the proposed strategies are mirrored by Mitnick et al. (2010) who proposed ethical guidance for consultations involving family members. However, further research is needed to more clearly understand the range of challenges faced in triadic encounters and specific strategies utilised to overcome them. Based on the preliminary nature of many included studies, the array of factors influencing family involvement (e.g. patient demographics, illness severity, patient-family relationship), and paucity of evidence based practical recommendations, further research is needed to empirically develop and evaluate specific strategies to enhance triadic consultations.

Prior to the development and evaluation of strategies, a deeper understanding of the attitudes and experiences of the various stakeholders is needed. This systematic review has revealed that little is known about health professionals’ attitudes and experiences of family involvement. Further research is needed to understand what family behaviours health professionals find helpful, the challenges health professionals face in triadic consultations and decision-making, and the strategies they find most useful in overcoming difficulties related to family involvement. These issues will be explored in the next chapter.
Box 2.5: Preliminary strategies for health professionals

- **Encourage, welcome, and involve family in consultations.** Most patients who are accompanied desire family involvement, and family are often perceived by the patient to have a positive influence on the consultation.

- **Ascertain from the patient and/or the family why the family member has accompanied the patient to the consultation.** Family may attend for a range of reasons, which may differ from the patient's wants and needs.

- **Highlight helpful family behaviours.** Family members may be unaware of, or confused about, what role they should assume. Health professionals could explain the different types of appropriate support they could offer (e.g. emotional, informational, logistical).

- **Clarify and agree upon the role preferences of patients and family members at commencement of the consultation.** There appears to be role confusion and mismatch in role expectations between some patients and family members.

- **Be aware of, and respect, the patient's preferences for family involvement.** It appears that many patients desire to maintain control over who attends the consultation, what information is conveyed, and how decisions are made.

- **Take opportunities to privately discuss sensitive information with patients alone.** Some patients expressed discomfort sharing sensitive information (e.g. sexuality, fertility, psychological health) in the presence of family. One example of an opportunity is to allow time before the patient undresses for a physical examination, after the family member has left the room, to discuss sensitive issues with the patient alone.

- **Be aware that family members are involved in decision-making discussions outside of the consultation.** Family are often actively involved in decision-making discussions both inside and outside of consultations; therefore actively engaging with family in the consultation may prove beneficial.

- **Reflect upon your own behaviours toward family members.** Some patients and family members reported that their physician engaged in blocking behaviours or made family feel unwelcome or superfluous within the consultation.
Chapter 3:
Family involvement in consultations and decision-making:
The attitudes and experiences of oncology health professionals
3.1 Introduction

Past research indicates that a physician’s behaviour towards family members during consultations is important to the patient and the family member. Both patients and family members have reported that they appreciate when health professionals are inclusive of, and connect with, the family (Morris & Thomas, 2001; Speice et al., 2000). However, some family members have reported negative experiences, such as being actively excluded or made feel superfluous by the physician (Morris & Thomas, 2001). Levinson and Roter (1995) found that a physician’s psychosocial attitudes can affect the way that they communicate within a consultation. Given the high proportion of cancer consultations which include a family member, it is important to understand health professionals’ attitudes towards, and experiences of, family involvement.

After conducting a systematic review of triadic (physician-patient-family) consultation research (Chapter 2), it became clear that there is limited evidence in this area. To date, only two studies (Beisecker & Moore, 1994; Speice et al., 2000) have qualitatively examined the attitudes and experiences of oncology health professionals towards family members. Beisecker and Moore (1994) interviewed 12 oncology physicians to ascertain their perceptions of family members. Speice et al. (2000) conducted focus group discussions with 58 oncology health professionals (oncologists and nurses). Within both studies, benefits (e.g. patient emotional support and encouragement, decision-making support, informational support) and challenges (dominant family members, requests for non-disclosure of information, dysfunctional dynamics) of family involvement were noted. Speice et al. (2000) also proposed a number of strategies for health professionals to utilise when family members are present, such as role preference clarification questions for the patient and family member. These two studies provide an important foundation for understanding the experiences of health professionals, however further research is needed to explore health professionals’ attitudes and experiences in greater depth, and to understand the specific issues faced by Australian oncology health professionals. More information is needed about the challenges that health professionals face during triadic consultations, and the strategies they use to overcome them. Finally, based on the growth of shared decision-making and relational autonomy in the past decade, it is crucial to gain a clear understanding of where family fit in the medical decision-making process, and how health professionals view family involvement in decision-making.

To date, only one study has examined the attitudes of physicians towards family involvement in medical decision-making, however this study was conducted in a primary care, not oncology.
setting. Gilbar (2012a, 2012b) conducted in depth interviews with ten general practitioners (GPs) from the UK. The views of GPs varied; some were accepting of active family involvement whereas others were reluctant to include family in the decision-making process. Although they firmly believed patients should retain decision-making authority, most GPs recognised that family members are an important and inseparable part of the decision-making process. Research is needed to understand how health professionals specialising in chronic or life threatening illnesses (such as cancer) view family involvement in medical decisions.

Thus this study aimed to understand the attitudes and experiences of Australian oncology physicians and nurses. Of particular interest was exploring: i) how health professionals perceive family involvement, ii) the nature of family involvement in cancer consultations, iii) health professionals’ attitudes towards family involvement in decision-making, iv) the challenges health professionals face as a consequence of family attendance, and v) the strategies health professionals use to overcome these challenges.

3.2 Methods

3.2.1 Participants and procedures

Eleven Australian oncology physicians (medical, surgical, and radiation) and ten oncology nurses (medical, surgical, radiation, and haematology) experienced in treating a range of cancer types took part in semi-structured interviews.

Health professionals were recruited through professional associations and from one participating tertiary hospital. All eligible participants were based in Sydney, Australia. Eligible physicians and nurses were sent an invitation letter or email (see Appendix C) and were asked to indicate whether they would like to participate in the study. Interested participants contacted the research team by email or telephone and were sent a study pack comprising an information sheet (Appendix D), consent form (Appendix E), and questionnaire (Appendix F).

Of the 18 oncologists initially contacted, 11 agreed to participate (response rate 61%). Of the 21 oncology nurses initially contacted, 10 agreed to participate (response rate 48%). It was planned to continue recruitment until theoretical saturation (no new information in three consecutive interviews) was reached. This was achieved with the current sample, so a second round of mail-outs was not initiated.

Participants completed a questionnaire detailing their demographic and professional characteristics, and upon return of the questionnaire an interview time was arranged. The semi-
structured interview was conducted either in person or via the telephone. The average length of interviews with the oncologists was 43 minutes and for the oncology nurses was 53 minutes. Interviews were audio-recorded and transcribed verbatim.

Ethical approval for all aspects of the study was obtained from The Cancer Institute NSW Human Research Ethics Committee (see Appendix G).

3.2.2 Measures and Materials

A questionnaire assessed participant demographic information such as age and gender, and professional characteristics such as oncology specialisation, current professional position, years in medicine, years in oncology, and hours of patient contact. Physicians were also asked whether they had completed any formal communication skills training since medical school (see Appendix F).

A comprehensive semi-structured interview protocol was developed by the candidate and supervisors, based on a systematic review of family involvement in consultations (Chapter 2) and a review of dyadic shared decision-making theory and research (Charles et al., 1997; Charles, Gafni, et al., 1999; Charles, Gafni, & Whelan, 2004; Charles, Whelan, et al., 1999; Elwyn et al., 2000; Légaré, Ratté, Gravel, & Graham, 2008; Makoul & Clayman, 2006). Participants were asked about a range of topics related to family involvement in cancer consultations, including their attitudes to family presence, the roles family member's assume, and the involvement of family in the decision-making process (See Box 3.1 for an overview of the interview items for oncologists, See Appendix H for full interview schedule with prompts). Interview items for oncology nurses covered similar topics, but were appropriately rephrased to assess their observations of physician-patient-family consultations.
Box 3.1: Oncology physician interview items

<table>
<thead>
<tr>
<th>Overview of Interview items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attitudes towards family members in consultations</strong></td>
</tr>
<tr>
<td>• What do you think about having family members participate in consultations?</td>
</tr>
<tr>
<td>• Are some family members more/less helpful than others?</td>
</tr>
<tr>
<td><strong>Family member roles in the consultation</strong></td>
</tr>
<tr>
<td>• What roles have you observed family members assume in a consultation?</td>
</tr>
<tr>
<td><strong>Family involvement in decision-making</strong></td>
</tr>
<tr>
<td>• What do you think about family members being involved in the decision-making process?</td>
</tr>
<tr>
<td>• Are there any challenges including family members in decision-making?</td>
</tr>
<tr>
<td>• What strategies (if any) do you use to overcome these challenges?</td>
</tr>
<tr>
<td><strong>Family involvement in decision-making stages</strong></td>
</tr>
<tr>
<td>• How is information about different options discussed in consultations which include a family member?</td>
</tr>
<tr>
<td>• Once the information had been discussed, what happens when different options (if available) are being weighed up within consultations? Are preferences discussed, if so by who?</td>
</tr>
<tr>
<td>• When it comes down to making the decision, what is the influence of the family?</td>
</tr>
<tr>
<td><strong>Family involvement in decision-making (barriers and facilitators)</strong></td>
</tr>
<tr>
<td>• What do you think prevents family members from participating in treatment decision-making?</td>
</tr>
<tr>
<td>• What do you think helps family members participate in treatment decision-making?</td>
</tr>
<tr>
<td>• Can you think of any strategies to manage or enhance family involvement in decision-making?</td>
</tr>
</tbody>
</table>

3.2.3 Data analysis

Demographic data were collected and analysed using summary statistics such as means and frequencies, using SPSS Version 18.

3.2.3.1 Choice of Qualitative Approach

Qualitative research is a naturalistic, interpretative approach concerned with understanding the meanings which people attach to phenomena (such as their attitudes, experiences, and decisions) within their social worlds (Ritchie, Lewis, Nicholls, & Ormston, 2013). There are many different qualitative approaches to understanding participants’ experiences including grounded theory (Corbin & Strauss, 1990), interpretive phenomenological analysis (IPA) (Smith, 2007), discourse analysis (Burman & Parker, 1993) and thematic analysis (Braun & Clarke, 2006). Whilst qualitative approaches differ in their theoretical underpinnings and practical application, many are based on similar underlying philosophies such as a focus on the individual person, open-ended inquiry, inductive knowledge generation, and the importance of context (Willig, 2013). The similarities among qualitative approaches mean that there is often more than one approach that could reasonably be employed to explore a particular topic. Given the numerous research aims for this
study, it was deemed important to select a flexible qualitative approach. IPA was not considered appropriate because of its deep focus on the individual's lived experience, which did not align well with the aims of the current study (Guest, MacQueen, & Namey, 2011). Grounded theory, whilst considered appropriate, was not selected due to its onerous analytical process which was not considered appropriate given the large number of interviews to be conducted for this project (85 in total) (Guest et al., 2011). Thematic analysis was selected as the most appropriate analytic approach given its flexibility and suitability for use in large data sets (Braun & Clarke, 2006). Thematic analysis is an approach for identifying, analysing, and reporting patterns to describe data in rich detail. It progresses from description of data to interpretation of the significance of patterns and their broader meanings and implications (Braun & Clarke, 2006). Whilst thematic analysis was selected as the broad research paradigm, a specific method of data analysis, framework analysis, was chosen to practically guide analyses.

3.2.3.2 Choice of Qualitative Analysis Method

Framework analysis, proposed by Ritchie and Spencer (2002), is an analytic method which sits within the broad family of thematic analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Gale et al. (2013) noted that framework analysis “is appropriate for thematic analysis of textual data, particularly interview transcripts, where it is important to be able to compare and contrast data by themes across many cases, while also situating each perspective in context by retaining the connection to other aspects of each individual’s account” (p. 6).

Framework analysis typically involves five steps in an iterative, rather than linear, process. The first step, familiarisation, is where the researcher becomes familiar with and immersed in the data, usually by listening to audio-tapes and reading transcripts. Second, identifying a thematic framework, entails recognising emerging issues, concepts, and themes which can be used to filter and classify the dataset. Third, indexing, is where sections of the data which correspond to themes are identified and classified. This process is applied to all of the data gathered. Fourth, charting, refers to the process of transferring data from transcripts into charts of themes, typically a matrix with participants as rows and themes as columns. Finally, mapping and interpretation, involves the analysis of the framework within and across themes and participants to identify overarching themes and relationships (Ritchie et al., 2013; Srivastava & Thomson, 2009). Framework analysis is considered to be a practical approach to analysing large datasets within qualitative health research. It provides transparent results and offers conclusions that can be related back to the original data (Ward, Furber, Tierney, & Swallow, 2013). In framework analysis, the researcher has the ability to
both look down the theme (thematic analysis) and look across the one participant across themes for greater context (case analysis).

3.2.3.3 Thematic Analysis using Framework Analysis

The framework analysis method for thematic analysis of qualitative data was utilised in this chapter. Whilst the analysis process for the current study was iterative and dynamic in nature rather than linear and stepwise, it followed the main steps identified by Ritchie et al. (2013).

1. **Familiarisation with the data:** The candidate became very familiar with the data, including conducting all of the interviews. Whilst transcription of the interview is clearly a valuable method to familiarise oneself with interview data (Mason, 2002), it is a time consuming process. Therefore, a professional transcription company was used to transcribe each of the interviews verbatim. For each transcribed interview, the candidate checked the transcript for accuracy by listening to the audio-tape while reading the transcript. The candidate re-read each transcript at least 3 times, and made copious notes identifying possible codes.

2. **Creating a thematic framework:** A preliminary thematic framework was based on the independent analysis of 20% of transcripts by the candidate and two experts in qualitative research. Data were independently organised according to concepts, themes, and sub-themes. Different interpretations of the data were discussed until consensus was reached on the main themes for the framework.

3. **Indexing:** All transcripts were coded by the candidate according to the framework, with new themes and revisions to the framework discussed with one expert in qualitative research.

4. **Charting:** Themes and supporting quotes from each transcript were transferred to the framework (a matrix with participants as rows and themes as columns). MS Excel was utilised as a computerised qualitative data analysis tool (Meyer & Avery, 2009).

5. **Mapping and interpretation:** The framework was examined within and across themes and participants to identify overarching themes, subthemes, patterns, and relationships. To ensure that the themes were grounded in participants' accounts, illustrative quotations were used to describe each theme.

Rigour was addressed by inclusion of several aspects of collaboration as discussed by Paulus, Woodside, and Ziegler (2008), including repeated coding of transcripts by different team members to ensure a comprehensive list of themes and sub-themes and collaborative and iterative discussion of emerging and final themes with experts in qualitative analysis.
3.3 Results

3.3.1 Participant Characteristics

The characteristics of individual participants are presented in Table 3.1. Pseudonyms are used in all data presentations. Table 3.2 presents an overall summary of participant demographic and professional characteristics. Mostly, physicians were male (72%) and nurses were female (90%). Both nurses and physicians were of a similar mean age (48-50 years). Both physicians and nurses were highly experienced (mean physician oncology experience = 19 years; mean nurse oncology experience = 21 years), and had practiced in a range of oncology specialities across a vast number of cancer types.
**Table 3.1: Individual participant characteristics**

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Pseudonym</th>
<th>Physician/Nurse</th>
<th>Age range</th>
<th>Gender</th>
<th>Oncology experience (years)</th>
<th>Oncology Sub-speciality</th>
</tr>
</thead>
<tbody>
<tr>
<td>D1</td>
<td>Lachlan</td>
<td>Physician</td>
<td>30s</td>
<td>Male</td>
<td>5-10</td>
<td>Medical oncology</td>
</tr>
<tr>
<td>D2</td>
<td>Aiden</td>
<td>Physician</td>
<td>40s</td>
<td>Male</td>
<td>10-15</td>
<td>Radiation oncology</td>
</tr>
<tr>
<td>D3</td>
<td>David</td>
<td>Physician</td>
<td>50s</td>
<td>Male</td>
<td>20-25</td>
<td>Medical oncology</td>
</tr>
<tr>
<td>D4</td>
<td>Georgina</td>
<td>Physician</td>
<td>30s</td>
<td>Female</td>
<td>5-10</td>
<td>Radiation oncology</td>
</tr>
<tr>
<td>D5</td>
<td>Colin</td>
<td>Physician</td>
<td>60s</td>
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<td>35-40</td>
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</tr>
<tr>
<td>D6</td>
<td>Eddy</td>
<td>Physician</td>
<td>50s</td>
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<td>Medical oncology</td>
</tr>
<tr>
<td>D7</td>
<td>Don</td>
<td>Physician</td>
<td>50s</td>
<td>Male</td>
<td>15-20</td>
<td>Medical oncology</td>
</tr>
<tr>
<td>D8</td>
<td>Elizabeth</td>
<td>Physician</td>
<td>50s</td>
<td>Female</td>
<td>10-15</td>
<td>Medical oncology</td>
</tr>
<tr>
<td>D9</td>
<td>Theo</td>
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<td>Male</td>
<td>20-25</td>
<td>Surgical oncology</td>
</tr>
<tr>
<td>D10</td>
<td>Rose</td>
<td>Physician</td>
<td>40s</td>
<td>Female</td>
<td>20-25</td>
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</tr>
<tr>
<td>D11</td>
<td>Bernard</td>
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<td>20-25</td>
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<tr>
<td>N1</td>
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<td>50s</td>
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<tr>
<td>N2</td>
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<td>Female</td>
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</tr>
<tr>
<td>N3</td>
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<td>20-25</td>
<td>Surgical oncology</td>
</tr>
<tr>
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<td>40s</td>
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<tr>
<td>N5</td>
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<td>All sub specialities</td>
</tr>
<tr>
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<tr>
<td>N7</td>
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<tr>
<td>N8</td>
<td>Louise</td>
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<td>Female</td>
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<td>N9</td>
<td>Gabrielle</td>
<td>Nurse</td>
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<td>Female</td>
<td>15-20</td>
<td>Radiation oncology</td>
</tr>
<tr>
<td>N10</td>
<td>Kara</td>
<td>Nurse</td>
<td>30s</td>
<td>Female</td>
<td>15-20</td>
<td>Haematology</td>
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Table 3.2: Demographic and professional characteristics

<table>
<thead>
<tr>
<th></th>
<th>Physicians [n=11]</th>
<th>Oncology Nurses [n=10]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age: Mean [range]</strong></td>
<td>50 [36 - 69]</td>
<td>48 [39 - 61]</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
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<tr>
<td>Male</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td><strong>Experience (Medical)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean [range]</td>
<td>24 [10 – 45]</td>
<td>27 [18 – 41]</td>
</tr>
<tr>
<td><strong>Experience (Oncology)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Specialty</strong> a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Oncology</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Surgical Oncology</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Radiation Oncology</td>
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<td>2</td>
</tr>
<tr>
<td>Other (e.g. Haematology)</td>
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<td>3</td>
</tr>
<tr>
<td><strong>Cancer type treated</strong> b</td>
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<td></td>
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<tr>
<td>Genitourinary</td>
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<td>1</td>
</tr>
<tr>
<td>Lung</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Breast</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Melanoma</td>
<td>2</td>
<td></td>
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<tr>
<td>Colorectal</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Gynaecology</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Head &amp; Neck</td>
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<td>Heterogeneous</td>
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<td>5</td>
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<tr>
<td>Haematology</td>
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<td>1</td>
</tr>
<tr>
<td><strong>Position</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consultant / Staff Specialist</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Other (e.g. Fellow)</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Clinical Nurse Consultant</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Other (e.g. Research Nurse)</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td><strong>Communication skills training</strong> c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

**Note:**

a Oncology nurses: Specialty exceeds total n, as nurses practiced in > 1 oncology specialty  
b Oncologist: Cancer type treated exceeds total n, as physicians specialised in > 1 cancer type  
c Any formal communication skills training since medical school- physicians only
3.3.2 Structure of presented data

The data are arranged into ten higher order themes which are numbered and bolded. An overview of themes is provided in Box 3.2. An illustrative quotation (signified by “quotation marks”) derived from interviews is included in each heading to further clarify the scope and nature of the theme. Some higher order themes also had sub-themes, which are bolded and underlined. Additionally, a few themes include lower order categories, which are signified by bolded and italicised text. Illustrative quotations are used throughout, signified by “quotation marks and italicised text”. Pseudonyms are used when describing the views of health professionals in all quotations (see Table 3.1). Important characteristics, such as cancer speciality or experience, which help interpretation of the quote, are also included. Three ellipses ( ...) indicate that irrelevant text has been removed to improve readability of the illustrative quotation. Parentheses [example] are used for clarification if part of the illustrative quote is unclear.

Words such as ‘all’, ‘most’, ‘majority’, ‘several’, ‘some’, and ‘few’ were used throughout the results section to describe the proportions of participant responses. Differences between sub-groups based on profession (physicians versus nurses) are noted where they emerged. No other sub-group differences (e.g. gender, sub-speciality) were apparent.

In addition to presenting the qualitative results, a discussion of the results is included within each theme, as described by Burnard (2004) and Burnard, Gill, Stewart, Treasure, and Chadwick (2008). The significance and implications of the findings in light of the existing evidence base is also explored within each theme.
Box 3.2: Overview of qualitative themes

<table>
<thead>
<tr>
<th>Overview of themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1:</strong> “It’s critical that family members are there”: Positivity toward family members</td>
</tr>
<tr>
<td><strong>Theme 2:</strong> “Family members are part of the team”: Family members are a valuable resource to health professionals</td>
</tr>
<tr>
<td><strong>Theme 3:</strong> “It depends on the individual”: Variability of family involvement</td>
</tr>
<tr>
<td>• Patient characteristics</td>
</tr>
<tr>
<td>• Family member characteristics</td>
</tr>
<tr>
<td>• Cultural characteristics</td>
</tr>
<tr>
<td>• Relationship characteristics</td>
</tr>
<tr>
<td>• Disease characteristics</td>
</tr>
<tr>
<td><strong>Theme 4:</strong> “They often do different things within the same consultation”: Family roles during consultations</td>
</tr>
<tr>
<td><strong>Theme 5:</strong> “Family are part of the decision-making process, but it’s about whose decision gets more weight”: Balancing patient authority and family involvement in decision-making</td>
</tr>
<tr>
<td><strong>Theme 6:</strong> “Decisions are made amongst a group”: What family involvement in decision-making looks like</td>
</tr>
<tr>
<td>• The trajectory of family involvement</td>
</tr>
<tr>
<td>• Styles of family involvement in decision-making</td>
</tr>
<tr>
<td><strong>Theme 7:</strong> “It’s worth the extra effort”: Triadic consultations are full of challenges, but worth it</td>
</tr>
<tr>
<td>• Characteristics of challenging family members</td>
</tr>
<tr>
<td>• Challenging situations</td>
</tr>
<tr>
<td>• Cultural challenges</td>
</tr>
<tr>
<td>• Costs and challenges of family involvement</td>
</tr>
<tr>
<td>• Balancing challenges and benefits</td>
</tr>
<tr>
<td>• Benefits to the physician</td>
</tr>
<tr>
<td>• Benefits to the patient</td>
</tr>
<tr>
<td>• Benefits to the family member</td>
</tr>
<tr>
<td><strong>Theme 8:</strong> “It’s about how you handle it”: Physician’s responsibility to manage and enhance family involvement</td>
</tr>
<tr>
<td>• Facilitating family involvement</td>
</tr>
<tr>
<td>• Managing challenges in triadic consultations</td>
</tr>
<tr>
<td><strong>Theme 9:</strong> “It’s just a fact of life”: Some issues are beyond the health professional’s control</td>
</tr>
<tr>
<td><strong>Theme 10:</strong> “I think most clinicians aren’t even aware of how they may be changing the way they are with family members”: Physician self-awareness of behaviours</td>
</tr>
</tbody>
</table>
3.3.3 Qualitative Themes

3.3.3.1 Theme 1: “It’s critical that family members are there”: Positivity toward family members

Health professionals displayed positive attitudes towards family involvement in cancer consultations. At the beginning of each interview, the majority of health professionals indicated that they are eager for, and recommend, family attendance. Eddy, an experienced medical oncologist, said “I think it’s a good thing. I’m very happy when family members come in, and I encourage people to bring a support person with them when they come in to see me”. Suzanne, a haematology nurse said “I think everybody would be in agreement that having somebody with the patient in all consultations...is something we all recommend”. Many health professionals described family attendance as “important”, “essential”, “critical”, or “imperative”. These results align with previous research which indicates that both oncologists (Beisecker & Moore, 1994; Speice et al., 2000) and general practitioners (Brown, 1998; Gilbar, 2012a, 2012b) hold positive attitudes towards family involvement in consultations.

Present in many of the interviews was a pervading sense of optimism about the intentions and actions of family members. Lachlan, a younger medical oncologist, stated “I really think almost always, the family members will act in the best interests of the patient”. This sense of optimism was also apparent when health professionals discussed challenging situations. Ian, an experienced oncology nurse, interpreting the behaviour of a domineering family member positively, said “There are occasions where certain family members are very dominant. And sometimes it’s the fact that they’re very concerned for the patient, and obviously they love the patient, and they just take on that dominant role... they want to protect that person”.

Whilst all health professionals claimed that they encourage family attendance and displayed favourable attitudes toward family members, the challenges of triadic consultations were more salient for a few physicians and nurses. David, a senior medical oncology consultant, started his interview by saying “I think it’s a good thing [to have family involved]. Oh sorry, let me say it can be a good thing”. David was clear that he did not hold any negative attitudes toward family members, stating “as a clinician, I don’t have a problem, or I don’t think anything negative about it... most of the time it’s a very positive and very good thing”, however he also believed that “there are occasions where it’s an incredibly negative influence”. Gabrielle, a radiation oncology nurse, also saw both the positives and negatives of family attendance: “Well, I think it’s probably two-fold. I can see the
advantage of having somebody there...But I can also see from the other side, when the treatment is being driven by the family and not the patient. There are two sides”.

Although the challenges associated with family attendance were more salient for some health professionals, the general consensus was that problematic family members are rare. Medical oncologist Lachlan stated “there are surprisingly little occasions where family members are a challenge or less helpful. On the whole, family members are usually very helpful”. Both physicians and nurses reported that family conflict within the consultation is uncommon, and that family members displaying problematic behaviours such as aggression, dominance, defensiveness, or manipulation of the patient are the exception. This aligns with the findings of Brown et al. (1998) where eight general practitioners rated 100 consecutive triadic consultations. Results showed that family involvement was generally positive (82%) or neutral (14%); and only a small proportion (4%) of family members had a negative impact upon the consultation (Brown et al., 1998). Additionally, Siminoff, Dorflinger, Agyemang, Baker, and Wilson-Genderson (2012) found that even when conflict and disagreements occurred in triadic consultations, physicians mostly viewed the conflict as minor with only a small proportion of disagreements rated as unpleasant. However, Siminoff et al.’s (2012) study also found that oncology physicians had difficulty detecting the presence of conflict in triadic consultations. It may be that the favourable views conveyed in the current study may be influenced by physicians’ lack of awareness of patient-family conflict.

Upon examination of participants’ responses, no systematic differences in health professionals’ attitudes towards family were apparent. Physicians and nurses appeared to hold reasonably equivalent initial attitudes when asked how they felt about family involvement. The thread of optimism runs through most themes in this chapter; where the contributions of family are positively regarded and the benefits of family involvement typically outweigh the costs.

3.3.3.2 Theme 2: “Family members are part of the team”: Family members are a valuable resource to health professionals

Health professionals consistently noted the usefulness of family both inside and outside of the consultation. Linda, a nurse, believed that family members are a crucial part of the multidisciplinary team. She stated “I think they do become part of a team with us. I find family members really valuable. I think they help our role as well a lot”.

Most health professionals highlighted that the informational assistance provided by family members is one of their most critical contributions. Medical oncologist Lachlan summarised the
valuable assistance they can provide "I think the most helpful thing is, as a support person, to monitor how the patient’s going in terms of taking information, help to clarify things, to be able to be a reinforcement person when they go home and discuss it, that there’s someone to remember, and to help support the decision that the patient makes". Family members can assist by recalling or clarifying information, asking questions, taking notes, or simplifying medical information for the patient. This support reassured some oncologists that the patient was better able to understand the medical information and was more informed during the consent process. Theo, a surgical oncologist, stated “[family] certainly help with the consenting process. There is so much information that needs to be discussed and digested in what is a relatively short period of time. Then their role is to help them [patient] decipher and remember, particularly when they are signing for major surgery”.

Other studies also affirm the notion of family as a valuable resource. Speice et al. (2000) reported that oncology health professionals considered family as ‘resources’ within the consultation, particularly when providing informational assistance to the patient and physician. Similarly, in a study of general practitioners, 88% of physicians agreed with the statement ‘doctors often get useful information from talking to relatives which helps them to care for their patients better’ (Toon & Southgate, 1987).

Family can provide a ‘second opinion’ to the physician about how the patient tolerated previous treatments or how the patient is coping at home. Oncologist Lachlan believed that family are an asset to the physician because they better understand the patient: "I think that the family members generally know the patient well, and will have a good sense of how they will tolerate a particular treatment... The doctor will almost always not know the patient as well as the family, so I think they can take into account extra factors that the medical staff aren't aware of".

Family may also contribute information about the patient’s life and help provide a broader perspective to the clinician. Ian, an oncology nurse, reported that family “add in all those little bits to make up the whole picture of the patient-centred care that you don’t often get from the patient”. Many health professionals found the contribution of greater social context to be extremely helpful, as this information may help in treatment planning discussions. Ian highlighted the usefulness of this social information, stating family members help “in planning, so their treatment regimes, how to get in and out, their appointment times, what are some of the hurdles going to be in coming in for treatment, but also going home... the patient obviously wants to be at their treatment, they want to get their cancer treated, and they often don’t look at some of the social and psychological aspects".
Several health professionals also discussed the need to form a partnership with the family member, as they are the one who provide post consultation and post treatment support. Once home, the family member may rediscuss what has been said in the consultation or enforce the consultation recommendations. Family are the ones who usually see the patient on an everyday basis and may provide home-based medical care. Medical oncologist Rose said “it’s really important to develop a partnership with, not only the patient, but with their person who is going to be supervising them during that time of the initial chemotherapy in order to keep them safe”.

Most health professionals highlighted that family members provide assistance to the physician, directly through the provision of information within the consultation, and indirectly through assistance to the patient. There appeared to be no differences between physicians and nurses, as almost all health professionals held similar views about the contribution of family members to the consultation.

By partnering with family members, health professionals may access rich information which may not have otherwise been provided within the consultation. In ethical guidance endorsed by the American College of Physicians, Mitnick et al. (2010) stated “Caregivers are valuable members of the healthcare team, helping patients manage and cope with illness. Patient information provided by the caregiver may be as pertinent and reliable as the medical record. Acknowledgement of the caregiver contribution is vital to ongoing trust and continued collaboration providing patient care” (p. 257). This recommendation aligns well with the attitudes of health professionals from our study. Similarly, Baile, Tacchi, and Aaron (2012) recently published recommendations for including family members in consultations, and noted that family members are an important resource and part of the treatment team.

3.3.3.3 Theme 3: “It depends on the individual”: Variability of family involvement

All health professionals spoke of the variability of family involvement in consultations and decision-making. The extent of family involvement appears to depend on the individual and varies from family to family. Medical oncologist David explained “Do different family member [types] behave differently?“ I actually think the answer, the more I think about it, is probably, no, they don’t. Different individuals behave differently. So if you think about wives that come along, wives sometimes... sit in the corner and don’t say anything, and other times, they are clearly running the show. And I suspect that is a property of that person”. The majority of health professionals specifically commented on the variability of family involvement in decision-making. Oncologist Lachlan explained "sometimes
the patient decides by themselves. Sometimes the family really makes up their mind and present it to the patient. And sometimes, there’s a real discussion between the two”. A few health professionals remarked that all families are different and there are no typical family members or situations.

Involvement not only varies across families, but may also vary within the one family over time. The role a family member assumes and the extent they are involved may vary as the disease, treatments, and goals change. Louise, a nurse, explained that family involvement shifts as the situation and needs of the patient change. She explained that the role of a family member “will vary in the situation and it might vary even at different consultations. So if it’s around the time of a new diagnosis, the information, the hearing, and clarifying is more important. Further down the line, [it is more about] the support. So it may, within one family dynamic, vary depending on the consultation and the outcome of that consultation. It’s a moveable dynamic”.

Although there is considerable variability in how family members are involved in consultations, some general characteristics were identified by health professionals as associated with the extent of family involvement. When Don, a medical oncologist, was discussing some of these characteristics he explained "these are generalisations, and there can be exceptions... but there are some really quite interesting behavioural patterns". Suzanne, a haematology nurse, provided an introduction to some of the factors that can influence family involvement “I think it [family involvement] is just a very individual thing. I think the gender comes into it. Where that decision is in their journey and the significance of that decision. Your generation comes into it and ethnicity comes into it. They all impact. And I think those of us that have been doing this for a long time see those similarities and those common themes and we use those common themes to start with, when we develop a relationship”. The characteristics associated with the extent of family involvement identified in this study can be divided into five categories: patient, family member, cultural, relationship, and disease characteristics.

**Patient characteristics**

Health professionals reported that a patient’s age, education, and health may influence the extent of family involvement. For middle aged patients, family often reportedly attended as supporters; whereas family may be more actively involved for young adult or elderly patients. A few physicians indicated that well educated patients may desire less family input than patients with limited education. Family may also be more involved if the patient is very unwell or frail, or is experiencing mental health issues. These characteristics indicate that those patients with greater need may be more likely to have higher levels of family involvement. Oncologist Lachlan explained "I think it’s
the more needy patients [who have active family involvement] – the very young and the very old are the most common, or the ones who are physically debilitated and needing the care for physical reasons. And then finally, those who either have a mental health disorder, severe anxiety or depression. So I guess it's usually some sort of vulnerability”. On the other hand, a patient who has less need may have family attend in a passive or supportive role. Radiation oncologist Georgina explained "typically, if they [patients] are ... still working, still very independent and they've just brought their daughter along for that extra bit of support, then it's more a supportive role, but not an active role”.

A patient’s personality may also affect family involvement, with two health professionals indicating that family are more actively involved with patients who are withdrawn, reluctant to ask questions, or intimidated by the healthcare system.

**Family member characteristics**

Several health professionals believed that family member age or generation was associated with greater involvement in the consultation. Actively involved family members are reportedly middle aged, particularly if they are attending with an elderly parent who is the patient. Family members were described as more actively involved if they are a different generation to the patient. Oncologist Lachlan explained “the parents of the younger [adolescent/young adult] children or the [adult] children of the older patients are actually taking a more active role in the decision-making”.

A few health professionals believed that female family members are more likely to be actively involved in the consultation than male family members. Nurse Ian explained “I think overall, female [family members] seem to be more dominant than males, so they take on that more paternal-type role in consultation. So if it's the reverse, like if the female’s the patient and the male’s the carer or the family member, then the male doesn’t seem to be quite as dominant in the consultation. Not in every case, but in the majority of cases”. Well educated family members may also be more actively involved in the consultation, with one nurse clarifying that family may be particularly involved if there is a discrepancy between the family's own education level and the patient's education level. Family members with medical or allied health experience were also reported to be more actively involved.

**Cultural characteristics**

A few health professionals noticed that family members from Asian, Mediterranean, Pacific Island, and Middle Eastern backgrounds are more likely to be actively involved in the consultation than Caucasian family members. Some health professionals also believed that family members are often
more heavily involved in the consultation and decision-making when the patient has limited English language capabilities. These cultural and language characteristics often co-occur as explained by Rose, a medical oncologist “in non-English speaking background families, it’s much more likely that the family is going to play a bigger role in decision-making, where you’ve got the overlapping issues of language and culture and sometimes generations as well, so they can’t really be seen in isolation”.

**Relationship characteristics**

Several health professionals believed that family members tend to be more involved in the consultation and decision-making when they have a strong relationship with the patient. Many indicated these close relationships occur most amongst spouses, parents, and children rather than distant relatives, friends, or neighbours. Kara, a nurse, stated “If you are a family member and you are close to that person – if you are a parent or a wife or a spouse or a child... there’s this real feeling of keeping them alive. When it’s an elderly lady and their niece comes along, and that’s sort of a bit more remote, then you tend to find the decisions are different, and the conversation is a little bit different. When it’s a close family member, it’s very passionate. You just feel their love for that person”. A few health professionals further clarified that close married couples are often more involved than any other family member, particularly when making important treatment decisions, as they approach the illness as a unit. David, a senior medical oncologist said: “In general, father-daughter relationships...You get the sense that...one person is there as a support for the other, but that their life will go on when the other person is gone. Whereas, with a married couple, you do get the sense from strong-married couples...that they’re a unit and that they’re doing this together”.

The pre-existing relationship dynamics between the patient and family member can also influence the extent of family involvement. Several health professionals believed that the dynamics between the patient and family member outside the consultation are mirrored within the consultation; if the family member is the dominant decision-maker at home, it is likely they will be dominant in the cancer context. Some health professionals stated that these dynamics and roles are resistant to change; medical oncologist David said “but that’s been like that for 40 years. It’s not going to change just because she got cancer”.

**Disease characteristics**

Almost all health professionals highlighted that family members are more involved when important decisions are discussed. Medical oncologist David provided an introduction to this concept: “I’m not sure that it’s very different than any other big life decision. So most people, for example, who buy a
house won’t just go to a real-estate agent by themselves, go off, look at the first house they see and buy it. On the other hand, if you are buying a toaster, you would very happily go and not ask any advice, not ask any opinions of anybody else... It’s very similar I think. So decisions that are big, complex decisions with long-term ramifications, you need help. I think we all need to be able to... give ourselves some certainty that we’re making the right decision, and it’s hard to do that in isolation”. Health professionals reported the important decisions where family are more involved include commencing treatment, changing treatment, treating disease recurrence, ceasing treatment, and making end of life decisions. Family tend not to be as active during regular check-up consultations or once the patient is in remission. Health professionals indicated that family involvement is dynamic, not static, and changes as the patient’s disease changes.

Most participants reported that family are particularly involved if the decision is complex; it may be that there are a range of treatment options (e.g. surgery, chemotherapy, radiation, hormone therapy) or that there is no clear choice when weighing up the benefits and risks of various options. Bernard, a surgeon, highlighted that it is helpful to have family involved when the decision is complex. He said “When it’s just operation or not, there is no real decision-making then. It’s really perhaps nice to have them [family] there, but there are no decisions... It’s really ‘do you want to die or do you want to have the operation and have a chance of living?’... But in the ones where there is a decisional conflict, then I think [family involvement is] even more helpful”. Family may also be actively involved in decisions which directly involve them, such as treatments which require the family member’s assistance or presence. Partners may also be more actively involved in decisions which affect the patient’s sexual function or fertility.

Upon examination of participants’ responses, no systematic differences based on health profession were apparent. Physicians and nurses equally discussed the variability of, and characteristics influencing, the extent of family involvement.

Most triadic consultation research conducted has examined the characteristics of accompanied versus unaccompanied patients, and to date only a small number of studies have explored the characteristics associated with the extent of family involvement, with some inconsistent findings. Some studies have found that demographic characteristics of participants (e.g. age and gender) may influence the family’s involvement. For example Hobbs et al. (2015) found that family members were more actively involved in decision-making for older patients and female patients. A non-significant trend highlighting that psychological factors of participants may impact upon family involvement was found by Street and Gordon (2008), whereby family members of patients
reporting better mental health tended to be less active in the consultation. In addition, Hobbs et al. (2015) and Pardon et al. (2010) found that the relationship between the patient and family member may impact on the level of family involvement, whereby preferred or actual levels of family involvement in decision-making increased for married patient-family pairs compared to other family member ‘types’. Patient and family culture may also influence family involvement, with Hobbs et al. (2015) finding that Chinese patients reported higher levels of family involvement in decision-making than Caucasian patients. Finally, the nature and severity of the disease may also influence the extent of family involvement, with Pardon et al. (2010) and Sekimoto et al. (2004) each finding that family may be more likely to be involved in decision-making for more severe illnesses. However, some of these findings may be inconsistent, as a study of coded audio-taped initial lung cancer consultations found that the activity level of the family member (coded as observer, partner, or surrogate patient) did not vary as a function of the patient’s age, education, or physical health status (Street & Gordon, 2008). Further insight into factors affecting the level of family involvement is warranted.

3.3.3.4 Theme 4: “They often do different things within the same consultation”: Family roles during consultations

Health professionals described general trends of family member attendance. They reported that the vast majority of patients have a family member attend at least some consultations. One health professional estimated that the majority (>90%) of patients attend with family members. However, several health professionals observed that it is common for family members to miss some consultations, particularly when no important decisions are being discussed or once the patient feels more confident to attend alone. Usually it is one or two family members who attend the consultation, and typically the same family members attend throughout the cancer trajectory. Health professionals reported that spouses and adult children are the most common attendees.

Whilst describing the many roles a family member can assume, health professionals highlighted that these roles are dynamic and varied. Medical oncologist David stated that family members often assume several roles within one consultation, he said “they [family] actually do a lot of different things...they are often flicking backwards and forwards between those different things. So it’s not that one person only behaves in one way. They are often doing different things within the same consultation”. Health professionals also believed that the roles can change over the course of the patient’s illness, as the patient’s needs change, so too do the roles a family member assumes.
Health professionals described many different roles. Family may act as a **supportive presence**, neither offering opinion nor advice, but just ‘being there’. In this role, family listens to the information and support the patient with their presence. An **emotional support** role was also described, where the family member comforts the patient verbally and/or nonverbally (e.g. holding patient’s hand). This role is often assumed during stressful consultations, particularly when there is bad news. As highlighted in the systematic review (Chapter 2), emotional support has been described as an important role in previous qualitative studies with oncology health professionals (Beisecker and Moore, 1994; Speice et al., 2000) and in an observational study of cancer consultations (Ellingson, 2002). The **patient advocate** ensures that the patient is receiving the best care or raises issues that the patient may not feel confident to discuss themselves. Nurse Louise summarised this advocacy role as “they [family] may often be more confident to bring up something that the patient may be reluctant to bring up, like... a second opinion. They are just sort of fighting in the patient’s corner in that way”. Many health professionals noted that these supportive roles are very helpful. Nurse Maxine stated “sometimes, I think the best [family member] role is as a supporter and as an advocate”.

All health professionals described the **informational support** role, where a family member may ask questions, take notes, ensure the patient understands the information presented in the consultation, prompt the patient to ask questions, act as a memory aid or ‘second pair of ears’, provide information about the patient’s history, or corroborate information provided by the patient. This provision of informational assistance was considered very helpful by most health professionals. Some health professionals highlighted that family members often assume this role in initial consultations and when important decisions are being made. Previous qualitative studies with oncology health professionals (Beisecker and Moore, 1994; Speice et al., 2000) and observational studies of cancer consultations (Cordella, 2011; Ellingson, 2002; J. Jansen et al., 2010) also highlight the significance of informational support. A related role described by some participants is the **watchdog of patient accuracy**. These family members often add extra information that the patient omits and correct the patient if they provide inaccurate information, particularly about how they are coping at home. Medical oncologist Eddy described an example of this role: “the man [patient] will be saying, “Oh look, I’m feeling okay and everything is going fine,” and the woman [family member] is in the background shaking her head”. Some family members assume the role of **interpreter** within the consultation. They may interpret language for non-English speaking patients, or they may interpret information for an English speaking patient, relaying technical or complicated information in an understandable manner. Health professionals
reported that many family members also assist in decision-making, which is discussed in detail in Theme 6. Whilst decisions are being discussed, some family members play devil’s advocate, questioning the information provided, the efficacy of the treatment, or whether a certain decision is the correct one.

Many family members also provide practical support. Medical oncologist David stated “they [family] are often the practical person, so they will bring the tablets, bring the scans, make sure things are there. They are often the gopher, so if the scans get left in the car, they run off to get the scans”. A study which conducted discourse analysis on cancer consultations reported similar findings, where family members can assume the ‘secretary’ role, looking after the administrative side of medical consultations (Cordella, 2011). Some family members may take on the role as student carer in the consultation, asking questions about how best to provide care to the patient at home. They may also act as a family liaison, communicating information discussed in the consultation with the wider family unit. Finally, family members may attend the consultation so that they are able to provide post-consultation support. Health professionals believe that family may recall and discuss information presented in the consultation or enforce consultation recommendations once home.

The systematic review (Chapter 2) confirms many of these family roles, such as logistical assistance, informational support, and emotional support. However, the results from the current chapter indicate that family members may also engage in an array of other, more specific, roles. Our participants highlighted several novel family member roles not commonly discussed in the existing evidence base, including the devil’s advocate, student carer, family liaison, and post-consultation support roles.

The majority of health professionals reported that there was no one most helpful role, and several health professionals suggested that the behaviours of family members should be based on patient preferences and need. Ethical guidance published by Mitnick et al. (2010) acknowledged the diversity of patient wishes and recommended that physicians routinely clarify patient preferences regarding the nature and degree of family involvement in consultations. Additionally, Speice et al. (2000) recommended that physicians ask each patient “How would you like your family to be included in your care? (for example... Being a ‘second set of ears’? Providing emotional support? Involved in decision-making?)”, and also recommended that physicians ask family members how they would like to be involved in their loved ones care. Additionally, Wolff et al. (2014) proposed a role clarification checklist for patients to complete prior to medical consultations, asking them to tick one or more roles on a list which they would like their family member to perform during the
consultation. The majority of patients in this study evaluated the tool as easy and useful. The many roles highlighted in the current study could be used as a catalogue of options to inform patients and family members of possible roles when asked about their preferences. Based on the results of the current study's interviews, it is important that health professionals understand that there are an array of roles family members can assume, that family members may assume several roles in the one consultation, and that these roles may evolve as the disease changes.

### 3.3.3.5 Theme 5: "Family are a part of the decision-making process, but it's about whose decision gets more weight": Balancing patient authority and family involvement in decision-making

Despite recognising the importance of family contributions, most health professionals stated that the focus of the consultation must be on the patient, and the patient's wishes during the decision-making process should be paramount. Eddy, a senior medical oncologist, said “they're [family] not really the ones who I'm primarily responsible to, or the ones who are kind of most important in the consultation”. Although many physicians and nurses acknowledged that family deserve to be involved in the consultation, they were adamant that the patient retain control of decision-making. Annette, an oncology nurse, acknowledged the impact of decisions on the family, but firmly believed that the patient should have authority when making medical decisions “the partner... is just sort of coming along for the ride, because at the end of the day, they can only make suggestions. And while it might have a big impact on them, it's the patient that will finally sign the paper and say, “Yes, I'm having this done... the bottom line... it's got to be the patient's decision”. Past empirical studies of health professionals’ attitudes (Beisecker & Moore, 1994; Gilbar, 2012a, 2012b; Toon & Southgate, 1987), endorsed ethical guidance (Mitnick et al., 2010), and legislation and professional standards (e.g. Australian Commission on Safety and Quality in Healthcare, 2008) affirm the participation and authority of the patient when making a decision.

Several health professionals within our study suggested that family members usually agree that the patient's preferences should be the priority. Nurse Ian said “in the majority of cases, they [family]... will support whatever the patient’s decision will be”. Although family members reportedly appear to agree that the patient is the priority, the main challenges discussed by health professionals were occasions when family involvement threatened the patient-centredness of the consultation. These included family requests for non-disclosure of the cancer diagnosis to the patient, family requests for private information without patient consent, and conflicting patient and family member treatment wishes.
When discussing the ‘patient as priority’ philosophy, a few physicians explained that they were guided by legal or ethical frameworks, which in Western countries such as Australia, promote patient autonomy and informed consent (Kerridge et al., 2013). Medical oncologist Don stated “increasingly it’s been made clear to us by privacy laws, the patient is our main concern. You certainly answer the relative’s questions and explain things to them. It’s all us and the patient predominantly. [Family] can help or hinder, but my relationship is with that patient”. It appears that although family are welcome to attend the consultation, support the patient, and may be involved in discussions, health professionals feel strongly that they must protect the right of the patient to have the final say. Interestingly, physicians in the current study appeared to more vehemently defend the patient’s right to retain decisional control when compared to nurses. Perhaps it is the more direct role that physicians play in the decision-making discussions, and perception of their own legal accountability, which prompts their greater defence of patient authority.

Despite the widely held view that the patient should retain decision-making autonomy, some health professionals suggested that family members deserve to be involved in the decision-making process, because cancer affects not only the patient but the entire family unit. Colin, a medical oncologist with more than 30 years of oncology experience, said “I think it’s also important [to have family involved] if the treatment is going to be very intrusive. One of the main side effects of treatment is inconvenience. If the inconvenience is affecting the whole support network, it becomes not just the patient’s wellbeing, which is important, but what about the whole unit which is meant to be coping with this?”. Some health professionals expressed that partners should be involved in decisions which clearly affect both the patient and partner, such as cancer treatments affecting sexual function or fertility. Annette, a prostate cancer nurse, stated “I think it is important, and particularly with this sort of a cancer [prostate] because of the effect that it has on sexuality… that partners are involved in [decision-making]”. Overall, several physicians and nurses stated that family are heavily affected by the patient’s illness and deserve to be involved in the consultation and decision-making process.

Some health professionals also noted that in some non-Western cultures it is normal for the family to take control of the decision-making process. Oncologist David said “in some cultures the family member is the spokesman… and the patient’s role in decision-making is actually questionable. Not in a bad way… You get the impression that that’s how things are done in that particular culture”. Oncologist Rose discussed the challenge of retaining patient autonomy whilst respecting cultural norms. She said “that notion that the final say… should be the patient’s, that’s not a shared value all around the world. It’s a challenge to us to actually be legal within the Australian framework, in terms
of the patient’s decision-making, but not to dislocate them out of what’s an appropriate cultural environment to them”. Some health professionals stated that family control of decision-making can be appropriate in some situations, provided it is the patient’s preference and not being imposed by the family. This notion is supported by the literature, which highlights that the Western ideal of individualistic autonomy is not universal (Ho, 2006); but rather, individuals from many countries, including China (Cong, 2004), Japan (Akabayashi & Slingsby, 2006), and Pakistan (Aslam, Aftab, & Janjua, 2005) regard active family involvement, and even control, in medical decisions as the norm.

The notion that family deserve to be included in decisions appears somewhat at odds with the belief that patients should have decision-making autonomy. Most health professionals, particularly physicians, in the current study strongly emphasised the patient’s decision-making authority; however several also asserted that family members deserve input. This dichotomy has been discussed in one prior study. Gilbar (2012a) found that while some GPs felt that family should share the decision-making because of the implications for their own lives, others were unaccommodating of family involvement in decision-making and strictly adhered to physician-patient dyad. Gilbar (2012a) reported that, irrespective of their position on who should be involved, most GPs recognised that family are an inseparable part of the decision-making process. These conflicting attitudes of ‘patient as priority’ and ‘family deserve input’ found in the current study are somewhat reflective of the ongoing tension within both the legal and ethical fields regarding family involvement in decision-making (see section 1.3 in Chapter 1). Whilst Australian law heavily protects patient privacy and autonomy, laws have also been introduced to increase the recognition and inclusion of family such as the Carers Recognition Act (Commonwealth Government of Australia, 2010). Additionally, some ethical guidance and discussion papers reiterate the importance of patient autonomy in decision-making (Blustein, 1993; Mitnick et al., 2010); whilst others have suggested that this approach be reconsidered, asserting that family deserve greater centrality in the decision-making process (Hardwig, 1990; Ho, 2008).

Whilst it remains unclear how these tensions are to be resolved given the current legal, ethical, and practical medical context; an important finding from the current study (Theme 3) is that the extent of family involvement is variable and may be influenced by patient, family, culture, relationship, and disease characteristics. The current study’s results indicate that there may be no universally desirable level of family involvement in decision-making, and it may be beneficial if health professionals navigate this process with flexibility. The ethical approach proposed by Levine and Zuckerman (2000) somewhat aligns with these findings, as it promotes a flexible approach to
family involvement, accommodating the varying individual roles and interests of patients and family members and advocates for a process of flexibility and negotiation of involvement.

Overall, health professionals in the current study indicated that family involvement in decision-making is welcome; however, many felt that the patient must remain the priority and the extent of family involvement should be based on the patient’s preferences. Further information about the different styles of triadic decision-making will be discussed in the next theme.

3.3.3.6 Theme 6: “Decisions are made amongst a group”: What family involvement in decision-making looks like

All health professionals acknowledged that family are usually involved in decisions; it is not only the patient and physician involved in decision-making. Nurse Suzanne highlighted “decisions are made amongst a group, and that group involves the patient, those close to the patient, and also health care professionals”. Indeed, the systematic review of triadic consultations also reflects this, finding that between 60-88% of family members reported involvement in cancer treatment decision-making (Chapter 2). As explained above however, participants in the current study often noted a tension between preferring patient authority and involving family members. Many health professionals in the current study indicated that the decisional support family members provide (e.g. acting as a sounding board) is very helpful to the patient. Family involvement may also help the health professional, by providing an opportunity to discuss the options in greater depth. Medical oncologist Don stated “it can be very helpful if they [family] are knowledgeable and supportive of a certain concept that agrees with mine. If they’re counter, that can also be useful because that enables us to go through the pros and cons of treatment”.

Health professionals were asked to describe what family involvement in decision-making looks like in clinical practice. Although physicians explained that there are limited ‘typical cases’ because of the individual differences of patients and family members, some health professionals suggested that some broad styles of family involvement in decision-making are apparent.

The trajectory of family involvement

Inductive and deductive methods were utilised for this section of analysis. In interviews, participants were asked to describe the involvement of family during key points in decision-making (information exchange, deliberation, decision) derived from the Charles et al. (1997, 1999) framework. However, some participants described additional stages of decision-making, therefore family involvement across five decision-making stages will be discussed (pre-consultation preparation, information exchange, deliberation, decision, and post decision discussions).
Firstly, several health professionals believed that family are sometimes involved in a pre-consultation preparation stage. Family members may research the disease and treatments, and may discuss the information and options with the patient before the consultation. Indeed, prior research has also found that family may be involved in decisions prior to the consultation. Zhang and Siminoff (2003) found that family decision-making about treatment for lung cancer patients may begin as early as selection of the physician.

Most health professionals reported that family are often actively involved in the information exchange stage of a decision. When discussing a treatment decision, several physicians stated that they present information about the treatment options to both the patient and family member. Typically after the information has been presented, they will ask if there are any questions. Some health professionals noted that they ask the patient for questions first, and then the family member. Health professionals reported that family members often provide informational assistance to the patient such as asking questions, taking notes, and simplifying information for the patient. Family members may also provide information to the physician, such as integrating the medical information they have heard with their personal knowledge of the patient, contextualising the information for the physician. Medical oncologist David noted “they [family] are often combining their knowledge and what they’re hearing with their prior knowledge of the person. That can be very helpful, because obviously as a clinician, often you’ve only met these people that day, or sometimes once or twice before”. Family members may also provide important social or logistical information about the patient, such as work commitments or their ability to travel for treatment, which may impact on the treatment decision.

Many health professionals reported that family members present and discuss information (sourced from the Internet, Cancer Council, newspaper, friends etc.) within the consultation. This research can be helpful to discuss, however some health professionals reported that it can be disruptive when the family member is ill-informed or makes unreasonable requests.

Several health professionals highlighted that information exchange does not only exist within the consultation, but believed that this process continues when the patient and family member are at home. Participants believed that the patient and family member may recall and discuss information presented in the consultation, discuss the information with other family members, or do more research once the consultation has ended. The only other study to examine family involvement in each of the decision-making stages was conducted by Hubbard et al. (2010). The cancer patients
and family members in Hubbard et al.’s (2010) study reported that family are often heavily involved in the information exchange phase.

Health professionals reported that family involvement in the deliberation stage is variable and depends on personal preferences and an array of characteristics such as the patient/family relationship or the complexity of the decision. The extent to which family are involved in deliberation appears to vary on a spectrum from no involvement through to dominating the deliberation process. Family members may assume a supportive role in deliberation, supporting whatever the patient’s preferences and opinions are. They may act as a sounding board for the patient, discussing the options with the patient and helping to clarify the patient’s own preferences and goals. Health professionals reported that some family members actively provide their own opinions and preferences for treatment; whilst others dominate the deliberation phase, leaving little room for the patient to express their own preferences. In Zhang and Siminoff’s (2003) study of advanced lung cancer patients, family regularly voiced their own opinions and preferences, sometimes resulting in family conflict. The patients and family members in Hubbard et al.’s (2010) qualitative study reported a wide variety of involvement in deliberation, similar to the results of the current study. Some patients and family members in Hubbard et al.’s (2010) study reported that it was upsetting if physicians did not include the family in the information exchange and deliberation phases, and this exclusion could lead the family to feel uninformed.

Some health professionals suggested that during deliberation, coalitions may form, particularly if the patient and family member have different treatment preferences. One oncologist stated that if the patient expresses a preference for a treatment that he thinks is the right one, he will openly support the patient’s preference in front of the family member. Patients and family members may also form a coalition in the consultation and confer about the decision. Rose, a medical oncologist, described this process “there’s usually a moment where they basically have to say, “Yes”, or “No”, or, “I will go away and think about it,” at which point they [patient and family] will normally turn to one another and say, “Well, this is what we’ve got to do”, or “I'm not happy”. So they’ll normally turn away from the doctor and toward one another”. This is referred to as a ‘family time out’ by Korfage et al. (2013), where the patient and family member converse between themselves without the physician’s participation. A conversation analysis on audio-taped cancer consultations by Korfage et al. (2013) found that the patient and family member may deliberate about the decision between themselves within the consultation.
Many health professionals in the current study believed that only part of the deliberation phase takes place inside the consultation. Most physicians stated that they encouraged the patient and family member to go home and discuss the decision as a family. Health professionals believed that a great deal of discussion and negotiation between the patient and family happens at home. Due to the paucity of research in this area, and the fact that very little is known about the nature of these at-home discussions, it is unclear whether home-based deliberation is helpful or potentially harmful in various situations. Korfage et al. (2013) proposed that the in-consultation ‘family time out’ might allow patients and family members to confirm their agreement with treatment recommendations or uncover potential conflicting treatment wishes under the observation of the physician, who can intervene with clarification or further discussion. Future research is needed to explore the benefits and challenges of at-home versus in consultation deliberation.

As with deliberation, health professionals noted that the involvement of family in the final decision is variable, lying on a spectrum ranging from family not at all involved in the final decision to family members forcing the decision to the point of conflict. Some health professionals reported that typically the patient and family member will discuss the information, deliberate about the decision together, but the patient will retain autonomy and make the final decision by themselves. Indeed, several health professionals reported that at this decision stage, family members generally support whatever the patient decides to do. Oncologist Lachlan said “I think in about 90% of situations, it will be the patient who verbally says, “I will do this, or I will do that”. [The family will say]... “What do you think, Dad? What are you going to do?”. So that means that they [patient] do have some autonomy in finally making that decision”. Some health professionals actively encouraged patient autonomy. Surgeon Theo recalled conversations in triadic consultations where he said to the patient “look, at the end of the day, you’re the one that has to make the decision, you’re the one that’s going to have to sign the consent form”. In a minority of situations described by health professionals, the family made the decisions for the patient. Although health professionals reported feeling uncomfortable when family dominate the decision, some highlighted that it may be appropriate for family to assume a more active role when the patient has willingly deferred the decision or is too frail to make the decision alone.

A few health professionals noted that family may continue to be involved in post decision discussions and arrangements. The patient and family members may continue to discuss the decision and may change their minds.
A limited amount of prior research on the involvement of family in treatment decision-making has been conducted to date. Based on the current health professional interviews and previous studies (e.g. Hubbard et al., 2010; Korfage et al., 2013; Öhlén et al., 2006; Zhang & Siminoff, 2003), it is clear that decision-making is not restricted to the physician-patient dyad, and family are often involved at every stage of the process, including pre- and post- consultation discussions. The level of family involvement in decisions appears to rest on a spectrum and most health professionals did not indicate a clear preference for a particular style of family involvement. However, it appears that whilst most health professionals accepted family involvement in the information exchange and deliberation stages, they believed that, whenever possible, the patient should retain authority when the decision is made.

**Styles of family involvement in decision-making**

A few health professionals described common decision-making ‘patterns’ or ‘situations’. Qualitative analysis of these patterns has resulted in the proposal of three styles of family involvement in decision-making. The first could be categorised as **facilitative triadic decision-making**. Family may be involved in the decision by facilitating the patient’s decision-making, for example by acting as a sounding board, helping to recall or interpret information, or explicitly stating support for the patient’s decision. In this style, the decisional authority rested with the patient. Medical oncologist Eddy described a facilitative style of triadic decision-making: "my role is advising the patient in making the decision. And having the family member there, the way I would see it is that they’re kind of helping the person [patient], supporting them. They [family] need to understand what’s going on, but it’s actually the patient who is the one who is going to be doing the driving". A similar style of triadic decision-making was proposed by Öhlén et al. (2006). After interviewing cancer patients and family members about decisions to use complementary and alternative medicine, Öhlén et al. (2006) reported that some family members adopted a decision-making role described as ‘creating a safe place for the patient to make a decision’. Family members gathered information in an unbiased manner, reflectively listened to the patient, and acted as a sounding board for the patient.

**Shared triadic decision-making** was another style of decision-making that emerged from the analysis, characterised by decisions being discussed equitably between the patient, family member, and health professional. Whilst each party expresses their opinions and the physician works to achieve consensus, health professionals maintained that the patient should retain decisional authority. Radiation oncologist Aiden discussed this shared, consensus building approach "we try as much as possible to share decision-making, and that you present options to a patient, and that you
work towards making a decision about what’s best. Obviously, the patient has the final say, but patients rarely want to go against the wishes of their significant others, and so the shared decision-making actually ends up being shared decision-making among all family members. So you really do have to work on getting consensus”. Öhlén et al. (2006) proposed a similar style, described as ‘collaborative decision-making between patient and significant other’. Öhlén et al. (2006) proposed that the family member provides advice, shares knowledge, and makes the decision jointly with the patient.

A third style of triadic decision-making could be categorised as family-led triadic decision-making, where the family member directs the decision-making process and the patient assumes a passive role. Medical oncologist Colin showed concern about this type of involvement “I always get a bit worried about the fact that the patient is being almost treated as an object rather than treated as a participant in decision-making”. However, other health professionals believed that this style of family involvement might be appropriate if the patient has actively and willingly deferred their say in the decision to a family member. Nurse Sarah said “there are times when patients will actually say, “Look, just ask him [husband]... I just don’t feel like I can make another decision”. Öhlén et al. (2006) described a style of involvement which may fall in this category, namely the ‘director’ taking over the decision-making on behalf of the patient.

It appears that the styles identified in the current study align well with the experiences of the patients and family members in the qualitative study by Öhlén et al. (2006). Of the health professionals who discussed the decision-making styles in our study, all believed that it is important to include family in the decision-making process to some extent. Whilst two physicians indicated a preference for family assuming a supportive/facilitative role, most stressed that there is no one best way family should be involved as it depends on the patient’s needs and a multitude of personal and situational factors. However, all health professionals agreed that patients should retain ultimate decisional control, assuming they are competent and willing to do so.

3.3.3.7 Theme 7: “It is worth the extra effort”: Triadic consultations are full of challenges, but worth it

Health professionals highlighted that involving family members brings many challenges, although these are typically outweighed by the benefits of family involvement. The reported challenges can be divided into four categories: characteristics of challenging family members; challenging situations in triadic consultations; cultural challenges; and costs of family involvement.
Characteristics of challenging family members

Family members who attend consultations with erroneous information, who cannot understand the information, or cannot keep up with the pace of the consultation, were considered challenging. Many health professionals reported discomfort with dominant, aggressive, or obstructive family members, as the patient-centredness of the consultation can be compromised and the patient may not retain decision-making authority. Family members with severe mental health issues or who are not coping with the patient’s illness were also described as challenging. Lesser involved family members (who may have a distant relationship with the patient or may only attend some consultations) were described as challenging because they often do not have the required knowledge of the patient’s history to effectively participate in important discussions. Finally, health professionals stated that they are also challenged when family members do not attend the consultation at all. Health professionals proposed that family may be disempowered or intimidated, not wanting to be perceived as pushy, lacking understanding of the healthcare system, or facing cultural or language barriers. This results in patients attending the consultation alone, which most health professionals were eager to avoid.

Challenging situations

Many health professionals described challenging ethical and legal situations, such as requests for non-disclose of diagnosis to the patient. Surgeon Bernard discussed this issue, saying “some relatives will try and take that [disclosure of diagnosis] away from the patient, saying, “You talk to me, not to the patient”. Another issue is when family request information without the patient’s knowledge. Several health professionals reported that they were uncomfortable with these requests, as the patient’s privacy is compromised. Whilst the health professionals in the current study appeared to be mindful of patient privacy, a previous study conducted in Spain found that 35% of primary care physicians reported providing family members with information about the patient without the patient’s permission (Pérez-Cárceles, Pereniguez, Osuna, & Luna, 2005). Pérez-Cárceles et al. (2005) noted the fine balance between the patient’s rights to privacy and the need to support, inform, and collaborate with family members.

The most common challenge highlighted by health professionals was dealing with conflicting treatment wishes of the patient and family member. Nurse Louise described this situation, “there sometimes can be issues, particularly in a palliative situation, where the patient wants something different to what the family wants. So perhaps when you are looking at the third or fourth chemotherapy, that’s not really having a response, but you know that it’s going to have toxicity. The
patient says, “I really don’t want anymore,” but the daughter or the husband says, “You must have it. Try it Mum. Try it for me. You can’t give up, you’ve got to keep fighting”. The notion that family may have different evaluations of treatment trade-offs and different treatment wishes was also found among lung cancer patients in Zhang and Siminoff’s (2003) and Zhang, Zyzanski, and Siminoff’s (2010) studies. Some health professionals also reported that conflict can arise when pre-existing family issues surface within the consultation, which can be difficult for physicians to manage. It appears that health professionals are often faced with conflicting values; namely maintaining the priority and protecting the autonomy of the patient whilst supporting and including the family.

Several health professionals reported that discussing sensitive issues, such as sexuality or prognosis, is challenging when family members are present - particularly when adult children accompany an elderly parent. Nurse Annette described this situation “with prostate cancer, a lot of the issues associated with treatment are sexual... Parents didn’t want to discuss sexual issues with their children. And it was awkward for children – even adult children – to be having those conversations. So that’s a difficulty having the family in there”. Another challenge reported by some health professionals is having several family members in the consultation. They reported that it is uncomfortable to fit many family members in the small space, and that having a productive conversation is difficult when too many family members want their opinions heard.

Cultural Challenges

Many health professionals found it challenging when a family member acts as the interpreter for a non-English speaking patient. Several health professionals doubted whether some patients receive accurate and complete information, and therefore may not be providing informed consent. Radiation Oncologist Georgina said “if they are from a non-English speaking background and you don’t have a formal interpreter... You worry that not everything is going through, or that information is being filtered in some way”. Consultation audio-tape analyses of immigrant cancer patients conducted by Butow et al. (2011) support this concern. Butow et al. (2011) found that family interpreters had a significantly higher rate of non-equivalent interpretations than professional interpreters and appeared more likely to hide diagnoses and prognoses.

Although most health professionals interviewed in our study reported attempts to arrange professional interpreters, some reported that patients and family members are resistant to accept such services. Several oncologists also highlighted that family members of non-English speaking patients may dominate the decision-making process. Radiation Oncologist Georgina explained “I
find that family members of some cultural backgrounds... almost take liberty and make decisions on behalf of the patient”.

Health professionals reported that requests for non-disclose of diagnosis or for information without the patient’s knowledge are more common among the family members of ethnic minority patients. Interviews with ethnic minority patients and family members confirm that family members often request information to be withheld, despite the fact that patients disagreed with this approach and often wanted full disclosure about their diagnosis and prognosis (Mitchison et al., 2012). A study of North American and Japanese physicians’ attitudes towards family involvement also reveals that the physician’s culture can impact upon non-disclosure practices (Gabbay et al., 2005). When asked about disclosure of a cancer diagnosis, almost half of Japanese physicians reported that they would inform the family first, whereas only 2% of North American physicians would follow this approach. Over three-quarters of Japanese physicians had ‘hidden’ a cancer diagnosis at the family's request (Gabbay et al., 2005). Amongst the current sample, Australian physicians were very reluctant to hide information from their patient, which may be reflective of the focus on patient autonomy in Australian (Kerridge et al., 2013) and North American (Van Norman, 2012) legal systems.

Costs and challenges of family involvement

Some health professionals reported that a cost of family involvement is the extra pressure it places on the physician - extra consultation time and complexity. Nurse Maria described this “because there are more people in the room, that can become more complex... managing people’s expectations and people’s feelings. So I guess if there is more than just the patient, the oncologist has to manage two people rather than just one”. Several health professionals noted that an additional cost of family involvement is the potential loss of patient centredness. Some patients may make decisions for their family and not themselves. Other patients may want to protect their family by not expressing their concerns or asking about prognosis or side effects. Additionally, when family are present they may speak for the patient and dominate the question asking. This loss of patient focus concerned some health professionals.

Some of these challenges were highlighted in previous studies by oncologists (Beisecker & Moore, 1994; Speice et al., 2000), general practitioners (Gilbar, 2012a, 2012b) and geriatricians (Barone et al, 1999). However, the health professionals in the current study reported a greater number and variety of challenges. Despite these numerous challenges, they retained an optimistic attitude toward family involvement (e.g. Theme 1).
Balancing challenges and benefits

As noted earlier, most health professionals indicated that the benefits of family involvement outweigh the challenges. Medical oncologist Eddy said “even though I ask them to do it [bring a family member], when I kind of walk outside and there are five people [family members], my heart rate goes up a little bit, and it is a little bit more stressful. But... I think it’s actually worth the little bit of extra effort”. Many health professionals appeared unfazed by the challenges, describing them as something ‘we just have to deal with’. However, this approach to challenging situations adopted by many interviewees may be a result of their extensive experience, as physicians and nurses had an average of 19 and 21 years in oncology, respectively. The notion that physician experience level may impact on their perception of challenges has been discussed in the dyadic literature, with a study by Steinmetz and Tabenkin (2001) finding that the more experienced the physician was, the less they perceived patients as ‘difficult’, and the more they perceived themselves as capable of managing challenges. Less experienced health professionals may find the aforementioned challenges more difficult to manage and therefore may have less favourable views towards family involvement. Future studies should examine the experiences and practices of less experienced health professionals.

A few health professionals focused on the ‘silver lining’ of some issues, describing opportunities that arise as a consequence of triadic challenges. Oncologist Lachlan described how conflicting treatment wishes can provide the opportunity for deeper discussions “if a family member is... quite firmly against the patient having that treatment ... I don’t think that’s a bad thing. I think it actually gives an opportunity to discuss more in detail about the benefits and risks of treatment”. A few health professionals described how the initial investment of time in triadic consultations is paid back quickly, because of the informational support provided to the patient and less follow up phone calls to the physician. Oncologist David said “I suppose there is a time cost. It certainly takes longer to discuss it, so there is sort of a time cost on the part of a doctor. That’s usually paid back pretty quickly though, because while it might take longer to discuss to begin with, it gets easier afterwards”.

Despite the challenges of family involvement, many health professionals reported that triadic consultations are preferable to patient-only consultations. Several health professionals believed that unaccompanied patients may have underestimated the seriousness of their illness or may have limited support. Radiation oncologist Georgina said “if they’ve come alone, that sort of gives me a bit of a warning bell that this patient might be a little bit isolated and may not have a lot of people out
there to have that dialogue with”. Although managing family members can be challenging, the benefits appear to make it more preferable to the alternative- a patient who attends alone.

Health professionals were acutely aware of the many benefits of including family members in consultations. These benefits can be divided into: benefits to the physician; benefits to the patient; and benefits to the family member.

**Benefits to the physician**

Several oncologists and nurses stated that family members make the health professional’s role easier. As discussed in Theme 2, family members can provide important information within the consultation, giving the physician greater patient insight. A few health professionals noted that they feel reassured when family members attend the consultation because the patient has informational support to better understand and recall information, and they know that emotional and medical support will be provided at home. Family attendance was also perceived as more time and energy efficient for the physician in the long run.

**Benefits to the patient**

Almost all health professionals reported that family involvement benefits the patient. Linda, an oncology nurse, stated “I think [family involvement is] really important for the patient...often it’s good for them to have the support there, and someone else to listen in case they don’t catch everything that’s being said, or misinterpret something that might be told to them”. Most health professionals believed that the informational assistance provided by the family helped the patient. Health professionals also noted that family members help patients feel less isolated when making a decision. Family can also reassure the patient about logistical factors affecting a decision (e.g. driving them to hospital to receive chemotherapy), about the impact of treatment on the family, and that the patient has made the right decision. Nurse Maria said “I guess the benefit is that when the patient makes the decision they feel supported, and that’s really important when you’re making a decision about treatment, that you know that your family is going to be behind you”. Health professionals believed that by sharing the experience with family, the burden on the patient may be lessened. Nurse Suzanne explained “I think there is also that shared burden of responsibility, clearly. I think these are significant decisions... Particularly in a malignancy that isn’t clear cut. ..there are a lot of significant decisions to be made...if you make a shared decision, the burden of responsibility, of the implications of that decision, are shared”.
**Benefits to the family member**

Some health professionals reported that family members may benefit from being present in the consultation. The evidence base has shown that family members are significantly affected by the patient’s diagnosis and treatment (Pitceathly & Maguire, 2003). Some health professionals in the current study believed that because of this impact, family members deserve to be included in the consultation and will benefit from involvement. Kara, a haematology nurse, said “I think we do really need to work on making them [family] feel as important in this, because they are going to go through so much as well. This is not just about the patient”. Some health professionals believed that by participating in the consultations and treatment decision-making process, family members’ information needs may be met, and they may feel more empowered. Oncologist Lachlan explained "I think it means that they’re better educated about the pros and cons of a particular treatment or decision, and so it means they feel part of the process and they feel more enabled as carers to look after the patient and understand what will happen in the future". Additionally, a few health professionals noted that by attending the consultation, family members may obtain a more accurate picture of the patient’s health status, removing uncertainty about what to expect or what the treatment goals are. Family presence was also proposed to prevent inaccurate second-hand information being passed on from the patient. Finally, one physician highlighted that family involvement throughout the disease trajectory may help with the grieving process if the patient dies, as they are better educated about the decisions made and treatments received. Oncologist Elizabeth said “I think it helps their [family’s] own grieving process... if they’ve been able to be involved. So it may help their acceptance... Often if they have been involved from word go, say a patient decides to pull out of treatment, they tend to be a bit...more accepting of that”.

Some of these benefits have been highlighted by health professionals in past research (Beisecker and Moore, 1994; Gilbar, 2012a, 2012b; Shepherd et al., 2008; Speice et al., 2000). Although most health professionals in our study discussed both challenges and benefits, physicians appeared to have discussed a slightly greater number of challenges, whilst nurses noted more benefits. Perhaps it is the physician’s direct exposure to the challenges whilst conducting the consultations, or responsibility they feel to manage these issues, which makes them more salient. It may also be that nurses often spend more time with the patient and family and may have more of an opportunity to notice these benefits.
3.3.3.8 Theme 8: “It’s about how you handle it”: Physician’s responsibility to manage and enhance family involvement

Many physicians appear to assume the responsibility for managing and enhancing family involvement. When asked to describe the facilitators of family involvement, most health professionals described only physician-led actions. Similarly, when asked about any strategies that may help to manage family involvement, most were physician directed. Whilst a few nurses believed that there should be limits to the physician’s responsibility, such as not dealing with pre-existing family tension during consultation time, most physicians indicated that they are responsible for managing the triadic consultation dynamics. Neither physicians nor nurses expressed any expectations that patients should manage the dynamics of the consultation or that family members should regulate their own behaviours.

Health professionals were generally confident that they could effectively manage family involvement. Medical oncologist Don said “I think the main thing is, from our perspective, to be open to their circumstance, try and understand who does what, what the issues are for the patient and their family. You just have to try and listen to what’s important for them... There are a whole range of different relationships you encounter”. However, the confidence expressed by our sample may be a reflection of their skill and experience level. Experienced medical oncologist David highlighted this point when asked about whether challenging family members are difficult to manage, saying “it can be, but it usually isn’t. I mean, I think there’s an element of skill and experience. So, you know, you’ve been doing it for 20 years so you sort of have seen most of those things”. The strategies suggested to involve family members and manage challenging triadic situations are discussed below.

**Facilitating family involvement**

Most health professionals noted the importance of actively encouraging the patient to bring a family member to the consultation, either over the phone prior to the consultation or encouraging unaccompanied patients to bring a family member to the next appointment. Nurse Annette said “I always encourage people to bring somebody with them... I would always request that partners were there, and explain why it was important that partners were there... And if it was somebody without a partner, then suggest that they bring somebody”. A few health professionals specifically encouraged early and consistent family attendance, rather than having a family member begin attending late in the cancer trajectory or different family members attending each consultation.

Some health professionals reported that they make family feel welcome by building rapport, learning the family member’s name and finding common ground with them. Nurse Maxine said “I
think we’ve gone to great lengths to be as welcoming as possible when people come, to be inclusive. We make sure that we find out the names of the family members. We introduce everyone. I guess they are just little things, but they actually do make a difference. Once people are acknowledged, they feel included, so they are part of the consult”.

Health professionals also noted the importance of making eye contact with family members, directing some information to them, and asking if they have any questions. Radiation oncologist Georgina suggested some strategies to include family members in the consultation “Try and make eye contact with all of them [family members] and observe their body language and address them. If one of them looks confused, stop and go, “Is there something you wanted to ask?”. Include them all in that whole process. Obviously it’s patient centred, but they are there because they’re important to the patient, so it’s important that they understand what’s going on”. Several nurses believed it was also helpful to provide family members with their contact details, making them feel involved, connected, and able to ask questions outside of the consultation. A few health professionals also provided family members with information relevant to them, such as a Cancer Council booklet ‘caring for someone with cancer’ or referred them to relevant carers support groups. Some health professionals suggested other strategies such as having enough chairs in the consultation room to accommodate family members and being open to alternative methods of involving family members, such as allowing interstate family members to join consultations via teleconference or audio-taping the consultation for the family member to listen to at a later time.

In their study of oncology health professionals, Speice et al. (2000) reported some of these strategies, such as inviting the family member into the consultation and knowing the family member by name. Studies indicate that both patients and family members appreciate these inclusive behaviours (Kimberlin et al., 2004; Sinfield et al., 2008; Speice et al., 2000). These aforementioned facilitators provide further evidence for the recommendation made in our systematic review (Chapter 2) for physicians to ‘encourage, welcome, and involve family members in consultations’.

**Managing challenges in triadic consultations**

Health professionals discussed both general strategies which may reduce the likelihood of issues arising in consultations, and strategies used to manage specific issues.

Some health professionals discussed strategies they use to minimise the risk of issues arising. One medical oncologist, Eddy, reserves the chair closest to him for the patient, to indicate their priority status. He explained “what will happen is I will have my desk here and the patient will be sitting in the
hot seat. So if they get in the wrong chairs, I’ll say, “Well, actually, that’s for...[the patient]”. Some health professionals reported that the physician should clarify the scope of family involvement early on in the cancer trajectory. They may reassure family members that it is ok to ask questions or take notes, highlight that some conversations are private and the family member will be asked to leave the room, or may ensure that the family member understands that the patient is the priority. One nurse also believed that preparing or guiding family members about the roles they can assume may be beneficial. These results provide further evidence for the role clarification strategies which we proposed based on the results of our systematic review (Chapter 2). These strategies included: i) ascertain from the patient and/or family member why the family member has accompanied the patient; ii) highlight helpful family behaviours; iii) clarify and agree upon role preferences of patients and family members at commencement of the consultation; and iv) be aware of, and respect, the patient’s preferences for family involvement. Similar strategies were proposed by Speice et al. (2000) who, based on their qualitative data, recommended that oncology health professionals ask role clarification questions in initial consultations such as [to patient] “What important things should I know about how you and your family members relate to each other?” and [to family member] “How would you like to be involved in your loved one’s care?”. The evidence base indicates that physicians need to provide information about potential family member roles, and subsequently clarify the role preferences of patients and possibly family members. However, navigating role clarification may be a challenging task for health professionals, and no studies have evaluated if this process is successful or even favourable. Further discourse is needed to devise appropriate strategies to ascertain role preferences in triadic consultations.

Several health professionals discussed the importance of reading consultation room dynamics so as not to upset any parties and to understand who the key decision-makers are. Oncologist David said “I think you need to understand the power within those relationships because you want to make sure that you’re dealing with the dynamics within that relationship as well. Otherwise, you’ll say something to the patient and it will all fall apart and they’ll walk out the room”. Some health professionals recommended utilising other professionals to help mitigate problems. They suggested that physicians should actively find out if the patient is non-English speaking and arrange professional interpreters. Other health professionals highlighted the importance of referring family members to psychologists or social workers to help coping and adjustment.

Participants described many strategies they use to manage conflicting treatment wishes of patient and family member, one of the most common challenges described by health professionals. Firstly, one nurse recommended assessing if the patient and family member have received and understood
all of the information. Some health professionals also suggested conducting open and detailed discussions with the patient and family member; providing detailed information, discussing the pros and cons of each option, and explicitly acknowledging the conflicting preferences of the patient and family member. Several health professionals reported that they found reflectively listening and openly discussing the conflict to be helpful in achieving consensus. Oncologist Rose said “sometimes it works to say, “It sounds like you’re really worried about side-effects and it sounds to me that what your partner is really worried about is you being around. It sounds like he’s prepared to wear some discomfort in supporting you through this phase, because he wants you to hang around, whereas it sounds like you’re really scared about those side-effects.” So it’s about trying to articulate back what you’ve observed about the differences of opinion”. When treatment wishes are conflicting, most health professionals said that they openly acknowledge that patient wishes are paramount, and the patient should make the decision. Some health professionals tried to get the family to see the patient’s perspective. Another strategy was trying to get the patient to speak up about their preferences within the consultation. A final strategy was to arrange time for the patient and family member to consult with a different health professional together, for example obtain a second opinion or meet with a nurse to discuss the treatments in more detail.

Health professionals also described strategies for managing dysfunctional family dynamics or family conflict within triadic consultations. Radiation oncologist Georgina discussed her strategy for dysfunctional family dynamics “the way that I’ve sort of dealt with it is to adopt a really calm approach and keep it patient centred. I might say,” I understand that you’ve got some things that you don’t agree on, I understand that, but what we now need to talk about is Dad and Dad’s treatment”. Another radiation oncologist, Aiden, tried to put a positive spin on family conflict, he said “you just try to explain to the patient, “there is conflict because they love and are concerned about you, and they’re just terrified and they’re scared”. You try and be understanding of that sort of conflict”.

However, a challenge with managing conflict is that firstly health professionals need to identify it. Although the experienced health professionals in the current study reported being able to identify and manage conflicting treatment wishes and dysfunctional family dynamics, research by Siminoff et al. (2012) suggests that oncology physicians may indeed have difficulty detecting the presence of patient-family conflict in consultations. A potential strategy to overcome this issue is use of Siminoff et al.’s (2008) Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) which measures communication concordance and discordance between the patient and family and includes items assessing the patient’s and family members’ approach to decision-making. Use of the CCAT-PF may assist physicians in identifying conflict (Siminoff et al., 2008). The acceptability
and effectiveness of the CCAT-PF as a routine screening tool should be further explored amongst the health professionals who may administer it (e.g. physicians, nurses) and with patients and family members across different cancer settings.

Additionally, several health professionals in the current study described strategies to manage dominant family members. Firstly, health professionals may provide direction to the dominant family member about their involvement, such as asking them to withhold comments or questions until the end of the physician’s spiel. Another strategy is to focus on the patient. Nurse Ian stated that he makes eye contact with the patient and explicitly asks the patient questions, he said “I would then look at the patient and say, “Well, what do you think? How do you feel?” and try and get the patient more engaged in the conversation”. Finally, some health professionals found an opportunity to speak with the patient alone to ascertain their preferences without the dominant family member’s presence. Nurse Louise explained “you often then need to take the patient out of the family. You need a one-on-one conversation, to actually find out what the patient truly wanted to do, without background noise”.

If a family member displays anger, two health professionals recommended letting the family member talk and then attempting to address the underlying causes of the anger. Medical Oncologist Elizabeth said “if you let them vent within reason, often you can see what the underlying issue is. Often you can say, “Look I can see that you are really upset because the news isn’t good, but what we need to focus on now is how we are going to move forward from here, what treatment we are going to do”... It’s trying to work out why that aggravation is there, and then seeing if you can address it - if it’s reasonable”.

Many health professionals found consultations where too many family members attend to be challenging. Most health professionals who highlighted this challenge explained that it was often beneficial to limit the number of family members in the consultation room. If faced with too many family members, some health professionals stated that they apologise that not all family members can attend the consultation, acknowledge the limited space in the consultation room, request that a fewer amount of family members attend the consultation, and ask that a family spokesperson be nominated (usually by the patient). This spokesperson would usually report the information back to the other family members after. Health professionals reported that the strategy to nominate a spokesperson also helped to avoid several family members calling or emailing the physician asking for information. Nurse Annette said “I think you probably have to get the family to come to terms with the fact that it’s impractical to have eight people in a room because they’re not built that big...But the other thing I think is that the family has to work out the dynamics of who is going to be the main
support. In fairness to the medical people looking after them, you liaise with one person – not four brothers and sisters all ringing up”.

Several health professionals highlighted the importance of obtaining permission from the patient before engaging in any discussions with the family member when the patient is not present. Medical oncologist Colin described his strategy, saying “certainly at the end of the consultation I will say, “If so-and-so [family member] calls me, am I allowed to talk to them?”... I think we often make too many assumptions, which are in a way trying to put patients into the passive role. I think it’s better to.... ask explicitly what is the relationship and how much can you disclose to them if the patient isn’t present”. Many health professionals also discussed the challenge of family requests for non-disclosure of diagnosis. The primary strategy employed by health professionals was to acknowledge that legally the patient must know their diagnosis in order to provide informed consent. Medical oncologist Elizabeth said “often the clincher seems to be by saying, “Look, in Australian law, I cannot give your Father chemotherapy without him giving informed consent. He has to know”.

Finally, several health professionals highlighted strategies to deal with sensitive information (e.g. discussing sexuality or prognosis) when family members are present. Some find an excuse to speak privately with the patient about sensitive issues. Oncologist Aiden said “sometimes you might excuse them [family] when you’re doing the prostate examination, and you say, “Just wait outside.” And then you might sort of talk [to the patient privately], “Do you want me to discuss this further at a different time and a different place, to discuss that sexual function issue?”. Other health professionals were more direct, highlighting that sensitive information needed to be discussed and the family member would be asked to step outside the room for a short period. Nurse Annette even clarified this prior to the consultation, she explained “because a lot of the issues that we talked about were sexual, then if it was a son or a daughter, I made it really clear... when we were organising the appointment, that we would ask the son or the daughter to leave at a particular time so that I could just talk to the parent”. These strategies align with the recommendation made in our systematic review that physicians should ‘take opportunities to privately discuss sensitive information with patients alone’. If family remain in the consultation room and sensitive information needs to be discussed, radiation oncologist Aiden proposed an alternative strategy. He said “you talk in more general statements about, “this treatment can affect sexual function this way.” You even just say, “I’ve just described generic sexual functioning”.

Because the nurses in our study mostly discussed the strategies used by their physician colleagues, comparisons between physicians and nurses was not appropriate for this theme.
Despite widespread acknowledgement that family involvement brings many challenges, a limited amount of strategies have been proposed in the existing literature by Speice et al. (2000), Lang et al. (2002), Burkhalter and Bromberg (2003), Mitnick et al. (2010), and preliminary strategies in Chapter 2. The current study provides a much needed thorough exploration of challenges and strategies unique to triadic consultations and decision-making, grounded in oncology health professionals’ experiences.

3.3.3.9 Theme 9: “It's just a fact of life”: Some issues are beyond the health professional's control

Although health professionals utilised many strategies to overcome the challenges of family involvement, there were a small number of issues they felt unable to manage or solve. Several health professionals believed that managing dysfunctional family dynamics is beyond their control. Nurse Sarah explained that some issues cannot be solved in the consultation, she said “tension in the relationship, I think that is a no-go area. Particularly if it’s a long standing problem, because these things don’t happen just because of a cancer diagnosis... they are pre-existing problems”. Nurse Louise indicated there are limited strategies health professionals can use to deal with this issue; she said “I think there are sometimes... quite heavily dysfunctional relationships... It’s a really challenging one, because you can’t say, “No, you can’t come into the room”. Aside from recommending early and consistent attendance, health professionals indicated that they have little control over who accompanies the patient and when they attend. Oncologist Rose highlighted this issue, she said “I guess what’s hard is family members who aren’t involved at all, and then things go bad for the patient and the family will weigh in at a late event. That’s a disaster because they don’t know me and they don’t know how the decisions have played themselves out to reach that point... So, I think it’s a time when you can really get into trouble with family members if they haven’t been involved”.

Health professionals also highlighted many barriers to family involvement which they felt were beyond their control, particularly logistical issues, such as work commitments, family commitments, or living in a different city to the patient. Nurse Louise said “people can’t always get time off work, or they’ve got other commitment... The practicalities of life can stop them from being as involved as they might wish to be. Therefore, they don’t get the information to be able to then help so much in the negotiation and deliberating”. Health professionals also noted that various characteristics of the family member can hinder their involvement, such as being too unwell to attend, struggling to cope with the cancer diagnosis, or lacking the maturity to help.
No systematic differences were apparent for health professional’s discussion of issues beyond their control. To our knowledge, the notion that some family-related issues are beyond the health professional’s control has not been discussed in the existing evidence base.

3.3.3.10 Theme 10: “I think most clinicians aren’t even aware of how they may be changing the way they are with family members”: Physician self-awareness of behaviours

Physicians appeared to be aware of the positive behaviours they engage in to facilitate family involvement in the consultation, but were unable or unwilling to articulate many negative behaviours that they or others may engage in. This contradicts the views of some nurses, who identified several physician behaviours that may block family involvement. Oncology nurse Maxine reported that some physicians she has observed were not comfortable with family members present. She said “some people [physicians] that are often uncomfortable in that sort of situation [triadic consultation] will not encourage family members to ask questions or to talk”. Maxine also said “I have observed over the years particular consultants that will actually put their hand up and block them [family] speaking”. Nurse Kara, when discussing how physicians can make family feel unwelcome, said “the manner of the consultation, the doctor’s approach, the time restraint... I’ve been with consultants who have been very dismissive of the ‘overbearing wife’”.

Additionally, physicians may not be aware that they are excluding the patient in a triadic consultation. Several nurses noted that some physicians engage in coalition formation with family members, that is, exclude the patient whilst forming a relationship with the family member. Nurse Sarah described a situation where the physician began speaking with the husband instead of the patient “I have seen and challenged, in fact, certain male surgeons that move their body to talk to... the male [family member] in the room... I don’t think that they are aware of it... but their eye contact will move to the male. Particularly if the male starts asking questions, it changes the dynamic in the room in lots of ways”. Nurse Sarah also highlighted that the physician may form a coalition with the family member if the patient is elderly and/or hearing impaired. She said “If you’ve got someone who is elderly and a bit deaf, they [physician] will start to give the information to the family member to pass on... most of the time it just happens, evolves that way in the busyness of the clinic. So it’s not that people’s intentions are bad or wrong, but there’s an imperative to get the information across”.

Surgeon Theo was aware that he sometimes excludes the patient, he said “one of the things that I’m aware that I do - I probably do a lot of bad things -... if the patient is not fluent in English, I tend to speak more to the person who is translating. I’ll often have to say, “Tell your Mum I am sorry that I keep on talking to you”. Nurse Sarah believed that how physicians behave toward family members
varies greatly "I think there is an enormous variability that comes about through subtle ways about how families are responded to... I think most clinicians aren't even aware of how they may be changing the way they are with family members”.

One recommendation proposed by Speice et al. (2000) was that healthcare professionals take a step back and assess their own attitudes and behaviours towards family members. They proposed a 14 item self-assessment questionnaire to highlight opportunities for improving interactions with family members. This strategy could assist in overcoming a possible lack of self-awareness amongst some physicians. Future research needs to assess the effectiveness of this self-assessment tool.

3.4 Discussion

Family involvement in cancer consultations is variable and dynamic. It appears that family members can range from passive to dominant, may assume one role or many, and the nature and extent of their involvement may shift over time. How a family member is involved in a consultation may depend on patient, family member, cultural, relationship, and disease characteristics. Despite this variability, the health professionals in our study held overwhelmingly positive attitudes towards family members and were appreciative of most forms of family involvement in cancer consultations. Most noted that there is no ideal role family members should assume, and that this fluidity of roles ensures that family members can adapt their involvement to the changing needs of the patient.

Although most health professionals held favourable views towards family members, they also reported that many challenges can arise as a result of family attendance. To overcome these challenges, many health professionals had developed an array of strategies. Our participants were very experienced, and perhaps it is this long exposure that has led to their acceptance of, and confidence in managing, the challenges associated with family attendance. Future research should examine how less experienced health professionals perceive family involvement, and whether they possess the skills to confidently manage issues arising in triadic consultations.

Despite the fact that many health professionals in our study appeared confident navigating the challenges of triadic consultations, it is unclear how they actually communicate within consultations, and how their patients and family members perceive this communication. Several physicians reported that they routinely encourage, welcome, and include family members in consultations. However, some nurses in our study, and family members in previous qualitative studies (Morris & Thomas, 2001; Sinfield et al., 2008), have reported that physicians can engage in
negative behaviours such as ignoring family members, using blocking behaviours, or forming coalitions. To date, there has been a paucity of research describing the actual behaviours of health professionals within triadic cancer consultations.

A major issue highlighted by health professionals was balancing the rights of the patient with the needs of the family. Indeed, most of the challenges that health professionals reported were occasions when family members potentially compromised the patient’s decision-making authority or the patient centredness of the consultation. All of the health professionals in our study believed that the patient should be the priority and should retain decision-making authority. This notion aligns with previous quantitative research of health professionals’ attitudes (Gabbay et al., 2005). However, the results of our study also show that family are an integral and inseparable part of the decision-making process. Whilst it remains unclear how exactly family can be included in decision-making without compromising the patient’s decision-making authority, it appears that several of the strategies used by physicians related to clearer communication within the triad about roles and preferences. Interestingly, active family involvement is particularly evident when the patient is more vulnerable or is from a non-Western culture, and these may be times where clear elicitation and subsequent respect of patient preferences (even if it is for family dominance during decision-making) may be appropriate.

Health professionals noted that the extent to which family members are involved in decisions is highly variable, and descriptions of family involvement led to the categorisation of triadic decision-making into three approaches: facilitative, shared, or family-led. Despite the fact that dyadic (physician-patient) shared decision-making is considered to be the pinnacle of patient-centred care (Barry & Edgman-Levitan, 2012), the results of our study indicate that it may not be appropriate to extend this aspirational model and aim to include family members as an equal party. Indeed, most health professionals in our study asserted that patients are the priority and family members should usually assume a secondary role when the decision is being made. Although shared triadic decision-making was presented as one option, most health professionals in our study reported that there is no ideal style of family involvement. Any one approach to triadic decision-making may be appropriate if based on patient preferences. However, patient preferences for family involvement in decision-making are variable (Nolan et al., 2005; Pardon et al., 2010; Sekimoto et al., 2004), and health professionals should regularly clarify patient preferences for the extent of family involvement in decision-making. Synthesis and expansion of the triadic decision-making styles identified by Öhlén et al. (2006) and in this study may yield a useful descriptive conceptual
framework of family involvement in decision-making. At this time, caution should be used if proposing a single ‘aspirational’ or ‘gold standard’ framework of triadic decision-making, due to the variability of patient preferences and physicians’ ambivalence about adopting one approach.

In addition to elucidating the nature of family involvement in decision-making, this study aimed to understand the challenges that health professionals face as a result of family involvement, and the strategies they use to overcome them. Health professionals proposed a range of specific strategies to manage challenges, and also suggested general strategies to enhance positive family involvement (see Box 3.3). Some of these strategies were also proposed by Speice et al. (2000), Lang et al. (2002), Burkhalter and Bromberg (2003), and Mitnick et al. (2010). The central themes running through many of the strategies proposed in the previous literature and in this study are that: i) family members should be acknowledged, included, and supported; however it is also critical that ii) all consultations be patient centred with the patient's wishes regarded as paramount, iii) health professionals regularly assess patient preferences for family involvement, and iv) patient privacy and confidentiality be maintained. The challenge is for health professionals to balance the important involvement of family whilst retaining focus on the patient.
### Box 3.3: Strategies proposed by health professionals

<table>
<thead>
<tr>
<th>General goals</th>
<th>Strategies</th>
</tr>
</thead>
</table>
| Facilitating positive family involvement | • Actively encourage the patient to bring a family member  
• Encourage early and consistent family member attendance  
• Welcome the family member to the consultation, build rapport, and learn their name  
• Include the family member in consultation discussions, make eye contact with them, and answer family member questions  
• Provide family members with relevant information and support, such as information booklets for carers or referring them to relevant support groups  
• Ensure that the consultation environment is conducive to family involvement, such as having chairs available for family members  
• Be open to alternative methods of family involvement such as teleconferencing with family members or audio-taping consultations |
| Minimising the risk of issues arising | • Reserve the chair closest to the physician for the patient to indicate their priority status  
• Describe the various options family involvement  
• Clarify the patient’s preferences for the nature and extent of family involvement  
• Be attuned to the relationship dynamics between the patient and their family member |

### Challenge

<table>
<thead>
<tr>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family members acting as interpreters for non-English speaking patients</td>
</tr>
<tr>
<td>Family member showing signs of distress in consultation</td>
</tr>
</tbody>
</table>
| Conflicting patient and family member treatment wishes | • Assess and clarify patient and family member understanding of information  
• Conduct open and detailed discussions with patient and family member highlighting the benefits and drawbacks of each option  
• Explicitly acknowledge the conflicting preferences of the patient and family member  
• Openly acknowledge that patient wishes are paramount  
• Facilitate the patient’s open expression of preferences  
• Arrange for the patient and family member to speak with a different health professional, such as another physician for a second opinion or with a nurse to discuss treatments in more detail |
| Pre-existing family conflict or dysfunction | • Keep calm and remain patient focused |
| Managing dominant family members | • Provide direction to dominant family member about involvement, such as asking them to withhold comments or questions until the physician or patient has finished speaking |
| Family member anger                                      | • Find an opportunity to speak with the patient alone without the dominant family member’s presence  
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Let the family member talk and attempt to address the underlying causes of the anger (if reasonable)</td>
<td></td>
</tr>
</tbody>
</table>
| Too many family members in consultation room             | • Apologise and acknowledge the limited space in the consultation room  
|                                                          | • Request that fewer family members enter the consultation  
|                                                          | • Request that a family spokesperson be nominated, who will attend the consultations and relay the information to family members |
| Managing family requests for patient information          | • Obtain permission from the patient before engaging in any discussions with the family member when is patient is not present |
| Family requesting non-disclosure of diagnosis to patient | • Clearly acknowledge that legally the patient must know their diagnosis in order to receive treatment |
| Discussing sensitive issues with the patient (e.g. sexual function) | • Find an excuse to speak privately with the patient about sensitive issues, such as asking the family member to leave the room for a physical examination  
|                                                          | • Highlight that sensitive information needs to be discussed and the family member should step outside the room |

### 3.4.1 Limitations

A number of limitations are present in the current study. The sample in this study was limited to health professionals practicing at tertiary hospitals in a metropolitan area. Due to the high proportion of physicians who have completed communication skills training programs (>80%) the attitudes and behaviours of health professionals in our study may be different from those who have not completed communication skills training. The health professionals in our study were also highly experienced and may have been more confident in managing the challenges associated with family attendance compared to less experienced health professionals. Future research needs to assess the attitudes and experiences of junior physicians and nurses. The health professionals who agreed to participate in the study may have a greater interest in medical communication or family involvement. Thus, the findings may be biased to reflect the views of more interested and inclusive health professionals. Finally, as with all qualitative research, objectivity of the findings can be compromised by the researcher. However, rigorous dual coding for 20% of interviews was utilised to minimise this bias.
Conclusion

Health professionals reported that family members are a crucial part of the multidisciplinary team and their involvement can lead to many benefits which extend beyond the consultation room. A thread of optimism ran through most interviews, with most health professionals indicating that the benefits of family involvement usually outweighed the challenges. Although there were many challenges inherent in triadic consultations, these experienced health professionals were mostly confident in managing them and utilised an array of strategies to do so. Interviews indicated that some physicians may lack awareness of the negative behaviours they may participate in when interacting with family members, therefore development of a triadic communication skills training program may be useful. This study has revealed a number of draft strategies to assist physicians in managing and enhancing family involvement. Momentum is gathering in the triadic consultation evidence base, yet there is a paucity of theoretical guidance for how family are involved in medical decision-making. A descriptive conceptual framework to guide future research would be a valuable theoretical contribution.

However, before the development of a conceptual framework or clinical strategies, an in-depth understanding of the attitudes and experiences of patients and family members is needed. These attitudes and experiences will be explored in the next chapter.
Chapter 4:

Family involvement in consultations and decision-making:
The attitudes and experiences of cancer patients and family members
4.1 Introduction

Family members are usually the main source of support throughout a patient’s cancer experience (Repetto et al., 2009), regularly attend cancer consultations (Eggly et al., 2006; Street & Gordon, 2008), and are often involved in discussions about important medical decisions (Schäfer et al., 2006). Given the frequency with which family members attend cancer consultations it is important to ascertain the preferences and experiences of patients and family members regarding family involvement in triadic consultations.

Of the limited research conducted into the patient’s experience to date, studies indicate that most patients appreciate family involvement in consultations. Kimberlin et al. (2004) found that cancer patients preferred having their family member involved in the consultation and felt that their family member made helpful contributions. Cancer patients in Speice et al.’s (2000) focus group study appreciated physicians’ attempts to build rapport with and involve their family members. Despite these positive findings, there is little extant literature on the views and attitudes of patients regarding optimal family member roles during consultations and in decision-making, and any strategies that may enhance family member involvement.

Of the studies examining family members’ experiences, it appears family members value the opportunity to be involved in consultations, but encounter some challenges. In a study of female partners of prostate cancer patients, Sinfield et al. (2008) found that family members felt their involvement in consultations was important, were pleased to be providing support, and appreciated the opportunity to hear medical information first hand. Morris and Thomas’ (2001) study found that family members reported many positive experiences (e.g. welcoming nature of staff, obtaining important information), but also negative consultation experiences (e.g. feeling superfluous or excluded, confusion about what role to assume). Additionally some family members may not attend consultations, or they may attend consultations in a passive role (Botelho et al., 1996; Schilling et al., 2002). Research is needed to better understand the challenges of family involvement, any barriers they face when engaging in consultations, and to elucidate strategies which may overcome these challenges.

Additionally, there is limited research which has compared and contrasted the experiences of patient-family pairs. Previous studies have indicated that patients and family members may have different expectations about what role the family member will assume throughout the consultation (Ishikawa et al., 2006), and that the roles that patients and family members assume may influence
the patient’s satisfaction with the consultation (Street & Gordon, 2008). Further research is needed to explore the level of congruence or mismatch in patient-family preferences and experiences.

Throughout the cancer experience many patients are faced with important decisions, and family members are often involved in discussions about these decisions (Schäfer et al., 2006). To date, quantitative studies have examined the: i) preferences of patients and family members towards family involvement in decision-making, and ii) actual experiences of family involvement in the decision-making process. Relevant oncology preference studies found that between 49-84% of patients want their family member to actively participate in the medical decision-making process (Gilbar & Gilbar, 2009; Gonçalves et al., 2005; Pardon et al., 2010; Schäfer et al., 2006), and one study found that 54% of family members feel they should have a say in the decision (Schäfer et al., 2006). Studies examining what actually occurred in the decision-making process found that 67% of patients and between 60-80% of family members reported active family involvement in decision-making (Schäfer et al., 2006; Srirangam et al., 2003).

It is clear that a substantial proportion of patients and family members want family to be involved in decision-making, and that family members are actually involved in the decision-making process. However, a very limited number of studies have qualitatively examined the nature and implications of the family’s involvement in decision-making. Hubbard et al. (2010) found that family are often actively involved in both the information exchange and deliberation phases of decision-making, and their role may be dependent on a number of factors such as the patient’s ability to process information or the family member’s ability to anticipate the patient’s needs. However Hubbard et al.’s (2010) study was limited as it only briefly discussed of family involvement in decision-making, and it failed to highlight the array of behaviours family can assume throughout the decision-making process. Another study, conducted in the general practice setting, found that family involvement varied substantially from active to minimal, that family’s information support was particularly important when making decisions, and in the majority of cases the involvement of family in the decision-making process enabled the patient to make decisions more autonomously (Gilbar, 2011). Whilst Gilbar (2011) provided an in depth exploration of the decision-making process, the sample was very small (11 patients, 6 family members), and may not have captured a wide array of views and experiences. Further research is needed to more comprehensively understand patients’ and families’ attitudes towards, and experiences of, triadic decision-making in the cancer setting.
Aims

This study aimed to elicit the attitudes and experiences of Australian cancer patients and their family members regarding family involvement in cancer consultations and decision-making. Of particular interest was exploring: i) the attitudes of patients and family members toward triadic consultations; ii) the nature of family involvement in cancer consultations; iii) patients' and family members' attitudes towards family involvement in decision-making; iv) the benefits and challenges of family involvement in decisions; v) barriers to family involvement in decision-making; and vi) any strategies to improve triadic consultations and decisions.

4.2 Methods

4.2.1 Participants and recruitment procedures

Eligible participants were English-speaking adult patients (aged 18 and over) who had a primary or secondary diagnosis of cancer within the past two years, had been involved in a significant treatment decision, and had an adult family member or friend who had accompanied them to at least one consultation. The adult family member or friend of a recruited patient who attended at least one consultation was also invited to participate in the study. Participants were recruited through one participating tertiary metropolitan hospital oncology clinic and one breast cancer patient advocacy group.

Initially the recruitment strategy was to recruit only members of the Breast Cancer Network of Australia's (BCNA) Review and Survey Group. A breast cancer advocacy group was selected because breast cancer is a common diagnosis, these women had indicated a willingness to participate in research, were considered to be informed and committed to improving cancer services, and were likely to provide considered and articulate views about the communication and decision-making issues raised (Brennan, Butow, Marven, Spillane, & Boyle, 2011). However, the majority of women recruited through this advocacy group had completed active treatment, and the experiences of individuals currently making decisions about active treatment were not being captured. Therefore, an additional strategy of recruiting patients through an oncology clinic was devised to ensure variety amongst the patient sample and provide a different perspective.

Breast cancer patient advocacy group: A proportion of group members were sent an invitation email to participate in the study by a national breast cancer advocacy group (See Appendix I for invitation email). Women who received the invitation email and who were interested in the study were invited to contact the study coordinator who then mailed an information package that
included a participant information sheet (Appendix J), consent form (Appendix K) and questionnaire (Appendix L). Women were also invited to provide contact details of a family member who had accompanied them to a cancer consultation and were willing to participate in the study. These family members were then mailed an information package (see Appendices M, N, and O). Participants who returned a signed consent form and completed a questionnaire were contacted by the research team to arrange a suitable time to conduct the interview. As it could not be determined which email participants fulfilled the eligibility criteria, it is unknown how many potential participants received and read the invitation email. All participants who returned a questionnaire completed the interview. A total of nine patients and seven family members were recruited through the advocacy group and completed the study. There were seven matched patient-family member pairs, with interviews conducted separately with each member. Mean duration of patient interviews was 43 minutes and mean duration of family member interviews was 35 minutes.

**Oncology clinic:** Oncologists were asked to identify suitable patients on their clinic lists. A member of clinic staff briefly introduced the study when the patient attended the clinic, and the researcher then discussed the study in more detail and invited participation. If interested, patients were provided with an information package (see Appendices J, K, L) for their own participation. Patients were also invited to nominate a suitable family member to participate. Interested family members were provided an information package (see Appendices M, N, and O). Patients were followed up by a phone call to confirm participation for themselves and/or their family member.

Of the 39 eligible patients approached at the oncology clinic, 21 completed the study (response rate 54%). Five patients completed the questionnaire but dropped-out of the study because they were too busy, too unwell, not contactable or did not want to be interviewed. Six patients declined participation because they were either too busy or for unstated reasons. Seven patients were unable to be contacted. Mean duration of patient interviews was 37 minutes.

Of the 39 eligible family members approached or nominated, 26 completed the study (response rate 67%). Four family members completed the questionnaire but dropped-out of the study because the patient was too unwell. Three declined participation because they were too busy; and six family members were not contactable. Mean duration of family member interviews was 33 minutes.
There were sixteen matched patient-family member pairs, with interviews conducted separately with each member, except in one case where the patient and family member did not want to be interviewed separately. The remaining four patients and nine family members were individuals who agreed to participation but whose family member did not wish to be involved.

Ethical approval for all aspects of the study was obtained from The Cancer Institute NSW Human Research Ethics Committee (see Appendix G).

4.2.2 Measures

A questionnaire assessed i) participant demographic information (age, gender, education, occupation, marital status, children, country of birth, language spoken at home), ii) clinical characteristics of the patient (cancer diagnosis, cancer stage, treatments received, current stage in cancer trajectory); and iii) information about which family members had attended consultations. See Appendix L for a complete patient questionnaire and Appendix O for a complete family member questionnaire.

A comprehensive semi-structured interview protocol was developed by the candidate and supervisors, based on a systematic review of family involvement in consultations (Chapter 2) and a review of dyadic shared decision-making theory and research (e.g. Charles et al., 1997; Charles, Gafni, et al., 1999, Charles et al., 2004; Elwyn et al., 2000; Légaré et al., 2008; Makoul & Clayman, 2006). Patients and family members were asked about a range of topics related to family involvement in cancer consultations, including their experiences, attitudes, the roles of family members, and the involvement of family members in treatment decisions (See Appendix P for patient and family member interview scripts).

4.2.3 Data analysis

Demographic data were collected and analysed using summary statistics such as means and frequencies, using SPSS Version 18.

Audio tapes of interviews were transcribed verbatim and checked for errors in transcription. While thematic analysis (Braun & Clarke, 2006) was selected as the broad research paradigm, framework analysis (Ritchie, 2002) was selected as the specific method of qualitative data analysis. Framework analysis, proposed by Ritchie typically involves five steps progressing from i) familiarisation, ii) identifying a thematic framework, iii) indexing, iv) charting, to v) mapping and interpretation which occur in an iterative, rather than linear, process. The current study adopted a similar approach to
qualitative analysis as the health professional interviews (Chapter 3 for additional details about choice of qualitative approach and methodology). The candidate became familiar with the data and a preliminary thematic framework was based on independent analysis of 20% of transcripts by the candidate and an expert in qualitative research. Data were independently organised according to concepts, themes, and sub-themes. All transcripts were then coded by the candidate according to the framework, with new themes and revisions to the framework discussed with one expert in qualitative research. Themes and supporting quotes from each transcript were transferred to a framework (a matrix with participants as rows and themes as columns) using MS Excel as a computerised qualitative data analysis tool (Meyer & Avery, 2009). The framework was examined within and across themes and participants to identify overarching themes, subthemes, patterns, and relationships. Rigour was addressed by inclusion of several aspects of collaboration as discussed by Paulus et al. (2008), including repeated coding of transcripts by different team members to ensure a comprehensive list of themes and sub themes and collaborative and iterative discussion of emerging and final themes with experts in qualitative analysis.

Analyses were inductive (data driven). One exception is in theme 8 where both inductive and deductive methods were utilised for a small section of analysis. Participants were asked to describe the involvement of family during key points in decision-making (information exchange, deliberation, decision) derived from Charles et al. (1997) and Charles, Gafni, et al. (1999). Other than describing family involvement within these broad categories, analyses were inductive.

4.3 Results

4.3.1 Participant Characteristics

Table 4.1 presents an overall summary of participant demographic and clinical characteristics. Patient age ranged from 30-80, with a mean of 56 years, and family member age ranged from 28-81, with a mean of 54 years. Fifty percent of patients and 61% of family members were female. Patient cancer diagnoses were varied, with the highest proportion of cancers being breast (33%) and lung (23%). Patient treatment stage ranged from discussing treatment options (3%), receiving active treatment (23%), through to having completed active treatment (30%) or palliative care (3%). The vast majority of family members were spouses, with 45% wives and 30% husbands of cancer patients.
### Table 4.1: Demographic and clinical characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Oncology Clinic</th>
<th>Breast Cancer Advocacy Group</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
<td>0</td>
<td>15</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year 12 or below</td>
<td>11</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>TAFE certificate/diploma</td>
<td>3</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>University degree</td>
<td>7</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or living with partner</td>
<td>18</td>
<td>8</td>
<td>26</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Separated or divorced</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Primary cancer diagnosis</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>7</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>7</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Breast</td>
<td>1</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>2</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Renal</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Current treatment stage of patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussing treatment options</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Receiving active treatment</td>
<td>7</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Clinical Trial</td>
<td>4</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Discussing treatment options after recurrence</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Receiving treatment after recurrence</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Completed active treatment</td>
<td>2</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Palliative care</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Family member type</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wife/Female Partner</td>
<td>15</td>
<td>0</td>
<td>15</td>
</tr>
<tr>
<td>Husband/Male Partner</td>
<td>4</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Son</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Daughter</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Sister</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other (Friend, brother-in-law, great-aunt)</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
</tbody>
</table>
4.3.2 Structure of presented data

The data are arranged into ten higher order themes. The structure of presented data is the same as in the health professional interviews (see Section 3.3.2 in Chapter 3). The dataset in this chapter was too large for meaningful use of pseudonyms. An overview of themes is presented in Box 4.1.

Box 4.1: Overview of qualitative themes

<table>
<thead>
<tr>
<th>Theme 1: “It just happened. He didn’t have to ask me, I didn’t have to ask him”: Negotiating and understanding family consultation attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Negotiating attendance and involvement</td>
</tr>
<tr>
<td>• Why attends, when, and why?</td>
</tr>
<tr>
<td>• General attitudes towards family attendance</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 2: “It’s incredibly powerful knowing someone is by your side”: Family provision of emotional support</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Supporting the patient</td>
</tr>
<tr>
<td>• Sharing the journey</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 3: “She was my ears and my voice”: Informational support provided by family members</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Pre consultation preparation</td>
</tr>
<tr>
<td>• In-consultation informational support for the patient</td>
</tr>
<tr>
<td>• In-consultation informational support for the physician</td>
</tr>
<tr>
<td>• Post consultation support</td>
</tr>
</tbody>
</table>

| Theme 4: “I get the information to let the family know”: Family as the messenger |

| Theme 5: “I wasn’t there to tell them how to treat my partner”: Family-physician relationship |

| Theme 6: “I think it made the process easier for the both of us”: Family members may also benefit from attending consultations |

<table>
<thead>
<tr>
<th>Theme 7: “At the end of the day it’s her health, her body, her life”: Patient decision-making authority versus the needs of the family</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient attitudes toward family involvement in decision-making</td>
</tr>
<tr>
<td>• Family attitudes toward family involvement in decision-making</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 8: “We sat at the table and discussed it together”: Family involvement in the decision-making process</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Styles of decision-making</td>
</tr>
<tr>
<td>• Factors influencing decision-making styles</td>
</tr>
<tr>
<td>• The trajectory of family involvement</td>
</tr>
<tr>
<td>• Benefits of family involvement in decision-making</td>
</tr>
</tbody>
</table>
4.3.3 Qualitative Themes

4.3.3.1 Theme 1 “It just happened. He didn’t have to ask me, I didn’t have to ask him”: Negotiating and understanding family consultation attendance

Negotiating attendance and involvement

The ways in which patients and family members negotiated family attendance, and the reasons that they attended, were varied and complex. Many participants recalled that there was no specific negotiation process or discussion, rather that family attendance in consultations was natural, expected, or ‘just a given’. Family members’ attendance and involvement was often an intuitive process, rather than an actively negotiated one. This was a particularly common response for the partners or married couples who participated in interviews. One family member, a husband, stated “Oh just there is no questions asked... I mean she is my wife. So I’ve got to go there [consultation]”. Another family member, a wife, highlighted that there was no explicit negotiation process, stating “it just happened. He didn’t have to ask me, I didn’t have to ask him was it ok if I go [to the consultation], it was just together”.

A much smaller group of participants actively discussed whether the family member would attend the consultation. A small proportion of family members made an authoritative decision to attend consultations, sometimes irrespective of whether they thought they were welcome. The female partner of a male patient recalled “I thought, I’m going [to the consultation] regardless because you don’t know what to expect”. Another small proportion of family members offered attendance or asked the patient for permission to attend; these family members were usually not spouses, but rather siblings, friends, or more distant relatives. The great-aunt of a young adult male with cancer stated “When he was diagnosed, I said to him, I’ll go there [oncology consultation] with you if you want and he said, “yes, yes”... I never insinuated that I should go”. Only a very small number of

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patients reported that they invited a family member to attend the consultation. Similar variability of negotiation was found in Beisecker et al.'s (1997) study, whereby sometimes family members asked permission to attend the consultation, sometimes the patient asked the family member to attend with them, and sometimes both the patient and family member just wanted to attend.

Only a few patients and family members negotiated the family member's roles in the consultation. One family member stated that prior to the consultation she was aware of the needs of the patient and proposed some of the roles she could assume. She said “I just suggested that we write some things down... She mentioned that she was feeling clouded about... the information so she wanted me to help in that way”. The concept of pre-consultation negotiation was tested by Wolff et al. (2014), who found that a pre-consultation information preference and role clarification checklist completed by patients and family members was evaluated by the majority of participants as easy and useful and led to more patient-centred communication and better patient understanding. It may be beneficial for future research to assess if pre consultation role negotiation and information preference clarification is a useful tool within the oncology setting.

Two family members stated that the patient gave feedback after consultations about what was helpful or unhelpful behaviour, such as being too eager to ask questions on the patient's behalf or asking too many clinical questions. Each of these family members found this clarification and role negotiation process helpful, and appreciated the feedback. One husband said “[Patient] had to beat me back a little bit to begin with because I was a bit too eager to leap in and I asked questions on her behalf. [Patient] didn’t want me to take control... It was kind of a negotiation process between [patient] and I. Talking afterwards, over the process of the first few visits, for me to learn to just sort of sit back and be patient and just listen. And maybe just pop in for the occasional question”. However, one patient stated that he and his wife no longer discuss her involvement, because previously those conversations were uncomfortable and it is now a very delicate topic. Therefore, role negotiation, although helpful for some, may not be an appropriate or easy process for all patients and family members.

**Who attends, when, and why?**

Although the majority of family members were spouses/partners, there were several other relationship types among participants. If the patient was partnered, their spouse was usually the person who attended the consultation. For four participants, it was an adult child who regularly attended consultations. A small group of patients without a long term partner reported that other
family members (e.g. sibling, great aunt) or friends attended the consultations. Past research has also found that the spouse/partner followed by adult child are the most common family members attending cancer consultations (Beisecker et al., 1997; Eggly et al., 2011; Labrecque et al., 1991), however limited research has explored the involvement of other family members such as siblings, parents, and friends. Our study suggested that most patients were satisfied with their family members’ involvement, irrespective of their relationship ‘type’.

A small number of patients noted that they had different family members attend consultations throughout their illness trajectory. A young adult patient stated that his parents initially attended consultations, but as his romantic relationship became more serious, his partner started attending more frequently. A patient, who preferred individual autonomy, stated that she usually attended consultations on her own, but various family members (husband, adult children, sister) had attended some consultations. Although these patients appeared satisfied with the pattern of their family’s attendance, several other participants noted the importance of having one family member attend consultations consistently. A patient, whose mother attended some consultations when her husband was unavailable, said “the difficult thing with having mum there was that she didn’t have all of the context whereas [husband] had been with me so I think having someone who has been through the whole thing is much easier... Because if you had different people coming it would be quite difficult... having the consistency of one person makes a massive difference”.

Despite consistent attendance being raised as an important aspect of family involvement by several participants in this study and the health professional interviews (Chapter 3), to our knowledge no previous studies have highlighted this issue. It may be beneficial if physicians encourage and facilitate consistent attendance by the same family member (if preferred by the patient) wherever possible. However, this consistency of attendance may not be possible for some family members. Several participants reported that there were barriers to family involvement, such as work and family commitments and living a long way from the hospital. One patient noted “you're seeing the oncologist once a week and you might wait 2 hours to get in with him. There is a lot of time spent at Doctors’ offices, many, many hours and so if you didn't have a work place that was helpful, that could’ve been really difficult.” Perhaps alternative methods of family involvement (e.g. teleconferencing) would assist the family member to participate in most consultations.

A few participants highlighted issues which arose whilst negotiating family attendance. A patient in her 30’s noted that choosing her partner to attend consultations caused conflict within the family, as the patient’s parents felt that they should be her primary caregivers. She stated “it caused a huge
amount of conflict in my family because I chose [partner] as my primary carer and that displaced my family... they responded really poorly to that”. Another younger patient felt it was difficult for his girlfriend to attend consultations because of the early stage of their relationship.

When asked about how often family attend consultations, the majority of participants stated that their family member attended most of the consultations, particularly when important discussions were going to take place, such as a new treatment or after a scan. Alternatively, a few patients reported that although their family members used to regularly attend, they now attend alone because of increased confidence.

One consultation where several family members were not present at was when the diagnosis was given, usually in a general practice setting. A few family members expressed guilt or regret that this had occurred. When recalling the day the patient was diagnosed with cancer, one wife said “[Husband] had the x-ray, the Doctor rang and said I have got your x-ray can you come and see me now... which should’ve rung alarm bells. I can remember ringing the Doctor’s surgery about half past 5 at night and asking the receptionist what was going on and she said “well you really should’ve come with him”...that, in the scheme of things, plays on my mind”. This same issue was also highlighted by Srirangam et al. (2003) who found that 52% of partners were not present in the consultation when their spouse was given the diagnosis of prostate cancer. Srirangam et al. (2003) reported that most of these partners regretted not being in attendance. He suggested that the onus should be on medical staff to include both patients and partners when informing of diagnosis. Perhaps health professionals, or their medical receptionists, need to encourage family attendance at any consultation where there is the potential for bad news (such as the diagnosis of cancer) to be delivered.

Another time when family members may not be present is if health professionals consult with patients whilst they are in hospital. A patient noted that her husband was not present when important information about her treatment was given by the oncologist on the ward after surgery. The provision of information on the ward may be problematic, as family members miss vital information and many patients are in a vulnerable position, unable to digest and discuss the information with their family as they normally would.

Family members stated that they attended consultations for an array of reasons. Many family members stated that they want to provide emotional support (see Theme 2), informational support (see Theme 3), to obtain information for themselves (see Theme 7), and to be involved in the
decision-making process (see Theme 9). Some less common reasons for attending the consultation were to provide logistical support for the patient, such as driving them to the consultation, carrying their scans, and helping arrange appointments, or to be an advocate for the patient's best interests. These results reflect the findings of Beisecker et al. (1997), who asked oncology patients and family members to evaluate the reasons family members attend consultations. The provision of support and companionship (emotional support) was ranked as the most important role followed by increasing understanding and asking questions (informational support). However, several family members in the current study recalled that they did not have a reason for attending; instead they stated that they “just wouldn’t miss it”, that it was natural for family to attend, or that they do everything together. Some family members indicated that they were unsure of what roles they had assumed, and whether their presence was useful.

**General attitudes towards family attendance**

When asked how they felt about family attendance, most patients held very favourable views. Most patients reported that their family members were helpful and several stated that they felt comforted, reassured, calmed, or stronger because of their family’s presence. A young adult breast cancer patient, whose sister attended consultations, stated “she just took on this strength that was amazing... there was no way I could've coped without having her there” and another patient said about her male partner “it's just incredibly comforting and reassuring to know that I actually have someone that I could really depend on, that would be there with me as I went through the process of cancer treatment”. Family members also appeared to appreciate being involved, reporting that their attendance helped the patients and also benefited themselves (see Theme 6). The findings of previous studies align with these results. Kimberlin et al. (2004), Repetto et al. (2009), and Speice et al. (2000) found that patients believe family involvement to be helpful and appreciated, while Petronio et al. (2004) and Sinfield et al. (2008) also found that family members appreciate the opportunity to be involved and believe that they can make a helpful contribution.

Four patients were non-committal about their family member’s attendance. One patient stated “I would’ve been quite happy to just go alone to all of them if [wife] said “no I’m too busy” or “I can’t make it.” Another patient, when asked how he felt about his wife’s attendance, said “Um...I'm not sure, it's part of our routine now because it's been going for so long. So it's just part of what we do. I don’t really have any particular feelings other than there is an appointment we’ve got to go to”.
Theme 2 “It’s incredibly powerful knowing someone is by your side”: Family provision of emotional support

Supporting the patient

All family members expressed that they wanted to help the patient, and one of the main methods for this was the provision of emotional or moral support to the patient. Family members explained that they wanted to “be there” for the patient or “comfort” the patient. When asked about why she attends cancer consultations, the wife of a patient said “because I love him, and to be supportive... My main [reason for attending] was I just felt I needed to be there for him”.

Patients appeared to appreciate the emotional support provided by their family. One patient with breast cancer said “it’s just incredibly powerful knowing that someone is by your side ... you’re sitting opposite the Doctor and they’re talking to you about your chances of dying and your chances of being infertile and what the treatments are going to involve. And you’ve just got this person sitting next to you holding your hand... that support is just incredibly invaluable”.

The importance of emotional support was amplified when there was bad news delivered, or at other times that the patient was particularly anxious or distressed. When asked why he attended consultations, a family member explained “I wanted to be there for her support. She was very anxious and scared at various stages of the process”. A patient stated that his wife’s attendance is “a great comfort because... there are some things in this consultation that are pretty brutal and... it’s great to know they are there as a comfort because you do break down at times”.

Patients and family members further clarified the methods used to provide emotional support. Some family members recalled that they gave physical signs of support to the patient in the consultation, such as holding the patient’s hand, touching the patient’s shoulder, or placing their hand on the patient’s leg. Several patients stated that they appreciated the physical support provided by their family member. A patient explained “[partner] would always hold my hand if I cried... that physical presence and him touching me... I just felt very loved and supported... It’s hard to put into words how powerful it was for me to be in this incredibly stressful situation but to have [partner’s] hand on my hand it made it ok”.

In addition to physical displays of emotional support, a few family members explained that they made positive comments to the patient, mostly after the consultation. These family members felt it was important that they stay optimistic and provide reassurance to the patient. One family member stated “I give him some mental support and say it [treatment] is working, it’s going to work and the
success rate is high... it makes him tough and happy”. de Rosenroll, Higuchi, Dutton, Murray, and Stacey (2012) found a similar theme in their qualitative study of family members’ involvement in dialysis modality decision-making. Family members described the importance of their ‘positive outlook’ role, defined as the conservation of an optimistic perspective. However, while a few patients in the current study stated that they appreciated the positivity of their family member, two patients recalled that there were times when they did not appreciate family positivity particularly when it was not warranted or felt like false cheerfulness. One patient explained “I know at one stage in between my surgery and my radio therapy I got quite stressed and actually said to [husband] stop saying that everything is going to be all right because you don’t know that”. However, a few patients described that their wives contributed to an optimistic or pleasant tone of the consultation, which was perceived as positive and supportive. Other studies have also examined patient preferences for positivity. Wilkes, O’Baugh, Luke, and George (2003) found that cancer patients reported that while they did not want other people to tell them to be positive, they needed to feel that their loved ones were demonstrating positivity, and felt that the positive support of their family members was essential to maintaining their own positive attitude.

Family members appeared to provide emotional support to patients both inside and outside of the consultation. A few patients reported than an important benefit of family attending consultations was that they were able to provide emotional support once the consultation had finished. Patients expressed appreciation that their family member understood the realities of the illness, and were able to discuss the consultation at home. One patient stated that a benefit of his wife’s attendance was “mainly support... for yourself especially when you get home. They get an idea of what’s going on with you”. Another patient appreciated being able to go through the ups and downs of consultations with her husband. She said “we always talk about it [consultation] afterwards which is really nice. We can go and say oh well, comfort each other or you know, rejoice!”.

An ethnographic study of oncology consultations by Ellingson (2002) identified similar types of emotional support to those reported by the participants in the current study. Ellingson (2002) observed that family members offered nonverbal indicators of support such as hand holding and verbal support such as reassurances about the patient’s future. Interestingly, Ellingson (2002) also observed that many of those family members offering emotional support also gave cues to the health professionals that they themselves needed emotional support. Health professionals may need to be aware of the emotional needs of family members who are providing support, but not receiving it themselves.
Despite several participants in the current study describing specific supportive behaviours of family members, other participants explained that family provide emotional support by “just being there” for the patient; providing a supportive presence rather than actively engaging in any specific behaviours during the consultation. A few patients stated that it did not matter what their family member did in the consultation, the fact that they were there with the patient provided a sense of security. One patient explained “it was just such a relief to know that he was there. Whether he was active or passive in the consultation didn’t matter, just that he was there, that was the most important thing”. Another patient provided an analogy for his wife’s emotional support during consultations, he said “it’s like when you’re sick and your mother holds you and rubs your forehead. She is not doing much but the fact that she is there makes you feel better”. A similar theme was identified in de Rosenroll et al.’s (2012) qualitative study, where the role of ‘being with’ was defined as the emotional, physical, psychological, and spiritual presence provided to the patient. Limited other research has commented on this valuable but intangible support provided by family members, and it is unlikely consultation analyses would capture the unspoken supportive presence of a family member. Researchers and clinicians should be aware that many patients value the silent support of their family member, and that family members can be actively supporting the patient without any overt behaviours.

**Sharing the journey**

Many of the family members expressed that they wanted to share the difficult cancer experience with the patient. One family member said “I feel sorry for [husband]… hearing all these things and knowing that I can’t do anything, but I just like to share it with him”. Many patients and family members, particularly couples, approached the diagnosis and treatment of cancer as a team, spoke of it as a combined or shared journey, and something that they wanted to face together. The male partner of a breast cancer patient highlighted “it’s a stressful process and I wanted to be there to help out. [Patient] and I discussed pretty early that the approach that we were going to take... do things together and go through the process together”. Other research has pointed to the importance of a shared approach to cancer. Speice et al. (2000) found that patients appreciated when family addressed the cancer as a “we” experience. The idea of the ‘shared journey’ was common amongst couples in our study. The husband of a patient stated “I feel very much that we are in this together, I feel that this is a crisis...or passage that we need to go through together. We’ve been married for 50 years and we feel that we are a ‘twosome’, we don’t really do things individually. Where there is suffering involved, we’d rather be in it together”. Given the high level of investment many family
members have in the patient’s illness, and the research showing high rates of morbidity, mortality, and mental health issues amongst family caregivers (e.g. Schulz & Beach, 1999), physicians may need to be aware of signs of distress among family members and refer them to support accordingly. In ethical guidance endorsed by the American College of Physicians, Mitnick et al. (2010) made a similar recommendation that physicians should be alert for signs of distress in family members and suggest appropriate referrals.

Patients also commented that the emotional state of the family member had an impact on the support they could provide. Several patients noted that they would not want a family member to break down or become overly emotional or “tragic” in a consultation. One patient explained “I would’ve hated to have someone there break down next to me. So I’m taking someone there for the support, to be strong for me”. A few patients also noted that it is important that a family member puts the patient’s needs above their own, as they do not want the consultation to become more about the family member than the patient. Whilst it is important that physicians acknowledge and refer distressed family members to appropriate support services, patients indicated they do not want their family member’s emotions to derail the consultation. Physicians may need to be aware of the difficult balance between identifying and providing support to family members whilst not allowing it to become the focal point of the consultation.

In summary, it appears that most family members want to provide emotional support, and patients are appreciative of this support. Interestingly, the ways in which family display this emotional support are varied but appear to be equally valued; emotional support can be overt, such as physical support in the consultation, delayed, such as support after the consultation, or almost intangible, such as ‘being there’ or sharing the journey. Additionally, it appears that family members who themselves are able to cope and adjust may be able to better emotionally support the patient.

4.3.3.2 Theme 3 “She was my ears and my voice”: Informational support provided by family members

All patients and family members described the importance of the family member’s provision of informational support. Most family members appeared to help the patient obtain, understand, and remember important information about the cancer and its treatment, and this type of support was highly valued by patients. Although informational support was provided by all family members, it appears that it was particularly valuable during ‘important’ consultations (e.g. diagnosis, treatment decision discussions) or when the patient was distressed or in shock. Family members with a scientific or medical background, those who had received more education than the patient, or those
who had prior experience with cancer, were seen as particularly helpful when providing informational support. This finding is mirrored by Pecchioni and Sparks (2007) who found that patients reported being most satisfied by the information provided by family and friends, which may be because family are often the most supportive and available information sources. Additionally, Pecchioni and Sparks (2007) also found that 50% of cancer patients turned to family and friends who had health related knowledge either professionally (e.g. physician, nurse) or personally (e.g. previous diagnosis of cancer).

Interviews revealed specific details about the informational support provided by family members provided prior to, during, and after cancer consultations. These are discussed below.

**Pre-consultation preparation**

Many family members assumed an active role in pre-consultation information gathering and preparation. Some family members helped find the cancer specialist and arranged the appointment. Several family members reported that they did research prior to the consultations, either on the Internet or by speaking with people who had previous experience with cancer. This helped family members to know what questions to ask in the consultation and keep up with information presented by the physician. One family member recalled "we’ve done our own research behind the scenes... from day dot when we found out he had... cancer I have done my own research so I have kept in front...knowing what’s going to be told to him as we go to each session". Very few patients expressed their feelings towards family research prior to the consultation; however one patient stated that although it was fine that his wife did Internet research, he thought that the information she produced was "rubbish". This indicates that some patient-family dyads may experience mismatched information source preferences. Pecchioni and Sparks' (2007) study revealed that patients found health professionals to be an important source of information whilst family members tended to rate the Internet as more satisfying in their search for information. Physicians may benefit from awareness of the role the Internet plays in many family members’ pre consultation research, and patients and family members may benefit from being directed to reliable and relevant Internet sites.

Several patients and family members revealed that prior to the consultation they would discuss the questions and issues they wanted to raise with the physician. The husband of a patient recalled “before we went into consultations we also listed off the things that we felt it was important to know from the consultation, what was the purpose of the consultation, why were we there, what we were
aiming to find out... and if they hadn’t addressed that, we asked about it”. A different patient recalled how she would practice raising difficult topics, such as death or sexuality, with her partner prior to the consultation. She said “[Partner] was coaching me and guiding me around the fact that I did actually need to talk about what did the future mean and what decisions should we be making, so in the car on the way there we would practice ways we could bring them up in the consultation... it was important that I was able to do that myself but... he would coach me around ways that I could talk about it that I felt comfortable”. Several patients stated that this pre-consultation preparation was very helpful. Pre-consultation preparation has not been highlighted in previous strategy or guidance papers (e.g. Burkhalter & Bromberg, 2003; Mitnick et al., 2010; Speice et al., 2000); however, these findings provide evidence for the importance of pre-consultation preparation tools similar to Wolff et al.’s (2014) pre-consultation information needs and role clarification checklist.

**In-consultation informational support for the patient**

Almost all family members recalled that they provided informational support to the patient within the consultation. Many participants described the importance of the family member acting as a “second pair of ears” in the consultation, with one family member stating “it’s helpful to have a second ear ... with two sets of ears there you’re more likely to get more of the information and you can bounce off each other... it’s a bit of a safety net”. The provision of informational support was greatly appreciated by patients, and described using words such as “useful”, “helpful”, “needed”, and “comforting”. A variety of informational support behaviours were described by participants, such as asking questions, providing information, and reporting symptoms. Previous studies have not specified the content of informational support provided by family members, focusing instead on the level of informational support provided.

Participants in the current study generally fit into three levels of activity in providing information support within the consultation: ancillary, active and dominant, described in more detail below.

**Ancillary informational support role:**

Many family members were reported to assume an ancillary informational support role during the consultation, where they would listen, absorb the information, provide information if asked, and ask follow-up type questions. Some family members also took notes during the consultation. Many family members consciously assumed this ancillary role, because of the view that the patient and/or physician should lead the discussions. A family member explained “I feel that basically if somebody is going to see the Doctor that’s the relationship between the patient and the Doctor and I’m
there just as a secondary back up”. Additionally, many family members reported that they censored
the amount of questions they asked or asked only follow up type questions, such as questions which
clarified or elaborated on the information, or those that the patient had forgotten to ask. A patient
explained “[wife] tends to ask the secondary questions after I’m finished... to follow up, to clarify... for
example she might clarify why the Doctor’s recommending a particular path as opposed to another...
It’s not always a totally new subject to what I have already raised it’s kind of clarifying it”. One family
member stated that he only asked questions about topics that the physician had raised, rather than
attending the consultation with his own agenda.

Some family members assumed an ancillary role in deference to the physician. One patient
explained “occasionally [wife] would have a couple of questions for the specialist and with his
approval she would ask them”. Additionally, a small number of family members felt that their
questions were unwelcome and would therefore censor their question asking. One family member
said “you felt like you were being a pain, like I think they like to keep their consults on time and you
just don’t want to hold them up”. It appears that through either self-censoring or feeling unwelcome,
many family members may not get the opportunity to ask their own questions in consultations and
may therefore have unmet information needs.

Other family members assumed the ancillary role because the patient was more knowledgeable
about the disease, had done more research, or was medically trained. One patient said “I am always
the primary person so I tend to ask all the questions in the first instance and I tend to be the one who
has thought of what I wanted to ask before and I also do probably the most reading up about the
condition and the treatment.... [wife] tends to ask the secondary questions after I’m finished”.

For many patients, the ancillary informational support role of the family member was preferred
and appreciated. When asked how an ideal family member would behave in a consultation, many
patients indicated that they preferred them to remain as a secondary participant in the
consultation, assuming a supportive or back-up role. Some patients noted that an ideal family
member would “keep a low profile”, listen, support the patient, not tell the patient what to do, and
not dominate the consultation. One patient stated “Ideally for me...good listening skills, being able to
recall what was said so that I can ask questions later...and probably just keeping a low profile other
than asking questions that I may not have asked that would be relevant”. Another patient said “what’s
helpful is someone to listen and process the information almost so that I can be the one asking the
questions I want to ask and I have got someone else whose acting like a tape recorder and backing me
up”.

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**Active informational support role:**

Other family members assumed a more active role in the provision of informational support. They would ask questions about a variety of topics such as treatment options, side effects, medications, disease progression, or the impact of disease on the family. Some patients appreciated their family member’s active question asking. A patient who relied heavily on her sister during the consultation showed appreciation of the questions her family member asked. She said “[sister] was asking all these questions and it was questions that I hadn’t even thought of... so I was like “yeah that was a really good question”... I basically just had it in mind I will do whatever the Doctor tells me to do and [sister] was more questioning and bringing up good points”. In addition, some family members helped patients to provide information. This included raising sensitive or difficult topics that the patient wanted to discuss, either by prompting the patient or starting the conversation with the physician. Examples of these topics included discussing trying complementary and alternative therapies, side effects of treatments, and obtaining a second opinion.

Some family members also assumed an active advocacy role. Within this role, family members asked questions to ensure that the patient was receiving the best possible care. One family member stated that he queried a number of things that the doctor was saying out of concern that his wife was not receiving the best care. Other family members advocated for better treatment of side effects being experienced by the patient by providing information about the patient’s health at home. Several patients stated that they appreciated the advocacy role that their family member assumed. Reust and Mattingly (1996) in their qualitative study of medical decisions highlighted that many family members assume an advocacy role, stepping in as an intermediary between the patient and physician to defend the interests and rights of the patient. Reust and Mattingly (1996) suggested that this role enhances the patient’s autonomy, by protecting, stabilising, and enhancing the patient’s right to decide.

However, a small proportion of patients reported challenges when their family member assumed a more active role in the consultation. A few patients believed that their family member asked too many questions or were too forthright with their questions. Some patients perceived their family members’ questions to be irrelevant or too basic. One patient stated that her husband asked questions about the patient’s prognosis when she did not necessarily want those questions asked or answered. She said “once I got diagnosed I just wanted to jump straight into treatment...Things like, what’s my prognosis like, I didn’t really want to ask, he asked more difficult questions sometimes”.


Dominant information provision role:

Only a few participants reported that the family member assumed a dominant role in the consultation. This role was usually assumed if the patient was elderly, very unwell, had an impairment (e.g., hearing impaired) or spoke English as a second language. A few family members assumed the role of translator for both the physician and patient when the patient had very limited English, and therefore assumed the dominant role providing information and asking questions. A different group of family members also provided interpretation for patients who could speak English. One family member provided a high level of interpretation and assistance for his hearing impaired father, while other family members reported that they helped patients with limited health literacy to understand the complex medical information.

The three levels of family involvement (ancillary, active and dominant) are similar to those proposed by Street and Gordon (2008) who reported the percentages of family members enacting each level as: passive <40%, partner 40-60%, surrogate >60% contribution. Although it appears that most patients in the current study were satisfied with their family member’s informational support irrespective of their activity level, there were more challenges reported when family members assumed more active roles. Given the variability in patient responses to active family member involvement, perhaps role negotiation and elicitiation of involvement preferences may help family members to provide the most desired style of informational assistance to the patient. Additionally, it appears that many patients preferred that their family member assume a role which complemented the patient’s involvement style.

Complementary activity levels:

It appears that active patients often preferred family members who assumed a more ancillary role, whereas passive patients often preferred it when their family members assumed an active role. Other family members assumed a flexible role; when the patient needed the family they were more active, whereas when the patient was more confident the family member adapted their role to be more passive.

Complementary family members assumed roles that the patient needed at the time, or in areas where the patient felt they were lacking, such as confidence to ask questions or ability to remember details. One patient explained “when I was strong I would speak for myself and ask the questions and when I wasn’t strong [husband] would step in and speak for me or...or ask the questions he knew I would want answers to but was perhaps not feeling confident to ask... Depending on how I was at the
time”. Other research also indicates that patients may appreciate when their family member assumes a complementary, rather than similar, role. Street and Gordon (2008) found that patients reported lower satisfaction levels when their family member assumed a comparable level of participation to the patient (e.g. both active); whereas those patients whose family member was either more passive or more active than the patient reported higher satisfaction. Further research is needed to assess how to best harmonise patient and family involvement levels to enhance patient satisfaction.

**In-consultation informational support for the physician:**

In addition to providing informational support to the patient, family members were reported to assist the physician. Family may provide information to the physician, such as recalling the recommendations of other specialists or providing information that the patient could not remember. Several family members also provided their interpretation of the patient’s functioning at home, highlighting new health concerns or the side effects of treatments. A few family members assumed a watchdog role, ensuring that the patient provided accurate or relevant information in the consultation. One family member recalled correcting his father, saying “You know they’ve just asked a series of questions which dad has just lied about. He is not getting out of bed, he is not moving around, he is in pain, he is taking more medication than what they anticipated, but he is telling them a completely different story... So I am telling them exactly what’s going on... I think the information I was providing them was basically the correct information”. It appears that health professionals appreciate the additional information provided by family members, as per the interviews with health professionals (Chapter 3) and other studies such as Rosland et al. (2011). Rosland et al. (2011) found that physicians believed that family members help the physician to better understand the patients concerns and help provide information that the patient does not give.

**Post consultation support**

Almost all patients and family members stated that they discussed the consultation after it had finished, and family members were often able to assist with recalling information provided by the physician. Many patients reported that this recall of information was very helpful, particularly for patients who felt they were unable to adequately absorb the information in the consultation. Both patients and family members commented that they found it helpful to discuss the consultation, as sometimes the patient and family member had interpreted or remembered the information differently. A patient recalled “[In a consultation] you’re listening and you can hear something in one
vain which could be a total misinterpretation. A couple of times [wife] has said to me when we’ve sat down and discussed it when we got home that I miss heard something and conversely one time she’d misheard something. So by both being there and coming home and discussing that we got a better understanding of what was going on”.

Posma, van Weert, Jansen, and Bensing (2009) found that both patients and health professionals believed that family attendance at the consultation could enhance the patient’s recall of the information, as the patient and family may remember different aspects of what was said in the consultation. J. Jansen et al. (2010) also highlighted the value of family involvement in recall. Their study, which assessed recall amongst accompanied and unaccompanied older cancer patients, found that recall in patient and companion couples together was higher than their separate recall scores, indicating that they were able to supplement each other’s knowledge. Unaccompanied patients had lower recall than combined patient and family dyads.

In addition to recalling the information, several family members spoke of how they helped the patient to analyse the consultation. This included discussing the meaning of what the physician had said, interpreting the verbal and non-verbal cues of the physician, and understanding the implications of the information conveyed. Patients appreciated the opportunity to discuss, analyse, and check their interpretation of the consultation with their family member. A patient describing the post-consultation behaviours that he most appreciated, said “active listening, retaining information,...retaining not just the facts but what's implicit in the doctors body language and behaviour... and then being able to have a discussion with me about it afterwards to analyse what we should do”.

Additionally, a small number of family members stated that after the consultation they would provide the patient with clear instructions of next steps, and help to organise and execute consultation recommendations. Some family members also engaged in additional research about the disease or treatments after the consultation. To date, the valuable post-consultation contributions of family members have not been described in strategy or intervention papers (e.g. Mitnick et al., 2010; Speice et al., 2000; Wolff et al., 2014). It may be beneficial to highlight some of these valued roles to family members who are unsure about how to best support the patient.
4.3.3.3 Theme 4 “I get the information to let the family know”: Family as the messenger

Several participants highlighted that the family member acted as the “messenger” or “middleman” between the consultation and the wider family, communicating with the extended family about the information obtained in the consultation. This role was reported to be helpful to the wider family and also to the patient. The wider family reportedly found the messenger role to be helpful as they were able to obtain information about the patient, which may be perceived as more reliable when being relayed by a family member rather than the patient. One patient said “when I first started going, my girls [adult daughters] didn’t believe me so now that my husband comes with me it’s a different story because he can tell them what’s going on and they know he won’t lie”. Additionally, the wider family’s views and needs may be more likely to be represented within the consultation if a family member is present. One family member, a husband, felt it was important to represent the needs of their daughter when they were making decisions. He said “part of my strength of feeling involved in the decision-making was also because of our daughter. And part of my desire to influence the decisions and to be part of it was because of how I felt about her as well... So as a family member my influence was not wildly strong but because of having the wider family aspect I was more passionate about it”.

The family as messenger role was also reported to be very helpful to patients themselves. Several patients reported that their family member could make the wider family/friends aware of the patient’s health status, one patient stated “[Husband] is also my mouth piece for the rest of my family and friends. When I’m sick... he gives people updates so they don’t ring me, which is good because sometimes I don’t feel like talking to people. So he’s my communication point, it’s a really good thing”. Another benefit to patients was that family members were able to protect the patient when discussing treatment decisions with the wider family. A patient recalled that her sister (who had attended the consultation) helped to explain to their mother why the patient was receiving a particular treatment. She said “we told my parents the results and my mum is like ‘why do they have to take your whole breast, why can’t they just take the cancer out, why does he have to take your whole breast’ she just couldn’t understand. And [sister] put her in her place by saying that’s the best option, that’s what the surgeon decided now we really need to do these other things”. Another patient stated that her husband, in his role as messenger, helped to protect the patient from the emotions of the wider family by taking over the communication of news to them. She said “when you start going through this process, after you have been through this story once, twice, three times, God you get
sick of it. And it’s also having to deal with the emotions of other people that you are talking to, so having someone else do that for you is sometimes a big plus”.

Although patients highlighted that the messenger role was very helpful, a few family members indicated that they found this role to be stressful and challenging at times. A wife reported that she felt pressure from the wider family to obtain information from the physician, to ask certain questions and get certain answers. Her family would call after the consultation and she indicated that she was stressed if she was unable to give them the information they needed. Another family member felt pressure being in the middle of all parties, particularly because the wider family had different beliefs about the treatments the patient should obtain. This pressure was difficult for the family member, who felt responsible for the patient’s decisions in the eyes of the wider family, as she was the one who attended the consultations. One family member explained an awareness of protecting the patient’s privacy and only relaying information to the wider family that the patient had approved of.

There is a paucity of research examining this significant role, which many family members appeared to assume. Despite the fact that the messenger role was reportedly appreciated by both the wider family and the patient, it can be stressful for the family member themselves. Development of strategies to assist family members to cope when assuming this challenging role may be beneficial.

4.3.3.4 Theme 5 “I wasn’t there to tell them how to treat my partner”: Family-physician relationship

Many participants described the dyadic relationship that existed between the physician and family member. When speaking about their relationship with the physician, many family members appeared to revere, respect or show deference. Several family members commented that the physician was the expert, while the family member was the novice. One family member recalled his interaction with the physician in an initial oncology consultation, saying “It’s very much my view that they’re the experts in relation to this... it wasn’t for me to challenge that... This is day 2 of my experience of cancer”. Some family members also highlighted that it was unlikely they would question or instruct the physician. The male partner of a breast cancer patient said “I wasn’t there to tell them how to treat my partner... I wasn’t there to judge whether they were making the right or wrong decisions. Unless they say something which contradicts something that I’ve heard from another one of the specialists, then really I’m not likely to challenge anything at all”. Several family members also noted they did not want to interfere with the physician-patient relationship. One family
A similar theme was found in Morris and Thomas’ (2001) qualitative study where family members were described as reticent to ‘butt in’ to the privileged physician-patient relationship. Family members also expressed an awareness of limited time in the consultation, and their wish not to take up time unnecessarily. One family member said “you don’t generally get that opportunity to ask questions... you basically have to push in a little bit while he is...having the consultation and...I just put that down to time”. The family’s deference to the physician and their perception of limited time may impact on the family member’s confidence and ability to ask important questions or contribute valuable information. This may be particularly stressful for family members who feel that they are the “messenger” to the rest of the family (see Theme 4). Physicians need to be aware that some family members may not feel confident to offer information or get their own information needs met.

Only a small proportion of family members highlighted that they felt confident and empowered to be actively involved in the consultation. Two family members said that they would ask questions even if the physician did not want them to, and one family member expressed the belief that answering family members’ questions was part of the physician’s job. He said “If anything came to mind, I’d ask, I didn’t hesitate. That’s what your there for, you’re paying those doctors big money and that’s their job”. A few family members believed that their presence helped the physician, and were confident that the physician wanted them to ask questions and appreciated their involvement. The very small proportion of confident or questioning family members stands in contrast to Zhang and Siminoff’s (2003) finding that a substantial number (35%) of family caregivers either questioned or challenged the physician regarding their opinions or practices.

Family members also highlighted some of the negative aspects of physician-family interaction. Some family members felt invisible or ignored, and highlighted that they had to initiate all interaction with the physician. Some recalled feeling tentative about asking questions, while others felt like they were “disliked” by the physician and that the physician would have preferred if the family did not attend. Additionally, a small number of family members described physicians as aggressive, dismissive, or condescending towards family members. Several family members reported that they would have preferred more direct engagement from the physician. Sinfield et al. (2008) found similar results in their qualitative study of partners of prostate cancer patients. These family members reported that they often had to take initiative to be included by physicians and some felt that their concerns were not taken seriously, they were perceived as trouble, or the
physician gave the impression that they did not want to be questioned. Perhaps it is the lack of engagement of physicians that may cause some family members to feel they are intruding or pushing in on a private patient-physician conversation, and therefore reluctant to ask questions or raise concerns.

Conversely, a few participants highlighted that too much engagement with the family, at the expense of patient involvement, was also perceived as problematic. A few patients and family members recalled consultations where the physician engaged primarily with the family member, and the patient was treated more like ‘a child’. Similarly, in a qualitative study of patients and their family members, Gilbar (2011) described a small proportion of family members who formed a coalition with the physician when there was decisional conflict. Gilbar (2011) reported that patients were dissatisfied with the coalitions and had reduced autonomy and independence as a result. Additionally, in Repetto et al.’s (2009) study of cancer patients, 5% of patients reported that the presence of a family member prevented a patient’s direct relationship with the physician in a consultation. A small but important proportion of patients may be experiencing exclusion as a result of their family’s attendance, and this may be impacting on their perception of autonomy. Therefore, it is important that physicians continue to build a relationship with the patient, and are aware of the potentially negative consequences of forming a coalition with the family member.

A challenging scenario raised by a few participants was when the family member wanted to obtain information without the patient present. Some family members highlighted that they would have found the opportunity to speak with the physician alone to be extremely helpful, as they could have asked sensitive questions about the patient’s prognosis and details about the way the disease would progress. A husband explained his information needs “I think if it was just me, I would ask more questions along the lines of what’s going to happen, tell me what we are going to be ready for and what we can plan for. Whereas, I don’t think we can do that when we are together [patient and husband present in consultation]. I have debated in my own mind about trying to get a phone interview with [doctor] when [wife is not present], so I can ask these questions. About where are we going to end up”. Morris and Thomas (2001) in their qualitative study found that many family members of cancer patients with a poor prognosis also desired separate conversations with the physician to understand what to expect. In many cases, the patient gave permission for this separate conversation to occur. However, in our study not all patients indicated agreement with their family member having a separate relationship with the physician. One patient stated that she wanted to be present for anything that her physician said about her. Other studies also suggest that
patients are usually happy for their family to know as much as themselves, but not more (Benson & Britten, 1996). However, the extent to which physicians adhere to privacy laws protecting patient confidentiality is mixed. A previous study conducted in Spain found that 35% of primary care physicians reported providing family members with information about the patient without the patient’s permission (Pérez-Cárceles et al., 2005). Additionally, Gilbar (2012b) highlighted that some physicians reported that they would not disclose any information to the family member of a patient without patient consent, while others described a moral conflict they felt when approached by concerned family members for information, knowing that they did not have the patient’s consent to discuss the information. Further guidance should be provided to physicians who are faced with this difficult situation. It may be beneficial if physicians openly discuss the patient’s wishes for information sharing, and if they do not consent to separate family-physician conversations, physicians could refer the family member to more general information sources.

4.3.3.5 **Theme 6 “I think it made the process easier for the both of us”: Family members may also benefit from attending consultations.**

Family members appreciated hearing information directly from the physician, learning about the disease and treatment, and being able to ask their own questions. Participants reported that hearing the information directly also helped to avoid misunderstandings. One family member stated “I think it made the process easier for the both of us, because we were both getting the same information at the same time. Therefore, there wasn’t any misunderstanding or confusion that might arise if [patient] was trying to relay information to me afterwards”. This finding is mirrored in Sinfield et al.’s (2008) qualitative study, where partners of prostate cancer patients reported that obtaining the information from the physician first hand was helpful and enabled them to better participate in subsequent discussions.

Additionally, some family members believed that attending the consultation gave them peace of mind (i.e. meeting the physician, hearing the details about the treatments and having the opportunity to clarify any misconceptions). One family member recalled that attending the consultation gave him the opportunity to “ask about chemotherapy, the side effects of chemotherapy... to clear my mind... you see things, you hear and read things about chemotherapy... and the same with radiotherapy so to hear first-hand from a person who’s involved in that is like clearing the pathway”. Hearing the information directly also helped one family member to feel more confident in the patient’s choices. A male partner stated that attending consultations “meant that when we were having discussions about what [patient] might like to do next... I had an
understanding of what the different approaches might be and what the complications or implications of making those decisions was...So in that sense I wasn't left in the position where I needed to second guess [patient’s] decision”.

Family members also felt reassured that there were no secrets being kept. This benefit was evidenced by a few patients who stated that after attending a consultation unaccompanied they did not disclose the whole truth to their family members. One patient admitted “there have been one or two occasions where in this process, that you get some unpleasant news, if [wife] is not there I have sometimes ‘sanitised’ it a bit”. Another patient said “if you were telling a family member you tend to try not to make it too dramatic... You don’t give them the full picture”. Additionally, a few family members recalled situations where information was disclosed by the patient in a consultation when it had not been previously discussed with the family. One family member recalled "[patient] was having symptoms about something... and she didn’t tell me because she’d knew I’d worry and then that came up with the oncologist”.

Some family members felt that obtaining information themselves and hearing the information “first hand” helped them to avoid denial about their loved one’s illness. A few patients also believed that understanding the realities of the illness can help the family prepare for any bad news. Additionally, family members may obtain a clearer picture of the patient’s illness and may better understand why the patient is behaving or feeling a certain way, perhaps due to treatment side effects, pain, or sickness. One family member stated “without being sick you don’t really realise what they go through and what sort of treatment they go through, the pain that they go through, so it’s just good to be there. Going to the consultations and hearing about the treatments and expressing how he feels about the pain... because sometimes he doesn’t tell you”.

By attending the consultation, family members may obtain a better understanding of why certain treatment decisions are made. This was thought to be particularly important in situations where the family member may need to take over the decision-making as a proxy. Additionally, by attending the consultation, family members were reported to be more likely to be engaged in the discussions around decisions, and may feel more comfortable about the decision knowing they played a part in the discussions.

Participants suggested that family members who attend consultations may also be better informed about how to provide care at home. A few family members stated that they benefited by knowing what to expect, what were normal and abnormal side effects, and what to do if the patient was
having a reaction to a treatment. One family member recalled a situation where he used the information provided in a consultation. He said “I've been to the consultations and been made aware of the reactions and what can happen, what shouldn't happen. When her temperature rose, [physician] said not to hesitate and call him, so I did that. If I hadn't been in those consultations and made myself aware of what was happening and what to look for, I wouldn't have known”.

Additionally, several patients and family members believed that family benefited from attending consultations as it made them feel as if they were doing something productive throughout a process where they often felt helpless and out of control. One patient explained “I think it’s really hard on partners because they can’t actively do anything and I think that [attending consultations] was one thing that he could actually do”. By being a part of the consultation and decision-making process, some participants suggested family felt engaged, valued, and included.

There is a paucity of studies which have explored the benefits of attending cancer consultations from the family member’s perspective. This may be valuable information to provide to family members who are uncertain whether to attend the consultation, or to patients who “don’t want to burden” their family member by having them attend the consultation. It may be beneficial if health professionals or written materials highlight the potential benefits (while not minimising the effort required) of family attendance not only for the patient but for the family themselves.

4.3.3.6 Theme 7 “At the end of the day it’s her health, her body, her life”: Patient decision-making authority versus the needs of the family

Both patients and family members provided their views about how much influence family should have in the decision-making process. Whilst acknowledging the importance of including the family in the process, most patients and family members agreed that patients should have ultimate authority over their medical decisions. Patients appeared to be more open to active family involvement in decisions than were family members, many of whom reported that they censored their views and supported the patient’s choices.

Patient attitudes toward family involvement in decision-making

Many patients displayed awareness that their medical decisions affected their family and acknowledged that their loved ones were heavily impacted by cancer and its treatment. A patient explaining the impact of cancer on his wife said “my observation has been that the carer has a worse time than the person suffering the disease, and the person suffering the disease focuses on themselves and the disease. The carer is coping with uncertainty... and so I believe that the carer has a much
tougher time. Part of my motivation has been to include [wife] in everything”. Many patients explained that family involvement in decision-making was important as the decisions had implications that reached beyond just the patient. One patient explained “because I am part of a family and it’s important for the family that we’re all together, we’re not individuals, we’re all together and the decisions that we were making were going to have massive impacts on my family so... they were decisions that were based on what was best for everybody”.

Some patients noted that family members were more directly affected by certain treatment decisions such as those affecting fertility. A breast cancer patient in her 30’s stated “I might have been the one having cancer but it had a huge impact on [partner] as well. I think it was important for him to be there because... he almost had an equal voting right in terms of the decisions we had to make, particularly around fertility”. A qualitative study by Reust and Mattingly (1996) obtained similar results, that patients consider the impact of their illness and treatments on the family’s daily routines, employment, and finances. Reust and Mattingly (1996) argued that, given that the impact of illness reaches beyond the patient, family should be treated as a significant moral participant in decision-making. In the study by Schäfer et al. (2006), 70% of cancer patients reported that family members should have a say in treatment decisions.

Several patients reported that they wanted their family to be involved in the decision-making process to some extent. Patients appreciated their family acting as sounding boards and showing faith in their decision. Some patients appreciated when their family provided opinions. One patient explained “it was my decision for everything but...I really wanted to know what they were feeling and what they were thinking but... at the end of the day it was all about me and my health”. Several previous studies have also found that most patients desire some level of family involvement in the decision-making process. In Gilbar and Gilbar’s (2009) study, 84% of patients rated the involvement of their partner in medical decisions as important, and 89% thought that their partner’s agreement with their decision was essential.

Whilst most patients preferred their family to be involved in the decision-making process, a few reported that they did not want their family to be actively involved. However, these patients noted that they took their family into account when autonomously making decisions. A female patient who preferred an autonomous decision-making style stated “I kind of separate them [family] from the decision-making in the way that it's part of my decision to do the best for them. Of course they're going to be considered, they’re considered right up the top there but at the end of the day I have to live with what I have decided to do as well”.

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Despite wide acknowledgement of the impact of cancer on the family and the importance of family involvement in the decision-making process, most patients wanted to retain final authority over the decisions they made. Patients noted that it was their body and they would be the ones receiving treatment, therefore they should make the decision. One patient stated “at the end of the day, you have to wear that decision, you are the one that has to be cut open. You’re the one that has to get through the treatment... I think it’s best to make the decision yourself”. Several patients noted it was important that their family did not dominate the decision “I find it very important [that family do not] push in any way shape or form the decision... In the end the person who is sick, it’s pretty much all on them”. Similar results were found in Gilbar’s (2011) qualitative decision-making study; where most patients indicated a preference for family involvement in the process of making the decision, but believed that the final decision should rest with the patient alone.

Although almost all patients desired authority, a few patients noted that they would engage in continued negotiation and discussion if their family member disagreed with the decision. One patient explained “I very much felt like it was my decision to make... If I really wanted to do it one way and [husband] thought it should be done a different way, I think we would have a much longer conversation but at the end of the day... I did feel empowered that it was my decision to make. However I really rely on [husband] to help me make decisions”. Schäfer et al. (2006) also found that patients want to include family in negotiations in the event of decisional conflict. They found that 78% of patients and family members believed that a disagreement concerning a medical decision should be solved jointly by the patient, family and physician.

**Family attitudes toward family involvement in decision-making**

The majority of family members believed that the patient should make their own medical decisions. Many family members acknowledged that it is the patient’s body and they are the ones who have to receive the treatment. One family member stated “my view has always been that [patient] makes the decisions and I have some input into it so... at the end of the day it’s her health, her body, her life”.

Whilst acknowledging that the patient has the right to make their own decisions, most family members also indicated that a level of family involvement in the decision-making process was important. Many family members felt that they could assist the patient, but acknowledged that their role was usually “secondary”, “backup”, or “auxiliary” to the patient. The sister of a breast cancer patient stated “at the end of the day, the individual’s health decisions or any decisions are their own and I guess people around them can influence them by supporting and helping with information”. This view is reinforced by Gilbar (2011) who found that whilst the patient may have control over the
decision, family can influence the decision by their involvement in the decision-making process, most notably the provision of informational support.

Although family members may indirectly influence the decision by their provision of support, most were determined not to directly impose their views or demands on the patient. Many family members recalled censoring their opinions when discussing the decision with the patient, and at times this was difficult. A family member said “I am very conscious of it being [husband’s] decision ultimately about his treatment. Obviously he takes into account how I feel but I guess the difficulty is... sometimes I get a bit frustrated and I just want to say something... and I have to step back and let [husband] do the talking”. A different family member explained “I have to try all the time to put myself in [wife’s] position and that’s not easy because I’m coming from that point of view that, this is her life and her decision, and I’m the one that’s’ going to be left behind, so to speak. It’s quite tricky trying to disentangle one’s own feelings from what she must be feeling”.

Several family members also indicated an understanding and acceptance that the patient must remain the physician’s first priority. A family member stated “I feel I am always included but I know which chair to sit on when I go in. And what I mean by that is that [husband] is the patient and... I know my place”. Gilbar’s (2011) qualitative study revealed similar findings, where family members did not impose their views on the patient and tried not to dominate the consultation. Gilbar (2011) also found that family members felt that they did not have the authority to make the decisions and typically accepted the decisions made by the patient.

A few family members stated that an additional reason that they wanted the patient to have ownership of the decision was because of fear that something would go wrong. They wanted to avoid guilt, regret or conflict with the patient. The male partner of a patient explained “I think if I actively pushed a position or I actively pushed a suggestion then I would have possibly been concerned that if the process that [patient] had gone through was the wrong one and... that would play on my mind... By not being the decision-maker... but being the facilitator, it takes away that risk for me, down the track”.

A few family members believed that they deserved to have input into the decision-making because the decisions impacted on them, as well as the patient. They wanted to be consulted about decisions because family may be involved in the logistics of receiving treatment or want to have input in decisions at the end of life. The wife of a patient with advanced cancer stated “cancer doesn’t affect one member, it affects the entire family... We’ve got big decisions to make as a family... So it’s very
important that I am included in the process because the bottom line for [Patient] and I is how much
time we've got left. It's probably more important for me than [Patient]... I need to know what to do, I
need the information so I can make a rational decision”. Despite the fact that some family members
expressed a desire to be actively involved in the decisions, almost all respected that the ultimate
authority should rest with the patient.

Very few of the participants had reported serious decisional conflict, which may have influenced
our findings. Indeed, many patients and family members reported that they agreed on the
treatment decisions made or they believed that there was a clear-cut choice. However, several of
these participants spoke hypothetically, and mostly they accepted that the patient would retain
authority to make their own decisions, but take into account information/views of the physician
and family. One family member summarised this by saying “it’s primarily the patient’s decision, but
the patient, I know her well, will definitely be influenced by what they [doctor] recommend and what I
[husband] think... Neither of them ultimately is going to be the determinant of the decision, it will be
her decision, but she will take notice of what the doctor says and particularly in what I [husband]
think”.

Overall, it appears that most patients and family members want family to be involved in the process
of making decisions. This may be through supporting or facilitating the patient, or being an active
contributing partner in the decision. However, the general understanding amongst almost all
participants was that the final decision should rest with the patient. This finding aligns with the
results presented by Gilbar (2011), that family is often involved in the process of decision-making
but patients want to retain the authority over the final decision.

Whilst some ethicists (Hardwig, 1990; Ho, 2008) have argued for family’s rights to involvement in
decisions, other ethicists argue that patient autonomy and decision-making authority is the
foremost concern (Blustein, 1993). Currently, it is the patient who is being protected by most
regulatory healthcare codes and charters, for example the Australian Charter of Healthcare Rights
(Australian Commission on Safety and Quality in Healthcare, 2008) and the NHS Constitution
(National Health Service, 2013). Gilbar (2011), however, argued that if law and policy aim to reflect
social practices in the area of medical decisions, then current legal and professional guidelines
should be amended to reflect the important and influential role played by family members in
medical decisions. It appears that there is a shift towards the recognition of importance of family
involvement, recently seen in legislation in the Affordable Care and Patient Protection Act (United
States Government, 2010), the Carers Recognition Act (Commonwealth Government of Australia,
2010) and professional guidelines such as the Australian Charter of Healthcare Rights (Australian Commission on Safety and Quality in Healthcare, 2008). However it remains unclear how physicians should balance the rights of the patient with the needs of the family.

Additionally, the results in this theme reflect a high degree of relational autonomy amongst many patients; with their decisions located within, and influenced by, their relationships with family. Whilst patients retained primary decision-making authority, almost all participants described decision-making as a collaborative process in which family support and input was crucial.

4.3.3.7 Theme 8 “We sat at the table and discussed it together”: Family involvement in the decision-making process

Most participants described the process of making medical decisions. Several different aspects of decision-making emerged from these recounts, including the styles of decision-making, factors influencing decision-making styles, the trajectory of family involvement, and the benefits of family involvement in decision-making.

**Styles of decision-making**

Patient and family descriptions of decision-making have resulted in the proposal of a spectrum of decision-making styles ranging from physician-led through to family-led. These styles will be contrasted with the triadic decision-making styles proposed by other authors (Boehmer & Clark, 2001; Gilbar, 2011; Hilton, 1994; Krieger, 2014; Öhlén et al., 2006; Reust & Mattingly, 1996) highlighted throughout.

**Physician led decision-making**

A small number of patients and family members reported that the treatment decision was deferred to the physician, with limited input from the patient or family. One patient explained “it’s pretty basic stuff... I go along with what the specialists recommend and I am not going to argue against what they say”. Some family members agreed with this approach, while others felt that they wanted more information and input into the decision. After interviewing breast cancer patients and family members, Hilton (1994) proposed a spectrum of triadic decision-making styles. ‘Deference to physician’, is similar to the current physician-led decision-making style, and describes situations where both the patient and family defer to the physician, and the physician usually does not involve the family.
Patient led with family support

A small proportion of patients were autonomous in their decision-making and family members assumed a passive and/or supportive role. A patient described his family member “Well... [she does] nothing really, she is just there for me and anything I want to talk about she listens and when I make decisions, I tell her what I am thinking and she listens to me” and another patient stated “I think [wife] really was listening - and this is all new, strange, challenging - and I was much more running [the decision-making]... so I think she certainly regarded it as my decision and I guess... she saw her role as supporting whatever decision I made”. Several patients felt strongly that they had ownership of their illness and the decisions they faced, and that the primary role of family members was to ensure that the patient could remain autonomous and to provide support for the patient’s decisions. These family members generally did not provide their opinion or preference, rather listened to the information, censored their opinions, and provided support for or confirmation of what the patient chose. Patients appreciated the support and faith of their family members, one patient stated “my husband made a comment...he feels that I am very capable of making the decisions on my treatment, so he feels very confident in my ability to understand what’s going on for myself... that’s support in itself”. This aligns with Gilbar’s (2011) proposed ‘minimal influence’ style, where the family provides emotional support, but does not actively participate in the decision-making process nor has an impact on the decision.

Patient led with family facilitation

A large proportion of patients and family members described a style where the family assisted and facilitated the decision-making process whilst the patient still retained primary control of the decision-making. A family member proposed the analogy “I am just here to...paddle the boat with you. [Patient] steers it and we’re just here”. Family members assuming this style were involved in the information gathering phase of the decision, such as sourcing and providing information and asking questions about treatments. One family member described her role in assisting the patient with the information, she said “I didn’t want to influence [patient’s] decision but I wanted to help her sort through that information... and I felt like I did that... I wrote down things to help her understand what was going on and probed her to ask about the alternative therapies that she was considering”.

Outside the consultation family members engaged in discussions about treatment options, and acted as a sounding board for the patient to discuss their feelings and preferences. A patient described her adult children’s involvement “they just allowed me to have the discussion with them, the pros and cons. They asked ‘if we do it this way or the other way, how would you feel about that?”
‘Would you go for a breast implant?’ I mean we talked about all of that stuff… the decision at the end of the day, they made it clear that it was mine”. Another family member recalled both providing information and facilitating the patient’s decision-making by assuming a devil’s advocate role. She said “it was his decision, every time. All I did was feed and occasionally provoke”. Mostly family members did not provide their own opinions. A family member recalled “[Patient] made the decision. She pretty much made it by herself… I deliberately wouldn’t have influenced the decision. So in a lot of ways it was “how could I make it easier for her?” or “how could I facilitate the process of [Patient] making the decision?”.

Öhlén et al. (2006) and Reust and Mattingly (1996) each highlighted similar facilitative decision-making styles. Öhlén et al. (2006) described the style ‘creating a safe place for the patient to make a decision’, where family members gather information in an unbiased manner, reflectively listen to the patient, and act as a sounding board. Reust and Mattingly (1996) highlighted that the majority of family members may assume a supporting role, providing informational support such as talking, listening, asking questions, and offering experiences. There appears to be consensus that a large proportion of family members assume a facilitative role in the decision-making process, helping the patient with information, assisting them to make informed and autonomous decisions, and trying to avoid imposing their own opinions. These family members appear to be enhancing the patient’s own autonomy.

**Collaborative decision-making**

Another large proportion of participants described a “collaborative” or “shared” decision-making approach. These family members actively discussed treatment options and provided their opinions. One husband stated “I think in a way it was a joint decision. [Patient] had her point of view and I gave my point of view and we sat down quietly and talked about it and worked out the pros and cons. I never forced [patient] into it... and she never forced me not to do it”. Family members reported that they felt that their opinions counted, and the patient took on board what the family member had said. The wife of a patient said “he always seems to consult... he will turn to me and say “well what do you think about this”...he in his own mind may have made the decision but my acceptance or my opinion does count quite a bit in his decision.” Several participants indicated that both the patient and family member deliberated over the options together going back and forth expressing viewpoints until a clear decision emerged. A few participants also emphasised that both the patient and family had to be comfortable with the decision. One patient stated “if my wife is not at peace with it [decision] or I am not at peace with it, well then we don’t do it. We’ve both got to be at ease
with it”. This decision-making style was mostly assumed by spouses and partners. Öhlén et al. (2006) proposed a similar style, described as ‘collaborative decision-making between patient and significant other’ where the family member provides advice, shares knowledge, and makes the decision jointly with the patient. Additionally, Krieger (2014) proposed a ‘collaborative decision-making style’ where both patients and families preferred to make decisions together.

**Family-led decision-making**

In three instances, the family member described being the main decision-maker within the family. Family members appeared to assume this role when they felt they had more knowledge or capability than the patient, such as greater perceived knowledge about medicine or English language capability. The wife of a patient, who is a nurse, believed that she was the key decision-maker because of her medical knowledge. She said “I run the ship... If I said to [Patient] you need to jump off the Harbour Bridge because that will fix it he will say ok”. Other authors proposed similar decision-making styles. Öhlén et al. (2006) described the ‘director’ style, where family take over the decision-making on behalf of the patient. Gilbar (2011) proposed that some family members have ‘substantial influence’ over the decisions, and these patients may struggle to make decisions without the family’s involvement.

**Concordance or mismatch of styles**

Most patients and family members indicated that they were satisfied with the decision-making style they assumed. However, a small number of patient-family member pairs appeared to have mismatched decision-making styles, namely occasions when family wanted either more involvement or less involvement. Two patient-family pairs described situations where the patient wanted to defer to the physician, while the family member wanted greater input into the decision-making discussions. Both family members expressed frustration and reported unmet information needs. Mismatch also occurred when family members wanted less influence over the decisions. One patient described frustration as she wanted the couple to have equal involvement, whilst her partner did not want to influence the decisions. Shin et al. (2013) also found mismatch of preferred decision-making styles among cancer patients and family members in Korea. Whilst most patients and family members appeared to value and expect family involvement in decision-making, participants in Shin et al.’s (2013) study showed that preferences for family involvement varied within the patient-family dyad. Shin et al. (2013) found that greater preference concordance was associated with higher patient education whereas lower levels of concordance were found among younger patients, less educated family members, and adult child-patient dyads.
Krieger’s (2014) typology focused on describing the decision-making styles which emerged when there were matched and mismatched patient and family preferences. Matched preference decision-making styles included i) independent where patients’ goals of maintaining autonomy were met by the family, ii) collaborative where patients’ and family members preferred an interdependent decision-making style, and iii) delegated where patients preferred to rely heavily on family’s input, and family agreed with this style. Mismatched styles included i) isolated, where the patient desired an interdependent decision-making style but the family desired the patient to make the treatment decisions themselves, and ii) demanding where the patient desired autonomous decision-making but family wanted a more collaborative approach. These two mismatch styles align well with the results of the current study. Given the potential for mismatch in patient-family preferred decision-making style, greater clarification and negotiation of roles may be beneficial.

Proportion of participants assuming decision-making styles

Our interviews indicated that large proportions of participants assumed either the patient led with family facilitation or collaborative decision-making styles. Fewer participants engaged in physician led or family led decision-making. Most family members reported that they engaged in supportive behaviours, but only a small number engaged in this behaviour alone. Quantitative studies provide further information about the proportion of patients who desire certain decision-making styles. Nolan et al’s (2005) study assessed the decision-making preferences of patients diagnosed with a variety of serious illnesses (e.g. heart failure, advanced cancer). When asked about the involvement of their family in decisions, 50% of patients stated that they preferred to make decisions independent of family, 44% preferred to share decisions with their family, and 6% would rely on their family to make decisions. In Pardon et al.’s (2010) study of advanced lung cancer patients, 70% stated that they wanted their family to be involved in medical decision-making. In the Schäfer et al. (2006) study of cancer patient and family member preferences, 70% of patients and 54% of family members believed that family should have a say in decision-making. Davison et al. (2002) assessed the preferences of partners of prostate cancer patients and found that 55% preferred to play a collaborative role, 41% preferred a passive role, and only 4% wanted to be active in making the decision for the patient.

It appears that the majority of patients want some level of family involvement in decision-making. Family members appear to desire either a collaborative or passive role in decision-making, with very few wanting to assume authority over the patient’s decisions. Given that patient preferences for family involvement vary, it may be beneficial if physicians ascertain patient’s preferred level of
family involvement. This aligns with the recommendation made by Mitnick et al. (2010) that "the physician should routinely assess the patient’s wishes regarding the nature and degree of caregiver participation in the clinical encounter" (p. 256). However, in the reality of clinical practice these assessments may be very hard to do. Further discourse is needed to identify appropriate and effective preference clarification techniques for health professionals.

Factors influencing decision-making styles
Participants proposed an array of factors that may affect the decision-making style adopted. These include patient, family, relationship, and decision factors.

Patient factors
The patient’s personality, medical knowledge, and approach to cancer may affect their decision-making preferences. Those patients described as ‘strong-willed’ or ‘stubborn’ often preferred making the decisions without active family involvement. Some patients who worked in a medical profession (e.g. nurse or physiotherapist) or patients who felt that they had a high level of medical knowledge were also reported to prefer a more autonomous decision-making style. One patient held strong beliefs about her approach to cancer (she would accept any/all treatments that were offered), so made decisions independent of the physician and family. Oncology health professionals (Chapter 3) proposed several additional characteristics which impact on family involvement in consultations, such as patient age, education, and health status, whilst Hubbard (2010) proposed that patients with low information processing ability may be more likely to involve their family member in decisions.

Family member factors
Family members with a health background (nurse, dietician, pharmacist) were reported to be more involved in the decision-making process. Health professionals in Chapter 3 also proposed that family members with medical knowledge or a higher level of education than the patient were more likely to be involved in consultations.

Relationship factors
The pre-existing relationship dynamics of the patient and family may influence the decision-making style assumed. Many couples expressed that they had a close relationship and always made decisions together. When discussing a collaborative decision-making approach, one patient stated “She’s my wife. She doesn’t want to be left out. I wouldn’t leave her out anyway because we share everything whether it’s the washing or the consultations with the doctors. We wouldn’t make a
decision alone; we make decisions that affect each other so why shouldn’t both of us get involved”. For many patient-family dyads, this collaborative decision-making style was reflective of the way they made decisions outside of the cancer context. A family member explaining the pre-existing decision-making dynamics between himself and his wife said “like buying a house and also a car they are major decisions and... I think we probably went about them in the same way”. The pre-existing relationship dynamics between the patient and their family were also suggested as important determinants of family involvement by health professionals in Chapter 3.

The nature of the decision
Some participants indicated that extensive family collaboration was not possible due to the urgent timing of some decisions. Other participants stated that because there was one clear recommended path, they felt there was very little need to discuss the decision with their family. One family member explained “it was hardly a decision. We just fell into line, essentially. The recommendation was made, we did have a little chat about it. We agreed that, it was that [treatment] or nothing”. Some participants noted that greater family involvement and discussion occurred when there was more time to make the decision, there were multiple options with no one clear path, the decision equally affected the family member (e.g. fertility), or the decision had very serious implications. Health professionals (Chapter 3) also suggested that family are more likely to be involved in complex decisions, where there are a range of treatment options, or when there is no clear choice.

Prior to our qualitative study of health professionals, patients, and family members, only limited research had been conducted to highlight the factors potentially affecting family involvement in consultations and decision-making. It is clear that there is no one set determinant of a particular style, rather an array of entwined characteristics which affect the decision-making style eventually assumed. Health professionals may be best served avoiding heuristics or assumptions about family involvement based on a presumed, actual, or single characteristic of the patient or family member, such as their age or relationship type/dynamics. Open discussion of role preferences may be a preferred strategy for health professionals to use in assessing the decision-making styles of patients and family members.

The trajectory of family involvement
Many participants detailed the specific involvement of family members during the decision-making process, both inside and outside of the consultation. Participants were asked to describe the involvement of family during key points in decision-making (information exchange, deliberation, decision) derived from Charles et al. (1997, 1999). Some participants described additional stages of
decision-making to those proposed by Charles et al (1997, 1999), therefore family involvement in five decision-making stages will be discussed (pre-consultation decision-making, information exchange, deliberation, decision, and post decision deliberation/monitoring).

**Pre-consultation decision-making**

Several participants noted that the family's involvement in decision-making can occur prior to the consultation. Many patients and family members engaged in research prior to consultations, preparing questions to ask, pre-empting the options, and discussing possible decisions. Two patients also noted that they examined the scan and accompanying report prior to the consultation to get an indication of the cancer progress. These patients were then able to discuss the anticipated decisions with their family prior to the consultation. Additionally, several patients and family members reported that family can influence the decision of which doctor to see. This initial stage of decision-making was also noted by health professionals in Chapter 3. Siminoff (2013) also discussed family involvement in decisions prior to the consultation, noting that family members can be involved in symptom recognition and the response to those symptoms.

**Information exchange**

Most patients and family members acknowledged that the exchange of information about cancer diagnosis and treatments occurred both inside and outside of the consultation.

In the consultation, patients and family members reported that physicians often highlighted the treatment options and provided details about how the treatment works, how it will be administered, and any potential side effects. Physicians generally provided this information to both the patient and family. Many family members recalled that the physician appropriately answered questions from family members; however fewer participants reported that the physician had invited family questions or comments. Within the consultation, family members often engaged in a variety of informational support roles (as per Theme 3) such as prompting patient questions and asking their own questions about the treatment and its side effects. Some patients and family members provided the physician with information about treatments they had researched or about the patient's lifestyle. In Gilbar's (2011) study, family members engaged in informational support behaviours such as listening to the information and asking questions, which helped the patient to obtain, absorb, and process the information. Hubbard et al. (2010) also described family members eliciting information from physicians and pre-empting the patients' informational needs during information exchange.
While many family members actively participated in this stage, several family members were described as passive, engaging in more subtle behaviours of observing, listening, and taking in information. Additionally, participants noted that patients and family members may engage with one another inside the consultation during information exchange. A patient noted that they looked at the family member to see if they had any questions or comments, and another patient and wife recalled discussing the information whenever the physician would leave the room.

Many patients and family members noted that the information exchange phase continued when the patient and family left the consultation. Several participants recalled that they would discuss and analyse the information provided by the physician. A family member explained “in every single one often those decisions during consultations we didn’t talk very much about it, we were both in questioning mode. Afterwards then we discussed with each other both immediately afterwards, that evening, the next day, we discussed what we believed the Doctor had meant... and then we discussed how [patient] felt about it”. Similarly, Hubbard et al. (2010) described that family members absorb the information in the consultation so that they can relay and explain it to the patient after the consultation. Information was often also exchanged with others outside the consultation, such as obtaining information and recommendations from family or friends who had previously been diagnosed with cancer or asking family or friends with medical knowledge for information. In their study, Sriringam et al. (2003) found that 52% of the female partners of prostate cancer patients sought further information outside the consultation from sources such as the Internet, friends with cancer, and other medical resources/contacts. Similarly, deRosenroll et al.’s (2012) study of family members of dialysis patients found that a key role of family members was acquiring knowledge to inform the patient. Information was often obtained through a number of sources such as information booklets, friends, and other health professionals. However, several of the participants in the current study commented this role was not always beneficial as some family members would provide (sometimes unwelcome) second hand stories about people who had been treated for cancer and for example push the patient to receive/avoid a certain treatment.

In addition, many patients and family members continued the information exchange process outside the consultation by researching the disease and treatments, mostly by reading websites, information booklets provided by health professionals, or Cancer Council materials. Participants were generally aware that caution needed to be exercised when researching, as the information they sourced themselves could be upsetting or inaccurate. One family member engaged in research outside of the consultation because she was concerned when the patient indicated a desire to
receive complementary and alternative medicines. She said “when she was looking at alternative therapy I was a little bit concerned about what she was considering... So I researched it myself and got more information and suggested that she discuss it with the oncologist”.

Overall, it appears that information exchange is not a single linear discussion confined to the consultation environment, but rather an iterative process, potentially occurring prior to, during, and after the consultation with a variety of participants and resources. These findings provide evidence for Epstein and Street's (2011) re-conceptualisation of decision-making from independent to connected, from isolated to interpersonal, and from linear to dynamic.

Deliberation

The nature of deliberation varied between individuals, with a few patients reporting that they discussed their preferences inside the consultation, whilst the majority waited until after the consultation to deliberate with their family members.

A small proportion of participants reported that the deliberation process took place only inside the consultation. Some patients felt that little or no deliberation was needed, often when they wanted to defer the decision to the physician or if they had already decided on a treatment. For patients who wanted some degree of family involvement, deliberation often occurred after the physician had provided information about the treatment options. A few participants recalled that the patient and family would make ‘contact’ inside the consultation. During this contact, patients informed their family member of what they thought or asked the family member for their opinion. A patient explained “there's a contact... between me and [wife] relating... to what the treatment is and how we're going to continue”. Another patient explained “we've sort of looked at one another before making the decision together, every decision has been one of mutual agreement... See when we've both been there it's very easy to make the decision because we're both getting the information and we sort of look at one another and go'yeah””. Korfage et al. (2013) refers to this contact as a ‘family time out’, where the patient and family member converse between themselves without the physician’s participation. Health professionals in Chapter 3 also noted, and accepted, this patient-family ‘in-consultation time out’.

During the consultation, family members may have provided their opinion, helped to highlight the patient’s preferences, showed support of the patient’s preference, or deferred to the patient. A few family members recalled that the physician actively engaged them in the deliberation process, either by asking the family member if they agreed with the treatment decided, or by openly
supporting the family member’s preferences. Some physicians promoted deliberation outside of the consultation between the patient and their family. A patient explained “the doctors would be good in giving us information and talking us through things, it was hard to know the right path and in the end my oncologist said “go home and have a glass of wine and talk it through as a couple”.”

Many participants expressed a desire to process and discuss the information outside of the consultation. Some family members assumed a very active role in the deliberation process outside the consultation, confidently expressing their treatment preferences. For example, one family member said “I discussed it, we bounced ideas around and I said to [Patient] I think we probably need to give it [chemotherapy] a shot because what if you’re the one that it works on... and you haven’t done it then you’d regret that”. Other family members would express their feelings, but in a more general sense. The adult daughter of a patient expressed a more general treatment wish, saying she wanted “anything that will keep you with me longer”. Some family members reported that they were careful to express their preferences very gently and subtly, such as providing a preference but acknowledging that the patient had decision-making authority. A family member explained the difficulty in providing his opinion subtly, he said “I wanted her decision to be something that she felt happy that she had decided... like I hadn’t told her what to do but that I had given my opinion... And that was in some ways a difficult line to walk”. In addition, some family members intentionally avoided providing their preferences, instead facilitating and encouraging the patient to make their own decisions. A family member explained “often a big part of my role isn’t the decision-making as it is the facilitating... I will push it and go well you know maybe we can ask him if we can have the biopsy, if that is feasible and I will make the phone call and I will do the pushing to facilitate [patient’s] wish I guess. So I do a lot more of that as opposed to the actual decision-making”. Facilitating behaviours during the deliberation process included asking the patient a series of questions, helping to recall information from the consultation, checking that the patient understood the information, and checking that the patient understood the implications of the decision. A family member explaining the way she facilitated the patient’s decision-making, said “I deliberately tried to play devil’s advocate every now and again... I wanted him to be clear about what he had wanted... I would say ‘do you not want to do any of that’, ‘why would you want to do that’, knowing that he was leaning towards doing it or the other way around...it helped him clarify”. Many family members avoided providing any preference or opinion throughout the deliberation process, and instead would listen to and provide support to the patient. Several of these family members stated that they actively censored their own preferences because they did not want to influence the patient.
The amount of time spent deliberating was also very varied, and ranged from hours to years. Several participants described the situation where deliberation about treatments was an ongoing discussion, over many weeks, months, or years. A patient recalled the ongoing discussions about treating his prostate cancer, saying “we have had discussions now for a couple of years as to whether we should be doing something or not and I think basically we talk about it... If there was any chances of improvement we are quite willing to take it provided there is no... really serious side effects”. In other situations, where a more immediate decision was needed, some patients described that this deliberation was relatively short-term and would commence as soon as they left the consultation.

Participants described an array of deliberation styles. Mostly it was an unstructured conversation, where the patient and family would discuss the options and eventually a decision would emerge with which they were both comfortable. A patient described this dialogue, saying “where it wasn’t a clear cut path I think that it’s sort of been a dialogue and... sort of a Socratic [method] in a way that it goes back and forth and back and forth and eventually...the pathway does sort of emerge”. She further clarified what occurred in the deliberation process, saying “we talked things through and we go through what I feel and [husband] feels ...and gradually a course of action evolves where you decide this is what we’re going to do so then I am the one who has to say ok, we will do that.” Another patient explained “we just talked it through until we both felt really comfortable that what we were doing was the right thing”.

One patient described a more structured deliberation process where she and her partner drew up a table of pros and cons which acted as a decision aid. She explained “Because I am such a structured person we literally came home and drew up pros and cons of the three different treatment options and mapped it all out... we did it together... we did a matrix of pros and cons for the three treatment options. We talked through everything”.

Hubbard et al. (2010) highlighted the importance of providing time for the patient and family to weigh up the information, and suggested that failure to allow time to process information and think through decisions can lead to reduced patient and family satisfaction. Hubbard et al. (2010) also commented that it may not be apparent to physicians the extent to which patients and family members deliberate, because this can often take place outside of the consultation. As per the recommendation made in Chapter 3, health professionals should be made aware that family members are involved in decision-making discussions outside of the consultation. The results of the current interviews further highlight that patients and family members often appreciate the
opportunity to deliberate outside of the consultation, and utilise this time to engage in important decision-making discussions.

**Decision**

As previously discussed in Theme 7, most patients and family members acknowledged that it was the patient that made the final decision. Many participants commented that it is the patient’s body, therefore they should have the ultimate say in what is decided. Many patients and family members reported that family adopted a secondary role during the final decision stage, describing their involvement as ‘backup’ or ‘support’. Other studies have also reported that most family members accept that the patient has final say over medical decisions. Sriringam et al. (2003) found that although most partners claimed to be actively involved in the decision-making process, they stated that they had a limited influence on the final decision of the patient. Gilbar (2011) also reported that ultimately most patients desired and retained autonomy when making their decision.

Once the patient had arrived at a decision, many family members provided outward agreement or support for the decision. One family member described her agreement with the patient’s decision as “icing on the cake”, making the patient feel more confident. Gilbar (2011) found that patients appreciated when family members approved of and agreed with their treatment decision.

Although most participants acknowledged that it was the patient who determined the final decision, a few believed that it was a more joint family decision, where no one party ever took primary authority of the decision. A family member explained “everyone one of us had a say...so it’s my whole family not only my mum [patient]”.

**Post decision deliberation/monitoring**

One family member suggested that an additional stage of making the decision was the ‘post decision phase,’ where after the decision had been made more deliberation and discussion took place between the patient and family member. He explained “I believe the concept of revisiting the decision is about reassuring yourself that you’ve made the decision that’s best for you before it becomes irrevocable... Sometimes you will revisit that decision because you come up with new information... my role there was to listen very carefully and when it was needed to annunciate what this information really meant for what we had decided and then discuss whether we felt we needed to change the decision”. Additionally, after the consultation a few family members reported convincing the patient to change doctors, change hospitals, or seek a second opinion. It may be that deliberation may continue after the decision has been made but is not irreversible. This further highlights the
iterative fluidity and dynamism of medical decision-making, rather than it being a linear stepwise and time-limited process.

Benefits of family involvement in decision-making

Mostly, participants reported that family helped the patient to make a "good" decision. They did this by acting as a sounding board, recalling important information, thinking of new perspectives, or challenging and clarifying the patient’s thinking. When asked about the benefits of including family, a patient stated “someone to bounce ideas and thoughts off. It’s much easier to make a decision when you can talk it through with someone”. Some participants believed that by discussing the decision with family members, the patient might avoid decisional regret. A patient explained “[husband] has been a sounding board, we’ve talked through the decisions... I have a great dread of thinking ‘oh if only I’d known’, so it’s nice to talk things through as well as we possibly can so there is no regrets, no looking back and wishing”. In addition, a few family members were reported to help in the decision-making process by being rational, clear, and logical when discussing the decision. One patient stated “I think family have to be definitely involved because your mind mightn’t be right either in making some of these decisions at the time that you’ve got all this happening. So having family there as well that has got a clear mind... I suppose they can look at it differently. It’s definitely a good thing to have your family support”.

A few participants felt that family can help the physician to gain a broader understanding of the patient. A family member explained that being involved “makes me feel that [physician] has a better understanding of the complete picture”. A patient explained that he appreciated the physician incorporating the impending birth of his first child into their discussions “I think sometimes having [family] there prompts them [physician] not to just talk about me. The most recent example with [physician] we were seeing if there was any other options before the surgery and... talking about whether it made sense to have the surgery and... he was saying “yeah I can see why you would want to have it now so you’re back on your feet by the time the baby is due”... recognising your personal situation and incorporating that”.

Another benefit recalled by many patients and family members was the emotional support patients received. Several patients felt that they were able to share the burden, pain, and worry of the decision-making process with their family. They felt supported and loved, and a few patients recalled how helpful it was feeling supported by their family no matter what decision they made. A patient explained that she appreciated “a shoulder to cry on, someone who is not going to judge you,
someone who is going to love you unconditionally no matter how you’re going to react... they’re all really important in helping you come to a conclusion, helping you make that decision... [husband] would have supported me either way and I think that’s really important”.

In one of the only other studies to describe the benefits of family involvement in decision-making, Hubbard et al. (2010), noted that family can: i) improve the quality and quantity of information exchanged about treatments in consultations, ii) help stimulate patient thinking about decisions by acting as a sounding board, and iii) encourage patients to think about other options. Greater awareness of the many benefits of family involvement in decision-making may help to improve the acceptance and encouragement of family in this process.

4.3.3.8 Theme 9 “They can create more confusion rather than clarity”: Challenges and costs of family involvement

Although providing many benefits, family involvement also raised challenges for the patient and/or family member. These included in-consultation challenges, decision-making challenges, emotional challenges, and relationship challenges.

In-consultation challenges
Several patients stated that they were unable to have private time with the physician when their family attended consultations and were reluctant to openly express certain feelings or provide private information. One patient felt unable to share feelings of depression, and another felt unable to share some of her medical and sexual history with the physician when her father was present. A few patients expressed that they felt inhibited asking questions about their prognosis because they wanted to protect their family members. A patient said “very early on when my prognosis was a little bit more confronting, I was worried about asking the Doctor, in [husband’s] presence what my chances of dying”. This challenge of patient privacy was found both in the systematic review (Chapter 2) and health professional interviews (Chapter 3). The results of the current interviews further evidence the proposed strategy from our systematic review for health professionals to “take opportunities to privately discuss sensitive information with patients alone”, and ethical guidance proposed by Mitnick et al. (2010) which states that the physician should “strive to provide the patient’s desired level of privacy”. Lang et al. (2002) proposed that a good opportunity to have a private discussion with the patient was when the family had left the room for the patient to be physically examined. Additionally, some patients in the current study found it challenging when family members asked too many questions in the consultation. Several patients highlighted that they were worried that their physician would get annoyed by the family member’s questions. Finally, a few patients
reported feeling uneasy when their family member questioned the physician in a forthright manner.

**Challenges during the decision-making process**

Both patients and family members found some aspects of decision-making to be challenging. Several patients noted that the involvement of family increased the complexity of the process, as they were considering the impact of decisions on the wider family. A few patients also noted that when several family members were involved it could become too complex and counter-productive; a patient explained "sometimes it's not as useful because you just want to make a decision and having too many people creates that conflict... [family members] can create more confusion rather than clarity".

Several family members found censoring their beliefs and opinions about the patient's decisions to be difficult. A family member explained "one of the really difficult challenges was to not just say this is what I want, do it ... I found that really hard to not just come out and say what I felt with [the treatment decision]".

A few participants acknowledged that one of the most difficult situations was when the patient and family member disagreed about a decision. Participants described situations where patient and family treatment wishes were conflicting, such as the patient choosing to delay chemotherapy to receive fertility treatment, using alternative therapies, or ceasing treatment. Some participants recalled that this led to open conflict between the patient and family. In other situations the family member outwardly acknowledged that it was the patient's right to make decisions, however they privately felt upset or angry about the patient's decision. However, only a limited number of participants in the current study raised conflicting treatment wishes as a challenge. By contrast, Zhang and Siminoff (2003) found that 65% of participants reported family disagreement at the end of life, mainly concerning treatment decisions, discontinuation of treatment, and use of hospice care. Conflicting patient-family treatment wishes were also raised as one of the main challenges faced by health professionals in Chapter 3.

**Emotional challenges**

One of the main challenges identified by family members was the emotional impact of attending consultations. Many family members reported finding consultations confronting and upsetting. A family member recalled that attending consultations "was very stressful. I just burst into tears at many times... It was very hard for me too". One family member stated that it was difficult trying to
keep his emotions under control during consultations, while another family member felt it was
difficult having to process and react to bad news in front of the physician, as she had strong and
unexpected reactions. Some family members highlighted that they felt helpless throughout the
cancer process, feeling unable to provide any meaningful assistance to the patient.

The stress family members were under was acknowledged by, and affected, many patients. Patients
reported concern over their family's ability to cope, and felt responsible for the burden, sadness,
and stress that their family had to endure. A patient discussed the challenges of her husband's
involvement "the stress that I knew it was causing him [was challenging]... I think it's sometimes
harder for carers in some respects because they are a bit powerless... he couldn't stop that I had cancer
and he couldn't stop that I had to go through treatment... I would worry about him". Protecting their
family was an additional challenge for some patients during this difficult time. These findings
mirror quantitative findings from Sanson-Fisher et al. (2000) who found that one of the greatest
unmet needs of patients with cancer are concerns about the worries of those close to the patient
(i.e. the family).

Some family members may require psychological support. It appears that additional support for the
family may also benefit the patient, due to their concern about the impact of cancer on the family.
Family members should be made aware that support is available for them, such as referrals to
psychologists, social workers, and the support services such as the Cancer Council helpline. Some
family members in the current study indicated that they were unaware of any support services they
could access, but would have appreciated being referred to them.

**Relationship challenges**
Challenges may result from the existing patient-family relationship dynamics. Several participants
highlighted mismatched patient-family information preferences and needs. Often the family
member wanted more information and detail than the patient. At times, this appeared to cause
frustration for both parties. A family member said "I think there are things I want to know, I don't
think necessarily dad wants to know... Dad is almost happy just to let the doctors talk and he doesn't
really ask any questions a lot of the time which can be a bit frustrating, so I have pushed it one time
but I think that did upset Dad". Several studies show that family members often have high
information needs, sometimes greater than the needs of the patient (Bee, Barnes, & Luker, 2009;
Chen, 2014; Echlin & Rees, 2002). The significance of these mismatched needs should not be
underestimated. In a study of seriously ill older adults, Fried, Bradley, O'Leary, and Byers (2005)
found that 40% of family members desired more communication about the illness, and the family
members who desired more communication reported significantly higher caregiver burden scores. Therefore, in consultation with the patient, family members with high information needs may benefit from being given the opportunity to ask questions or being referred to appropriate information sources if the physician is unable to meet their information needs.

Conflict between some patient-family dyads was reported to mostly occur as a result of the stress and exhaustion felt during the difficult time of cancer treatment decision-making. One patient explained that conflict was a result of mismatched decision-making styles. He stated “[conflict] is not usually to do with the final decision but it’s in the process leading up to it... When we were talking about the radiotherapy, if [wife] is criticising my ability to make decisions and the way I was approaching it that can lead me to be defensive and argue back”. For another couple, conflict resulted from the exhaustion related to continual discussions. A husband explained “the conflict was not around the decision to have radiotherapy or not … the conflict was around the amount of time that we were able to devote to the decision-making whilst still maintaining all the other things [going on in life]”.

The nature/stage of the patient-family relationship also raised challenges for some. Two young adult couples reported difficulty in the decision-making process because they were in the early stages of their romantic relationships. One patient expressed that it was difficult involving his girlfriend in decisions because they had not yet discussed their commitment to one another. He said “In the beginning I think she [girlfriend] found it quite difficult because... we weren’t at the point where we had got married or engaged... But I was expecting a lot out of her and it was probably quite difficult for her to live up to those expectations given the stage of the relationship we were in”. Another patient noted that the decision-making process was challenging because the couple had not made any important decisions prior to the cancer diagnosis. She explained “we hadn’t crystallised the way we wanted to approach our relationship... really prior to me having cancer the biggest decision we used to make was where to go to dinner, because we weren’t living together, we had separate finances, we had very separate lives... we actually hadn’t really been forced to make any big decisions”. Therefore, particular assistance may be needed for young adults making decisions about their cancer, as these patients may be becoming less reliant on their immediate family and creating strong links with peers, and their adult decision-making styles may not yet be established (Davies, Kelly, & Hannigan, 2015).

Despite reporting a number of challenges, it appears that for most patients and family members the benefits of family involvement far outweighed the challenges. In addition, many of these challenges
represent opportunities for physicians or other health professionals to improve the experiences of patients and family members.

4.3.3.9 Theme 10 “The doctor always included her in the conversation”: Physician behaviours in triadic consultations

Positive physician behaviours
The majority of participants reported that most of the physicians throughout their cancer experience had engaged in positive behaviours towards family. These actions had a positive impact, with many patients and family members highlighting that they appreciated the inclusiveness of their physician in consultations.

Several participants noted that physicians’ early encouragement of family attendance was a positive behaviour. One family member reported “[physician] said “well we would like to see you [family member] each time”, and I thought ‘that’s nice’”. A patient recalled asking if it was ok that her adult children attended consultations, to which the oncologist replied “I love them being here, I think it’s great.” These responses made family members feel welcome and that their presence was valued, which aligns with the recommendation made in Chapter 2 that physicians should try to “encourage, welcome, and involve family members in consultations”. Some physicians reportedly highlighted the importance of family involvement or affirmed the family member’s important role throughout the cancer process. A patient explained “I was really pleased that [physician] always included [partner] in the conversation... [physician] was very engaging, and really affirming of [partner] in terms of the important role that [partner] was playing”. Affirming the important role of the family member was also proposed by Mitnick et al. (2010) who stated “physicians should routinely validate the family caregiver’s role” and went on to add “acknowledgement of the caregiver contribution is vital to ongoing trust and continued collaboration providing patient care. The degree to which family caregivers feel supported by the physician may influence the caregivers’ burden, attitude, and emotional health status” (p. 257).

Several participants spoke of the importance of physicians remembering and using the family member’s name, when calling the patient (and family member) into the consultation room and using their name throughout the consultation. One family member also reported that she felt included because the doctor would wait for her as she came into the consultation. She recalled “if we’re in the waiting room and I am a bit slow getting up because I usually have all [patient’s] bags that I am holding, they wait for me as well to come”. Several patients and family members
acknowledged that having a consultation room that was spatially inclusive of family members was also important.

Several other physician behaviours were reported to make the family member feel included, such as shaking the family member’s hand at the start of the consultation and building rapport with the family member. Several participants also believed that it was positive when physicians asked the family about themselves or engaged in social discussions with the family. One patient described the relationship between her physician and husband “[Physician] includes him [husband]... The oncologist and [husband] they talk trees and things like that, it's quite a good relationship. [I feel] very, very pleased with how we’re treated as a family unit”. A patient reported being particularly pleased when social information shared by her partner was remembered by the physician in a subsequent consultation. Many participants reported that they appreciated the physician making eye contact with the family member throughout the consultation. Family members also appreciated when physicians specifically asked them if they had any questions or how they felt the patient was going. Some family members also appreciated when the physician acknowledged the impact of cancer on the family and asked how the family member was coping. In the latter, some patients and family members believed it was positive if the physician recognised family distress and referred the family member to appropriate support services. One family member who was not offered any psychosocial support stated “if he [oncologist] doesn’t want to talk to me without the patient being there, then point me in the direction of counselling... that might have been a good thing for him to do, to say to me that, “you’ve got your own journey here as well and you might like to talk to someone about it””.

Finally, a few family members recommended that the physician engage in role clarification. One family member believed it was important for the physician to ascertain who the family member is for the patient and why they attended the consultation. Another family member appreciated when an oncology physician attempted to ascertain the decision-making dynamics of the patient and family member, and tailored his interaction accordingly. She said “[The physician asked] “ok how does this work”, and I said I am at the pointy end of the ship and he is down the back keeping the motor running... then he fell straight in with how we function”. She then went on to recommend “the first thing that [physician] should track down when he has a couple sitting there is... what's your role in the relationship here”. Perhaps this brief role clarification may be a useful tool for physicians to utilise during decision-making discussions.
Many of these positive behaviours, which could be integrated into regular clinical practice with relative ease, may make a meaningful difference to family members who are going through a stressful period, often with limited support.

Whilst participants reported that their physicians mostly engaged in positive behaviours, a substantial proportion also described occasions where the physician had engaged in negative behaviours, particularly towards the family member.

**Negative physician behaviours**

One of the main negative behaviours reported by participants was when the physician ignored or excluded the family member via both verbal and non-verbal language. Several family members recalled that the physician treated them as if they were not in the consultation at all, did not make eye contact, or did not know their name. One family member stated “I would have to initiate questions... if I didn't initiate a question I probably wouldn’t get any interaction other than hello”. Another family member reported feeling upset and excluded when a physician pulled the curtain around her husband to do a physician examination without explanation. Patients appeared to be displeased when physicians engaged in excluding/negative behaviours towards their family. One patient said “very often the surgeon would answer [husband’s] questions by looking at me... I don’t think he completely appreciated that the past 18 months was a mutual thing. Yes I was a patient who had the surgery, had the chemo... but it affected [husband] almost as much as it affected me. And I don’t think [surgeon] quite got that, so he wasn’t all that open to bringing [husband] into the conversation... I would've been happier if he had been more open to seeing [husband] as someone who was going through this as much as me and showing more compassion towards him”. Some family members in Kimberlin et al.’s (2004) study reported similar experiences, describing some healthcare professionals as abrupt, offensive, and disrespectful towards family. Health professionals have an opportunity to potentially improve the experience of both patients and family members by acknowledging the family's presence, showing respect and warmth, and providing family with an opportunity to contribute.

Some participants were dissatisfied with the physician's tone in consultations. One patient reported that her usually light-hearted physician became more serious when a family member was present; while another got a sense that his physician was unhappy about having family in the consultation. This aligns with the findings of Ishikawa, Roter, et al. (2005) who found that physicians engaged in less partnership building and positive talk when family members were present. Physicians may need to be more aware of their own views and verbal and non-verbal language with which they
communicate to both patients and family members. Speice et al.’s (2000) proposed self-assessment tool for physicians may be a beneficial exercise for health professionals to identify any negative attitudes or behaviours when interacting with family members.

Some physicians reportedly did not adequately respond to family members’ questions, through having a set response, brushing aside the question, rushing the answer, having a condescending tone when responding, or rolling their eyes at the family member. Additionally, a few family members reported unmet information needs because the level of information was insufficient. As highlighted throughout this chapter, family members often have important information needs that warrant addressing. This finding is reiterated by Sklenarova et al. (2015) who found that 43.6% of family caregivers of cancer patients and survivors reported at least ten unmet needs, including addressing fears about the patient’s physical or mental deterioration and accessing information about treatments. If physicians feel they are unable to provide adequate information in the consultation, perhaps they could identify alternative avenues for the family to obtain reliable information such as cancer care nurses or the Cancer Council helpline.

In contrast, some physicians may have engaged with family members too much. Three participants reported that a physician had engaged in a physician-family coalition, speaking almost exclusively with the family member instead of the patient. Participants reported feeling uncomfortable; with one patient recommending “definitely not do the conversation like I am not in the room...I had that with one [physician] who talked to [partner] like I was a child or I wasn’t present and that is not nice for [partner] and it’s not nice for me”. It appears that there is a fine balance health professions need to be aware of, sufficiently engaging with family whilst maintaining focus on the patient.

A small number of family members reported that their physicians’ approach was neither positive nor negative. They reported the physician was never rude or excluding, but not particularly inclusive. One family member explained “I wouldn’t say there’s anything great, I wouldn’t say that there’s anything wrong either really. [Oncologist] just went about and did his job”. This approach appears to reflect acceptance of, but not active engagement with, family in the room.

4.4 Discussion

Overall, family members appear to make valuable contributions to cancer consultations and the decision-making process. In our study, most patients appreciated their family’s presence, and both patients and family members were aware of the many benefits their involvement provided.
The contributions of family members were numerous and diverse. They provided emotional and informational support to patients and often facilitated the patient’s decision-making. Participants highlighted several family member behaviours not commonly noted in the existing literature, such as helping the patient to prepare for the consultation, acting as the messenger between the consultation and wider family, and providing support after the consultation had finished. Although family members engaged in many helpful behaviours, our interviews revealed that at times the provision of this support was exhausting, stressful, and upsetting for some family members. Some situations were reported to be particularly difficult for family members, such as when bad news was delivered in consultations, when health professionals ignored them, when deliberating about a difficult decision, or when the family member became the messenger to the wider family. A few family members in our study who expressed distress stated that they were unaware of the support services available to them, and would have appreciated referral to psychological support services. Mitnick et al. (2010) recommended that “physicians be alert for signs of distress in the family caregiver and suggest appropriate referrals” and the Family Caregiver Alliance (2006) called for a caregiver assessment to be routinely conducted to ascertain the psychosocial needs of family members. Despite the important role family members assume in consultations, and the psychological toll caregiving can take, the results of our study suggest that very limited support is offered to some family members. Whilst there has been a strong international call for routine psychosocial screening of cancer patients (Jacobsen & Wagner, 2012), family members often report higher distress and anxiety than patients and are unlikely to be screened for distress in consultations. Additionally, most family members in the current study emphasised that the patient is the central person in the consultation, and therefore may mask their distress in consultations. Implementation of family caregiver-tailored screening instruments into clinical routine should be considered (Sklenarova et al., 2015).

In our study each patient and family dyad had different personal, clinical, and relationship characteristics. Our interviews suggest that there are no clear factors (e.g. family member ‘type’, gender, or age) which might predict the nature or extent of family involvement. Street and Gordon’s (2008) quantitative analysis of cancer consultation audiotapes found similar results that family activity levels (passive, partner, surrogate patient) did not vary as a function of the patient’s age, education or physical health status. A recent study did find a number of significant associations between patient characteristics and the extent of family involvement. Hobbs et al. (2015) found that family members were more actively involved for older patients, female patients, married patients, and patients with a Chinese heritage. Similarly, health professionals in Chapter 3 proposed that a
wide array of characteristics may affect the family member’s level of involvement, and that it may be helpful to use these characteristics as a guide when initially interacting with family members. However, perhaps health professionals may be better served clarifying patient and family preferences and needs rather than relying on assumptions based on characteristics, as it appears that family involvement levels are affected by a complex web of characteristics.

Some patient-family dyads had mismatched information needs, information source preferences, and decision-making styles; which also indicates a need for role clarification. Some family members in the current study proposed that physicians should ascertain why the family member has attended the consultation and clarify how the patient-family dyad plans to make decisions. Baile et al. (2012) similarly proposed that physicians determine patient preferences for family involvement and establish the family member’s role. Whilst these recommendations have been made, it is currently unclear if physician-led role clarification is a feasible, acceptable, and effective process. An alternative method of role clarification, a pre-consultation information preference and role clarification checklist such as the tool developed by Wolff et al. (2014), may help to reduce the occurrence of mismatched preferences and behaviours. Wolff et al. (2014) developed a pre-consultation information preference checklist in which patients and family members independently rated the importance of common concerns. It was designed to elicit and align patient and family perspectives regarding health concerns to discuss with the physician. Additionally, a role clarification checklist was provided to patients to help simulate thought and discussion about the family member’s role in the visit. The structured checklists were evaluated by the majority of participants as easy and useful and led to more patient-centred communication and better patient understanding. However, this checklist was developed for, and pilot evaluated in, a geriatric population for routine medical visits. Therefore, the suitability and effectiveness of this tool for other medical settings, such as cancer, still needs to be established.

Despite previous studies identifying dominant family members as a challenge (e.g. Shepherd et al. 2008) few participants in our study reported dominant family behaviours in both the consultation and subsequent decision-making discussions. These results align with the views of many health professionals (Chapter 3) who reported that dominant family members are the rare exception, and previous studies such as Brown et al. (1998), who found that of 100 consecutive general practice consultations, family involvement was generally rated as positive (82%) or neutral (14%), with very few family members rated as having a negative impact (4%). Physicians may feel reassured that it appears that the majority of family members have a neutral or positive impact on the
consultation. However, the majority of the evidence base has examined only stakeholder attitudes towards family involvement, and future research is needed to examine the actual behaviours of family members in consultations, particularly the proportion of family members in cancer consultations engaging in problematic or patient autonomy-detracting behaviours. Reassuringly, a study conducted by Clayman et al. (2005) found that typically family members engaged in more autonomy enhancing (e.g. facilitating patient understanding, facilitating patient involvement) than detracting (e.g. controlling, coalition building) behaviours.

In the current study, many family members reportedly displayed a degree of deference or submission in the consultation, and many perceived that the physician did not have sufficient time to deal with their concerns. Because of these issues, several family members appeared to hold back from asking questions or contributing information in consultations. It is important that physicians recognise that family members may have unmet information needs or may be inhibited from sharing important information. Additionally, a few family members of patients with advanced cancer expressed that they wanted to ask the physician questions without the patient present. Health professionals need to be aware of the needs of family members and explore legally and ethically appropriate channels to meet these needs, whilst adhering to the patient’s preferences for confidentiality.

The ‘submissiveness’ of many family members did not appear to be restricted to information gathering, but characterised the whole decision-making process. Most participants stated that family members should assume either an ancillary or collaborative role in decision-making, and that the patient should remain the priority and retain decision-making authority. However, despite these strong beliefs, many patients and a few family members also acknowledged that family are heavily impacted by the patient’s illness and deserve some level of involvement in the decision-making process. Finding the balance between individual patient autonomy and the rights of the family has previously been debated in several ethical commentary papers (e.g. Blustein, 1993; Hardwig, 1990; Ho, 2008; see Chapter 1 for a discussion of these ethical perspectives). The findings of the current study align most with a combined model of patient autonomy, which advocates for patient authority in decision-making, yet acknowledges that family input into the decision-making process is often welcome and needed (Gilbar, 2011). The current study found that many family members respect, support, and facilitate the patient’s autonomy and informed decision-making. Their involvement in the decision-making process was often beneficial to the patient, making them feel more informed, supported, and confident in their decision. Gilbar (2011) found similar results
and suggested that if law and policy are to accurately reflect clinical practice, the important role of the family in assisting the patient to make informed decisions should be reflected.

This study also provides further clarification about the key features of family involvement in medical decision-making, whilst also highlighting its complexity. It is clear that there are a variety of ‘triadic’ decision-making styles (ranging from minimal family involvement to family dominance), each of which may be appropriate if these align with the patient’s (and potentially family member’s) preferences. It appears that information gathering and exchange are an iterative process, often commencing before the consultation, occurring in the consultation with the physician, and continuing outside the consultation again between the patient-family dyad. The deliberation process is similarly iterative and dynamic, occurring before, during, and after consultations and sometimes over many months or years. The results of our study provide evidence for a more fluid, dynamic, and interactional conceptualisation of medical decision-making, as highlighted by Epstein and Street (2011), rather than a stepwise and linear process highlighted in many of the earlier decision-making models (e.g. Towle & Godolphin, 1999). However, further research is needed to more objectively examine decision-making discussions in cancer consultations, rather than relying on the attitudes and experiences of stakeholders alone.

Finally, a number of strategies for health professionals have been proposed based on the interviews with patients and family members (see Box 4.2). Synthesis and subsequent evaluation of strategies proposed throughout this thesis, and in the wider evidence base, is needed to develop clear, practical, ethical, and effective clinical guidelines for health professionals to use in triadic consultations.
Box 4.2: Proposed strategies based on interviews with patients and family members

**Role education and preference clarification**

- Highlight helpful roles that family members can assume such as pre-consultation preparation, emotional/informational/decision-making support, advocacy, post-consultation discussions
- Find out who the family member is, why they are attending the consultation, and potentially ascertain the nature of the patient-family relationship.
- Elicit patient and family members’ information preferences
- Ascertain patients and family members’ preferred level of family involvement in consultation and decision-making
- Encourage patients and family members to discuss the roles they would like each other to take, inside and outside of the consultation.

**Including and supporting the family member**

- Support and affirm family attendance. If patient attends consultations unaccompanied, encourage family attendance and highlight the benefits of family involvement
- Particularly encourage family attendance if delivering bad news (e.g., diagnosis consultation)
- Encourage consistent family attendance (where possible)
- Attempt to overcome barriers to family involvement (such as arranging teleconference consultations)
- Welcome family members to the consultation
- Engage in rapport building behaviours, shake the family member’s hand, learn their name, engage in eye contact
- Respond to family members’ questions and include them in conversations (to extent preferred by patient)
- Acknowledge the impact of cancer on the family member
- Be alert for distress in family members. If distressed, refer to appropriate psychological support services

**Avoiding/managing challenging situations**

- Some family members feel that they are infringing on the patient-physician relationship and therefore may not feel confident to ask important questions. Be aware that some family members have unmet information needs.
- The patient and family may have misaligned information needs and preferences. Physicians should be aware of unmet information needs of the patient/family.
- Some family members may request private time to discuss the patient’s health with the physician, without the patient present. Physicians need to be aware of both the family’s need for information and the confidentiality patient’s should be afforded.
- Avoid forming an exclusive relationship or ‘coalition’ with the family member, particularly if it comes at the cost of patient involvement.
- Despite the importance of referring distressed family members to support services, it is also important that the family member’s distress does not derail the consultation or detract from the focus of the consultation.
- The patient may feel unable to discuss sensitive issues with the physician, such as depression, sexuality, or prognosis, when the family is present. Physicians may need to arrange for some private time with the patient to discuss these issues.
4.4.1 Limitations of the study

Although we attempted to recruit a variety of participants through advocacy groups and a tertiary hospital, 70% of patients and 76% of family members were recruited from one major tertiary hospital. Therefore, it is possible that the experiences of participants may be unique to this setting. The nine breast cancer patients and seven family members recruited through a national advocacy group represent a wider experience of different treatment settings. However, these participants volunteered after receiving an invitation email, and self-selection biases are possible. As hospital-based recruitment was supported by clinician referral, self-selection biases are less likely but still probably present. Due to practical limitations, we were unable to recruit and interview patients with limited English language capabilities. Therefore, it is unlikely that we have captured the unique experiences of patients and family members from culturally and linguistically diverse backgrounds. This has, however, been explored elsewhere (e.g. Huang et al., 1999).

In our study, very few of the participants reported disagreement with their family member; therefore the decision-making process when the patient and family have conflicting wishes may not have been adequately captured in our study. Zhang and Siminoff (2003) found that 65% of participants reported family disagreement at the end of life, mainly concerning treatment decisions, discontinuation of treatment, and use of hospice care. These were not decisions faced by the majority of participants in the current study. Although we included patients at different stages of the disease trajectory, few were in the palliative phase; therefore our description of the decision-making process may not apply to situations commonly characterised by a high incidence of conflict, such as the end of life. Additionally, given that patients and family members were often approached together in the oncology clinic it is unlikely that controlling family members or those experiencing a high degree of family conflict would have consented to participate.

Additionally, our study findings may be biased towards the views of married/partnered patient-family dyads. Despite purposely creating wide selection criteria to recruit any family member/friend/neighbour, 76% of the family members interviewed were the spouse or partner of the patient. However, as the majority of patients are married or partnered, this does reflect the majority experience of family involvement in cancer care (e.g. Eggly et al., 2011). Wherever possible, we have highlighted the unique experiences and perspectives of non-partnered patient-family dyads.
Finally, as with all qualitative research, objectivity of the findings can be compromised by the researcher. However, rigorous dual coding for 20% of interviews was utilised to minimise this bias.

4.4.2 Conclusion

Overall, it appears that both patients and family members appreciate family involvement in consultations and decisions. Although challenges may occasionally arise as a result, there are a number of strategies available to improve the experiences of patients and family members. This study has further clarified the spectrum of ways family can be involved in medical decision-making. Whilst this study has provided a comprehensive exploration of the attitudes and experiences of patients and family members, the evidence base regarding what actually happens in triadic consultations is still very limited. In order to gain a more complete picture of family involvement, research is needed to clarify the behaviours of family members and the family-relevant behaviours of patients and physicians in cancer consultations. This is explored in the next chapter.
Chapter 5:
Development and application of a triadic coding system of communication and decision-making
5.1 Introduction

Given the frequency with which family members attend cancer consultations, it is important to gain a clear understanding of the ways in which physicians, patients, and family members behave in triadic consultations. As discussed in the systematic review (Chapter 2) and interviews with oncology health professionals (Chapter 3) and patients and family members (Chapter 4), family members can assume a variety of roles such as providing informational, emotional, and decision-making support (Ellingson, 2002), and their level of involvement can range from passive to dominant (Street & Gordon, 2008). However, it is unclear what factors affect the extent of family involvement. In Chapter 3, health professionals suggested that their own level of experience, the severity of the disease, and the patient-family member relationship type can impact upon the extent of family involvement. In Chapter 4, family members indicated that some patient and physician behaviours may facilitate active family involvement, such as making the family member feel welcome or asking if they have any questions. These interview results, along with most of the studies describing triadic consultations in the cancer setting (Beisecker & Moore, 1994; Kimberlin et al., 2004; Morris & Thomas, 2001; Sinfield et al., 2008; Speice et al., 2000), are mostly based on qualitative accounts. Analysis of actual consultations is needed to more objectively elucidate the nature of triadic consultations and to ascertain if there are factors associated with active family involvement.

To date, limited studies have assessed the actual behaviours of physicians, patients, and family members in triadic consultations using audio- or video-taped consultations. Of those studies which have utilised these more objective methods, most have compared dyadic and triadic interactions (Eggly et al., 2006, 2011; Labrecque et al., 1991; Street & Gordon, 2008) focusing on behaviours common to both contexts. There is a paucity of evidence regarding the behaviours of physicians, patients, and family members specifically related to inclusion of family members during cancer consultations, with no studies having comprehensively examined the triadic treatment decision-making process within these consultations.

Additionally, no triadic oncology interaction analysis coding systems have been developed to date, with only three previous studies, based in either the geriatric or general practice setting, having developed family-relevant items to be used when coding audio- or video-taped consultations (Clayman et al., 2005; Greene et al., 1994; Ishikawa, Roter et al., 2005). Thus there is a need for an oncology-specific coding frame which examines both the medical communication and decision-making behaviours of family members, and family-relevant behaviours of physicians and patients.
The current study aimed to develop a TRIadic Oncology (TRIO) coding system and to apply it to initial medical or radiation oncology consultations to elucidate the nature and dynamics of triadic cancer consultations.

Aims

1. To develop a triadic interaction analysis coding frame which captures the behaviours of physicians, patients, and family members in oncology consultations
2. To examine the nature of triadic consultations, including:
   • the roles family members assume during the different stages of an initial triadic medical or radiation oncology consultation
   • the family-relevant behaviours of physicians in initial triadic medical or radiation oncology consultations
   • the family-relevant behaviours of patients in initial triadic medical or radiation oncology consultations
   • the behaviours of family members in initial triadic medical or radiation oncology consultations
3. To examine selected variables associated with physician, patient and family member behaviours in triadic cancer consultations.

5.2 Method

5.2.1 Development of the TRIadic Oncology (TRIO) coding system

Development of the TRIO coding system was based on several levels of inquiry. Each of these steps will be discussed in detail.

5.2.1.1 Previous triadic interaction analysis coding systems

The TRIO coding system was informed by a review of previous studies which applied an interaction analysis coding system to triadic medical consultations. The coding methods of thirteen studies assessing consultation communication in any medical setting (e.g. general practice, geriatrics, oncology) were reviewed. In four studies, family member verbal activity was assessed numerically, for example number of speech turns or words per visit (Beisecker, 1989; Clayman et al., 2005; Ishikawa et al., 2006; Shields et al., 2005). Three studies conducted content analyses, where the quantity and quality of each family member question or statement was assessed (Eggly et al., 2006, 2011; Greene et al., 1994). Six studies assessed patient and/or physician communication (such as...
applying the Roter Interaction Analysis System or measuring patient-centred behaviours) in unaccompanied versus accompanied consultations (Ishikawa, Hashimoto et al., 2005; Ishikawa, Roter et al., 2005; Ishikawa et al., 2006; Labrecque et al., 1991; Shields et al., 2005; Street & Gordon, 2008).

Five studies proposed items specifically related to family involvement. Clayman et al. (2005) coded for five family member relevant behaviours in their video-taped geriatric consultation study. Three items assessed the ‘autonomy enhancing’ behaviours of the family member (facilitating patient’s understanding, facilitating patient involvement, facilitating physicians’ understanding). Two items assessed the ‘autonomy detracting’ behaviours of the family member (controlling behaviours and alliance building behaviours). Ishikawa, Roter et al. (2005) developed ten new family member relevant items in their audio-taped geriatric consultation study. The behaviours assessed included: i) repeat/clarification for patient; ii) repeat/clarification for physician; iii) facilitation; iv) ask for agreement; v) show agreement; vi) show disagreement; vii) criticise patient; viii) persuade; ix) discuss companion health problems; and x) other. Greene et al.’s (1994) audio-taped general practice consultation study targeted two triadic-specific behaviours: i) third person answering questions for patient when the patient was able to respond, and ii) physician reliance on third person when the patient was able to provide information. A further two studies coded for specific consultation behaviours relevant to triads, such as humour (Baker et al., 1997) and coalition formation (Coe & Prendergast, 1985).

Two studies assessed the global roles assumed by family members in medical consultations. Street and Gordon (2008) categorised family members as observers (<40% verbal contribution), partners (40-60% contribution), or advocates (>60% contribution) in their audio-taped cancer consultation study. Similarly, Beisecker (1989)’s study categorised family members as watchdogs, significant others, or surrogate patients.

Mostly, the abovementioned studies have focused on specific subsets of family involvement in consultations and none have developed or utilised a comprehensive coding system capturing the behaviours of family members and the family-relevant behaviours of patients and physicians.

Items from Baker et al. (1997), Clayman et al. (2005), Coe and Prendergast (1985), Greene et al. (1994) and Ishikawa, Roter et al. (2005) and global roles from Beisecker (1989) and Street and Gordon (2008) were considered for potential inclusion in the TRIO coding system.
5.2.1.2 Relevant behaviours identified in a systematic review of triadic consultations

In addition to examining previous triadic interaction analysis coding systems, other triadic studies exploring family-relevant attitudes or experiences were identified during the systematic review (Chapter 2). Potentially relevant behaviours of the physician, patient, or family member during any triadic medical consultation (e.g. general practice, geriatrics, oncology) were identified in ten studies. Some studies highlighted family member behaviours in consultations, such as providing information about the patient’s history, correcting the patient, or asking questions about treatments (Barone et al., 1999; Hubbard et al., 2010; Main et al., 2001; Petronio et al., 2004; Schilling et al., 2002; Silliman et al., 1996). Other studies highlighted positive behaviours that physicians should ideally engage in, such as welcoming the family member, including family members in conversations, acknowledging the important role of the family member, and ascertaining the family member’s understanding and expectations (Kimberlin et al., 2004; Morris & Thomas, 2001; Sinfield et al., 2008; Speice et al., 2000). Some studies also noted negative physician behaviours to be avoided, such as ignoring or interrupting the family member (Morris & Thomas, 2001; Sinfield et al., 2008). These behaviours were added to the list of potentially relevant items to include in the TRIO coding system.

5.2.1.3 Relevant behaviours identified from interviews with patients, family members, and health professionals

Next, the TRIO coding system was informed by the qualitative studies presented in Chapters 3 and 4. Roles and behaviours related to family involvement in cancer consultations discussed during these interviews were added to the list of potential items.

Physician behaviours: Positive behaviours included welcoming the family member, learning their name, engaging in conversation with the family member, inviting and responding to their questions, showing appreciation for the family member’s role, and ascertaining patient and family member preferences for decision-making. Negative behaviours included interrupting or ignoring the family member, ignoring the patient and speaking only with the family member, or revealing sensitive information about the patient at inappropriate times.

Patient behaviours: Potentially positive behaviours of the patient discussed included asking the family member questions during the consultation and including the family member in the decision-making. Potentially negative patient behaviours included interrupting or answering for the family member.
**Family member behaviours**: Potentially positive family member behaviours discussed included recalling patient history, providing information, showing partnership with the patient, prompting patient questions, confirming or summarising information for the patient, making positive statements, and actively participating in the decision-making process. Potentially negative behaviours included arguing with or interrupting the patient, interrupting the physician, or asking about irrelevant issues relating to themselves.

5.2.1.4 **Relevant behaviours from a qualitative analysis of audio-taped initial medical consultations**

In addition, a qualitative analysis of 20 audio-taped and transcribed initial medical oncology consultations was conducted to determine the nature of family involvement. A content analysis (Hsieh & Shannon, 2005) of communication behaviours was undertaken by the candidate and another researcher, with discussion amongst candidate and supervisors used to identify discrete categories of behaviour. General communication behaviours of the family member included recalling or confirming information, prompting patient questions, asking questions, interrupting or disagreeing with the patient or physician, engaging in humour, making positive or optimistic comments, and showing partnership with the patient. Family member decision-making behaviours were also noted such as asking questions about treatment options, providing information relevant to decisions, expressing preferences for involvement during the consultation, expressing preferences for the decision, and supporting patient autonomy during the decision-making process. Any new roles or behaviours identified through this qualitative analysis were added to the list of potential items for the TRIO coding system.

5.2.1.5 **Previous dyadic communication and decision-making coding systems and theory**

A review of medical communication coding systems (e.g. RIAS, Roter & Larson, 2002), medical decision-making coding systems (e.g. Butow et al., 2004), and decision-making theory (e.g. Makoul & Clayman, 2006) was conducted to identify relevant themes and items. Items from the Butow et al. (2004) coding system included physician behaviours such as: social interaction and laughter, interruptions, establishment of agenda, invitation of questions, and delay in making treatment decision offered. Patient behaviours included voicing preferences for involvement in decision-making, seeking supplementary information, and questioning information provided by the physician. Shared decision-making theory was also reviewed to identify relevant themes (e.g. Makoul & Clayman, 2006). Triadic adaptations of decision-making coding frame items and theory were added to the list of potential items for the TRIO coding system.
5.2.2 Finalisation of the TRIO coding system

An initial list of physician, patient, and family member behaviours was developed based on the aforementioned steps and was reviewed and refined by the candidate, two experts in medical communication and decision-making, and a consumer representative. The preliminary coding system was applied to a pilot sample of ten randomly selected consultations in order to ascertain its applicability, comprehensiveness and ease of use. Items were subsequently further refined. A coding manual was developed, including definitions and examples of each item (see Appendix Q). A coding marking sheet was also developed (see Appendix R).

The final TRIO coding system has a total of 80 items (see Table 5.1). Four global role assessment items were developed to ascertain the level of family member activity (passive, supportive, active, and dominant) across four distinct consultation phases (history taking, information exchange, deliberation and decision, logistical arrangements). These categories were developed inductively from a qualitative analysis of 20 consultation transcripts. Although the deliberation and decision phases are analytically distinct in Charles et al.’s (1997) framework, in the current study the deliberation and decision discussions were entwined and therefore a combined deliberation/decision global assessment was considered to be more appropriate. Twenty four items captured physician behaviours towards the family member (15 overall communication items, 9 decision-making items); 14 items captured patient behaviours towards the family member (8 overall communication items, 6 decision-making items); and 38 items captured the family member’s behaviours within the cancer consultation (18 overall communication items, 20 decision-making items).

Table 5.1: Overview of TRIO coding system items

<table>
<thead>
<tr>
<th>Coding system category</th>
<th>Item description (number of items)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Global role assessment</strong></td>
<td>History taking (1 item)</td>
</tr>
<tr>
<td></td>
<td>Information exchange (1 item)</td>
</tr>
<tr>
<td></td>
<td>Deliberation and decision (1 item)</td>
</tr>
<tr>
<td></td>
<td>Logistical arrangements (1 item)</td>
</tr>
<tr>
<td><strong>Physician behaviours</strong></td>
<td>Overall communication (15 items)</td>
</tr>
<tr>
<td></td>
<td>Decision-making (9 items)</td>
</tr>
<tr>
<td><strong>Patient behaviours</strong></td>
<td>Overall communication (8 items)</td>
</tr>
<tr>
<td></td>
<td>Decision-making (6 items)</td>
</tr>
<tr>
<td><strong>Family member behaviours</strong></td>
<td>Overall communication (18 items)</td>
</tr>
<tr>
<td></td>
<td>Decision-making (20 items)</td>
</tr>
</tbody>
</table>
5.2.3 Application of TRIO Coding System

The data reported here were based on transcripts of audio-taped initial medical or radiation oncology consultations collected as part of two previous studies conducted by Butow et al. (2004) and Dear et al. (2012). De-identified consultation transcripts from these two studies were included to increase the overall number of available consultations for analysis, the number of physicians represented, and to prevent a single study bias.

The Butow et al. (2004) study included consecutive patients with heterogeneous cancers attending an initial appointment with one of four medical or radiation oncologists (at a single Australian tertiary cancer centre). Patients were recruited into a study examining the effectiveness of a consultation preparation package, with half of participants randomised to a control condition (receiving a control booklet which informed patients about the physical characteristics, staffing, and procedures of the cancer centre) and half of participants receiving a cancer consultation preparation package which contained the control booklet plus three resources: a booklet providing general information about medical decision-making, a booklet on patient rights, and a question prompt sheet. All consultations were audio-taped and transcribed, and patients completed questionnaires assessing patient anxiety, depression, perception of information provided, and decisional satisfaction, before and immediately after the consultation and at 1 month follow-up. Due to the potentially confounding nature of the intervention, only control consultations were included in the current study. Ethical approval for the original Butow et al. (2004) study was obtained from relevant ethics committees. In the original consent process participants agreed to secondary analysis of transcripts for other cancer consultation communication studies, under which the current study applies.

The Dear et al. (2012) study included patients with heterogeneous cancers attending an appointment with a medical oncologist where a treatment decision was likely to be discussed. Thirty medical oncologists from a range of urban and rural cancer centres across Australia participated. Patients were recruited into a study examining the impact of a clinical trials website, with half of patients randomised to refer to the website and half of participants receiving usual care. The primary outcome was the proportion of patients with whom participation in any clinical trial was discussed. All consultations were audio-taped and transcribed. Only those consultations where clinical trials were not discussed were included in the current study. Due to the lack of relevance of the intervention to our current study aims, both intervention and control patients were included in our analyses. Ethical approval for the original Dear et al. (2012) study was
obtained from relevant ethics committees. Given the very different focus of the secondary analyses, ethical approval for the secondary analyses was obtained from the University of Sydney Human Research Ethics Committee (see Appendix S).

From these two study databases, we selected transcripts of adult cancer patients (any age, gender, cancer type or stage) who were accompanied by an adult family member (e.g. spouse, adult child, friend) to an initial medical or radiation oncology consultation which involved consideration of a medical decision (e.g. adjuvant therapy after surgery). Transcripts were excluded if: i) more than one family member was active throughout the consultation (as this would conflate family member behaviours); ii) more than one physician was active throughout the consultation (as this would conflate physician behaviours); or iii) the decision centred on involvement in a clinical trial (as the decision-making dynamics and discussion can be different from standard consultations). A total of 72 consultation transcripts were included in the current analysis; 26 from the Butow et al. (2004) study and 46 from the Dear et al. (2012) study.

Of the 72 coded transcripts, one primary coder coded all transcripts, and recoded a random 20% to establish intra-rater reliability. Intra-rater reliability for individual items ranged from .44-1.0. The average of the four role items was calculated to be Kappa = .75, and the average of all other items was Kappa = .82. One secondary coder coded a random 20% of transcripts to establish inter-rater reliability. Inter-rater reliability for individual items ranged from .46-1.0. The average of the four role items was calculated to be Kappa = .74, and the average of all other items was calculated to be Kappa = .81. According to Landis and Koch (1977), a Kappa of .41-.60 is considered moderate, .61-.80 is considered substantial and .81-1.00 is considered almost perfect agreement.

5.2.4 Data Analysis

Demographic and coding data from the two banks of audio-recordings were combined into one dataset and analysed using summary statistics such as means and frequencies. Descriptive statistics, including frequencies and percentages, are reported for each physician, patient, and family member behaviour. The proportion of behaviours coded is displayed in tables and some results are highlighted in text. Illustrative examples of noteworthy behaviours derived from the consultation transcripts are provided throughout. Predictors of the absence or presence of consultation behaviours were assessed. Comparisons of the proportion of behaviours coded were analysed using Generalised Estimating Equations with a binomial distribution and logit link function. Correlations of observations within physician were accommodated by specifying an
exchangeable working covariance structure. Results are presented as the exponentiated parameter estimate, similar to an odds ratio. Items were selected based on empirical considerations. Due to the limited variance in many of the items, outcomes with sufficient variability were selected. Three level outcome variables (e.g. never, once, two+ times) were collapsed into dichotomous (yes, no) outcome variables for the purpose of these binomial analyses.

Due to the exploratory nature of the study, multiple tests were conducted. A significance level was set as $p<.01$ for the Generalised Estimating Equations to adjust for this multiple testing. SPSS Version 21 was used for all analyses.

5.3 Results

5.3.1 Participant Characteristics

The available characteristics of all consultation participants (patients, family members, and physicians) are presented. Table 5.2 presents the demographic and clinical characteristics of the 72 patients. Patients ranged in age from 28-84 years, and there were marginally more female patients (57%). Most patients were married or in a de facto relationship (76%), and over half had completed a tertiary qualification (57%). The majority of patients were born in Australia (81%) and most reported English as their main spoken language (97%). The majority of patients were diagnosed with an early stage cancer (67%) and a variety of cancer types were represented, including breast (46%), gastrointestinal (18%), and genitourinary (14%).

Due to the aims and scope of the two primary studies from which the audio-tapes were derived (Butow et al., 2004; Dear et al., 2012), no family member data was obtained at the time. However, the family member’s relationship to the patient was able to be determined from the consultation transcript in 59 out of the 72 consultations. Table 5.3 presents the available family member data. Spouses most often accompanied the patient (wife= 36%, husband= 31%), with daughters (15%) and sisters (7%) the next most frequently attending relationship groups.

Table 5.4 presents the demographic and professional characteristics of the 18 participating physicians. The number of consultations per physician ranged from 1-16, with an average of 4 consultations per physician. The majority of physicians were aged between 40-50 years (71%), with more male (61%) than female physicians. Oncology experience ranged from 5-30+ years, with three quarters of physicians reporting more than 10 years’ experience.
Table 5.2: Patient demographic and clinical characteristics [n= 72]

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N [%]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age*1 missing</td>
<td>60 [28-84]</td>
</tr>
<tr>
<td>Mean [Range]</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>31 [43%]</td>
</tr>
<tr>
<td>Female</td>
<td>41 [57%]</td>
</tr>
<tr>
<td>Education *1 missing</td>
<td></td>
</tr>
<tr>
<td>Prior to final year of HS</td>
<td>21 [30%]</td>
</tr>
<tr>
<td>Completed final year of HS</td>
<td>10 [14%]</td>
</tr>
<tr>
<td>Tertiary, non-university</td>
<td>14 [20%]</td>
</tr>
<tr>
<td>Tertiary, university</td>
<td>26 [37%]</td>
</tr>
<tr>
<td>Marital Status*1 missing</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>6 [9%]</td>
</tr>
<tr>
<td>Married or living with partner</td>
<td>54 [76%]</td>
</tr>
<tr>
<td>Separated or divorced</td>
<td>7 [10%]</td>
</tr>
<tr>
<td>Widowed</td>
<td>4 [6%]</td>
</tr>
<tr>
<td>Occupation *3 missing</td>
<td></td>
</tr>
<tr>
<td>Managers &amp; Administrators</td>
<td>9 [13%]</td>
</tr>
<tr>
<td>Professionals</td>
<td>24 [35%]</td>
</tr>
<tr>
<td>Paraprofessionals</td>
<td>3 [4%]</td>
</tr>
<tr>
<td>Tradespersons</td>
<td>10 [15%]</td>
</tr>
<tr>
<td>Clerks</td>
<td>5 [7%]</td>
</tr>
<tr>
<td>Sales &amp; personal service workers</td>
<td>10 [15%]</td>
</tr>
<tr>
<td>Plant &amp; machine operators &amp; drivers</td>
<td>2 [3%]</td>
</tr>
<tr>
<td>Labourers &amp; related workers</td>
<td>2 [3%]</td>
</tr>
<tr>
<td>House duties</td>
<td>4 [6%]</td>
</tr>
<tr>
<td>Country of birth *2 missing</td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>57 [81%]</td>
</tr>
<tr>
<td>Other</td>
<td>13 [19%]</td>
</tr>
<tr>
<td>Main language*1 missing</td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>69 [97%]</td>
</tr>
<tr>
<td>German</td>
<td>1 [1%]</td>
</tr>
<tr>
<td>Chinese</td>
<td>1 [1%]</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>33 [46%]</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>12 [18%]</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>10 [14%]</td>
</tr>
<tr>
<td>Lung</td>
<td>4 [6%]</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>3 [4%]</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>3 [4%]</td>
</tr>
<tr>
<td>Gynaecological</td>
<td>2 [3%]</td>
</tr>
<tr>
<td>Urological</td>
<td>1 [1%]</td>
</tr>
<tr>
<td>Melanoma</td>
<td>1 [1%]</td>
</tr>
<tr>
<td>Head and Neck</td>
<td>1 [1%]</td>
</tr>
<tr>
<td>None</td>
<td>1 [1%]</td>
</tr>
<tr>
<td>Cancer stage</td>
<td></td>
</tr>
<tr>
<td>Early</td>
<td>48 [67%]</td>
</tr>
<tr>
<td>Advanced</td>
<td>20 [28%]</td>
</tr>
<tr>
<td>Unknown</td>
<td>3 [4%]</td>
</tr>
<tr>
<td>N/A</td>
<td>1 [1%]</td>
</tr>
</tbody>
</table>
### Table 5.3: Available family member characteristics [n= 59]

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N [%]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family member’s relationship to cancer patient</td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>21 [36%]</td>
</tr>
<tr>
<td>Husband</td>
<td>18 [31%]</td>
</tr>
<tr>
<td>Daughter</td>
<td>9 [15%]</td>
</tr>
<tr>
<td>Son</td>
<td>2 [3%]</td>
</tr>
<tr>
<td>Sister</td>
<td>4 [7%]</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>1 [2%]</td>
</tr>
<tr>
<td>Female Partner</td>
<td>1 [2%]</td>
</tr>
<tr>
<td>Male Partner</td>
<td>2 [3%]</td>
</tr>
<tr>
<td>Friend</td>
<td>1 [2%]</td>
</tr>
</tbody>
</table>

### Table 5.4: Physician demographic and professional characteristics [n= 18]

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N [%]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of transcripts per physician</td>
<td></td>
</tr>
<tr>
<td>Mean [range]</td>
<td>4 [1-16]</td>
</tr>
<tr>
<td>Age * 1 unknown</td>
<td></td>
</tr>
<tr>
<td>30’s</td>
<td>1[6%]</td>
</tr>
<tr>
<td>40’s</td>
<td>12 [71%]</td>
</tr>
<tr>
<td>50’s</td>
<td>1 [6%]</td>
</tr>
<tr>
<td>60’s</td>
<td>3 [18%]</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11 [61%]</td>
</tr>
<tr>
<td>Female</td>
<td>7 [39%]</td>
</tr>
<tr>
<td>Oncology experience* 2 missing</td>
<td></td>
</tr>
<tr>
<td>5-9 years</td>
<td>4 [25%]</td>
</tr>
<tr>
<td>10-14 years</td>
<td>5 [31%]</td>
</tr>
<tr>
<td>15-19 years</td>
<td>3[19%]</td>
</tr>
<tr>
<td>20-24 years</td>
<td>1[6%]</td>
</tr>
<tr>
<td>25-29 years</td>
<td>2 [13%]</td>
</tr>
<tr>
<td>&gt; 30 years</td>
<td>1[6%]</td>
</tr>
<tr>
<td>State</td>
<td></td>
</tr>
<tr>
<td>NSW</td>
<td>13 [72%]</td>
</tr>
<tr>
<td>VIC</td>
<td>5 [28%]</td>
</tr>
<tr>
<td>Area</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>13 [72%]</td>
</tr>
<tr>
<td>Rural</td>
<td>5 [28%]</td>
</tr>
</tbody>
</table>
5.3.2 Family roles in the consultation

The role a family member assumed at four distinct time points throughout the consultation was coded (see Table 5.5). In the **history taking** stage, which typically occurred at the beginning of an initial consultation, family members were most commonly coded as assuming the ‘supporter’ role (40%), with relatively equal proportions of family members assuming the active partner (28%) or passive observer (26%) role. In the **information exchange** stage, where information about the treatment options was exchanged, almost half (46%) of family members assumed the active partner role, with 36% acting as a passive observer. During the **deliberation and decision-making** stage, 42% of family members passively observed, while 32% assumed the active partner role.

During the **logistical arrangements**, which typically occurred at the end of the consultation, almost half (46%) of family members assumed the passive observer role, and 29% were coded as active partners. Less than 10% of family members were coded as ‘dominant’ for any consultation stage.

Upon examination of the data, only 13% of family members maintained the same role throughout all four stages of the consultation, with 33% of family members assuming three or more roles throughout the one consultation (e.g. history taking = supporter; information exchange = active partner; deliberation/decision-making = passive observer; logistical arrangement = passive observer).

Table 5.6 highlights that during the two decision-making phases of the consultation (information exchange; deliberation/decision-making) there was a high level of between-triad variability. Fourteen different combinations of activity level were apparent, with ‘passive-passive’ (23%), ‘active-active (21%)’, and ‘active-passive’ (14%) the most common decision-making combinations. Just over half (53%) of family members assumed the same role throughout the decision-making phases (e.g. active-active).
Table 5.5: Family roles throughout consultation stages

<table>
<thead>
<tr>
<th>Consultation stage</th>
<th>Roles</th>
<th>N [%]</th>
</tr>
</thead>
<tbody>
<tr>
<td>History Taking</td>
<td>Passive</td>
<td>19 [26%]</td>
</tr>
<tr>
<td></td>
<td>Supportive</td>
<td>29 [40%]</td>
</tr>
<tr>
<td></td>
<td>Active</td>
<td>20 [28%]</td>
</tr>
<tr>
<td></td>
<td>Dominant</td>
<td>4 [6%]</td>
</tr>
<tr>
<td>Information Exchange</td>
<td>Passive</td>
<td>26 [36%]</td>
</tr>
<tr>
<td></td>
<td>Supportive</td>
<td>7 [10%]</td>
</tr>
<tr>
<td></td>
<td>Active</td>
<td>33 [46%]</td>
</tr>
<tr>
<td></td>
<td>Dominant</td>
<td>6 [8%]</td>
</tr>
<tr>
<td>Deliberation/Decision-making</td>
<td>Passive</td>
<td>30 [42%]</td>
</tr>
<tr>
<td></td>
<td>Supportive</td>
<td>10 [14%]</td>
</tr>
<tr>
<td></td>
<td>Active</td>
<td>23 [32%]</td>
</tr>
<tr>
<td></td>
<td>Dominant</td>
<td>8 [11%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>1 [1%]</td>
</tr>
<tr>
<td>Logistics</td>
<td>Passive</td>
<td>33 [46%]</td>
</tr>
<tr>
<td></td>
<td>Supportive</td>
<td>9 [13%]</td>
</tr>
<tr>
<td></td>
<td>Active</td>
<td>21 [29%]</td>
</tr>
<tr>
<td></td>
<td>Dominant</td>
<td>2 [3%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>7 [10%]</td>
</tr>
</tbody>
</table>

Table 5.6: Change in decision-making roles across information exchange and decision-making phases [n=71]

<table>
<thead>
<tr>
<th>Decision-making roles</th>
<th>Proposed role descriptions</th>
<th>N [%]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive-Passive</td>
<td>Passive observer</td>
<td>16 [23%]</td>
</tr>
<tr>
<td>Active-Active</td>
<td>Information gatherer, co-decision-maker</td>
<td>15 [21%]</td>
</tr>
<tr>
<td>Active-Passive</td>
<td>Information gatherer</td>
<td>10 [14%]</td>
</tr>
<tr>
<td>Passive-Active</td>
<td>Co-decision-maker</td>
<td>5 [7%]</td>
</tr>
<tr>
<td>Active-Supportive</td>
<td>Information-gatherer, decision-support</td>
<td>4 [6%]</td>
</tr>
<tr>
<td>Passive-Supportive</td>
<td>Decision support</td>
<td>4 [6%]</td>
</tr>
<tr>
<td>Dominant-Dominant</td>
<td>Dominant decision-maker</td>
<td>4 [6%]</td>
</tr>
<tr>
<td>Active-Dominant</td>
<td>Dominant decision-maker</td>
<td>3 [4%]</td>
</tr>
<tr>
<td>Supportive-Active</td>
<td>Information support, Co decision-maker</td>
<td>3 [4%]</td>
</tr>
<tr>
<td>Supportive-Supportive</td>
<td>Supporter</td>
<td>2 [3%]</td>
</tr>
<tr>
<td>Supportive-Passive</td>
<td>Information support</td>
<td>2 [3%]</td>
</tr>
<tr>
<td>Dominant-Active</td>
<td>Co decision-maker</td>
<td>1 [1%]</td>
</tr>
<tr>
<td>Dominant-Passive</td>
<td>Information gatherer</td>
<td>1 [1%]</td>
</tr>
<tr>
<td>Passive-Dominant</td>
<td>Active decision-maker</td>
<td>1 [1%]</td>
</tr>
</tbody>
</table>
The following sections will present the family-relevant behaviours of physicians, patients, and family members. The proportion of behaviours coded will be displayed in tables and some results will be highlighted in text.

### 5.3.3 Physician Behaviours

Table 5.7 presents the family-relevant behaviours of physicians.

Nine items assessed physicians’ **overall consultation communication**, which is defined as non-decision related discussions occurring in a consultation. In a minority of consultations, physicians engaged in social interaction or laughter with family members (18%). Qualitative examination of this item showed that social interaction topics were varied. A male physician engaged in discussions with the wife of a patient after she mentioned recent home renovations. The physician said “Do you watch that English show about building houses? Some of those people are living in a caravan in the freezing cold for a year”. In another consultation, a female physician engaged in a light-hearted exchange with the patient’s adult daughter. She said “Are you the baby or the oldest... [family member responds that she is the middle child]....The middle child does everything. Is that right? According to my middle child...[laughter]”.

In a quarter of consultations, physicians asked family members questions not directly related to the treatment decision. The content of these questions was varied, including questions about patient functioning at home, changes in patient symptoms (e.g. a rash), and psychosocial questions about the family member such as their employment status, where they live, and their own physical health. In over half of the consultations (58%), the physician interrupted the family member at least once; whilst in 17% of consultations, physicians engaged in a conversation exclusively with a family member, potentially excluding the patient. Only a small proportion of physicians explicitly highlighted their appreciation of the family member (6%). In one consultation, after a patient’s daughter stated “This is the first time someone’s come [to a consultation] with Dad”, the male physician affirmed the daughters presence by stating “it’s probably a good thing”. Whilst asking the patient about his support network, another male physician acknowledged the support of the patient’s wife. He said “So, obviously, you have got your wife, who is a good support. Who else are your supports?”.

Six items assessed **role or preference clarification** conducted by the physician. In no (0%) consultations did the physician establish the family member’s reason for attending, clarify the
family member’s role, establish patient or family member preferences for family involvement in decision-making, or confirm the family member's role in the decision-making process. In 2 (3%) consultations, the physician highlighted that the patient should be the focus of the consultation.

Five items assessed physician behaviours during the **information exchange phase** of the decision-making process. Whilst in only 10% of consultations the physician invited family member questions during a treatment decision discussion, the majority of physicians were fully responsive (71%) to family member questions related to a decision. Physicians rarely asked family members questions related to decisions (4%), nor did they routinely provide information about how a decision would impact upon the family (7%). In those consultations where the physician did provide this information, it was usually presented to partners of patients regarding the impact of treatment on fertility or sexual functioning. During the decision-making process, exclusive physician-family conversations occurred in 17% of consultations.

Two items assessed physician behaviours during the **deliberation phase** of decision-making. No physicians ascertained family member preferences for a decision; however in 6% of consultations the physician encouraged the patient and family member to discuss the decision outside of the consultation.

Two items assessed physician behaviours during **determination of a decision**. Whilst no physician confirmed that the family member was happy with the decision, in 11% of consultations physicians highlighted that it should be the patient's final decision. An example of this is when a male physician emphasised the autonomy of a breast cancer patient by stating “*Well you can do what you like. It’s a question of getting you the information... And you’re the boss*.”
### Table 5.7: Physician behaviours during triadic consultations

<table>
<thead>
<tr>
<th>Item</th>
<th>Response</th>
<th>N[%]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall communication</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Actively engages in social interaction/laughter with family member</td>
<td>Yes</td>
<td>13 [18%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>59 [82%]</td>
</tr>
<tr>
<td>Responsive to family member questions/comments (not related to decision)</td>
<td>Ignores</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>Occasionally responds</td>
<td>6 [8%]</td>
</tr>
<tr>
<td></td>
<td>Mostly responds</td>
<td>55 [76%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>11 [15%]</td>
</tr>
<tr>
<td>Asks family member a question (not related to decision)</td>
<td>Yes</td>
<td>18 [25%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>54 [75%]</td>
</tr>
<tr>
<td>Asks family member to confirm/corroborate patient information</td>
<td>Yes</td>
<td>4 [4%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>68 [96%]</td>
</tr>
<tr>
<td>Interrupts family member</td>
<td>Never</td>
<td>30 [42%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>19 [26%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>23 [32%]</td>
</tr>
<tr>
<td>Engages in conversation explicitly with family member (not related to decision)</td>
<td>Never</td>
<td>60 [83%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>9 [13%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>3 [4%]</td>
</tr>
<tr>
<td>Family member not acknowledged or spoken to</td>
<td>Yes</td>
<td>1 [1%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [99%]</td>
</tr>
<tr>
<td>Reveals potentially sensitive information</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td>Shows appreciation or respect of family member</td>
<td>Yes</td>
<td>4 [6%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>68 [94%]</td>
</tr>
<tr>
<td><strong>Role/Preference clarification</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Establishes why family member has attended the consultation</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td>Clarifies family member role in consultation</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td>Establishes patient’s preference for family involvement in decisions</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td>Establishes family members preference for involvement in decisions</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td>Confirms family members role in decision-making</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td>Clarifies that patient is focus of consultation</td>
<td>Yes</td>
<td>2 [3%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>70 [97%]</td>
</tr>
<tr>
<td><strong>Information exchange</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invites family member question (related to decision)</td>
<td>Yes</td>
<td>7 [10%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>65 [90%]</td>
</tr>
<tr>
<td>Responsive to family member questions/comments (related to decision)</td>
<td>Ignores</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>Partially responds</td>
<td>6 [8%]</td>
</tr>
<tr>
<td></td>
<td>Fully responds</td>
<td>51 [71%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>15 [21%]</td>
</tr>
<tr>
<td>Item</td>
<td>Response</td>
<td>N[%]</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------------</td>
<td>------</td>
</tr>
<tr>
<td>Asks family member question (related to decision)</td>
<td>Yes</td>
<td>3 [4%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>69 [96%]</td>
</tr>
<tr>
<td>Engages in conversation explicitly with family member (related to</td>
<td>Never</td>
<td>59 [82%]</td>
</tr>
<tr>
<td>decision)</td>
<td>Once</td>
<td>10 [14%]</td>
</tr>
<tr>
<td></td>
<td>More than</td>
<td>3 [4%]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides information about how decision will impact on the family</td>
<td>Yes</td>
<td>5 [7%]</td>
</tr>
<tr>
<td>member</td>
<td>No</td>
<td>55 [76%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>12 [17%]</td>
</tr>
<tr>
<td>Deliberation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invites family member preference for decision</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>64 [89%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>8 [11%]</td>
</tr>
<tr>
<td>Encourages family member and patient to discuss decision outside</td>
<td>Yes</td>
<td>4 [6%]</td>
</tr>
<tr>
<td>consultation</td>
<td>No</td>
<td>61 [85%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>7 [10%]</td>
</tr>
<tr>
<td>Decision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highlights that it is the patient’s final decision</td>
<td>Yes</td>
<td>8 [11%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>56 [78%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>8 [11%]</td>
</tr>
<tr>
<td>Confirms family member is happy with final decision</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>59 [82%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>13 [18%]</td>
</tr>
</tbody>
</table>

5.3.4 Patient Behaviours

The family-relevant behaviours of patients are presented in Table 5.8. Five items assessed patients’ overall consultation communication (non-decision related discussions). Almost half (42%) of patients asked a family member a non-decision related question during the consultation. The content of these questions varied, and included asking the family member about the patient’s own medical history, their family history, lifestyle questions such as diet and exercise, and the results of previous tests. Twenty-one percent of patients corrected or disagreed with their family member during a non-decision related discussion and 31% of patients interrupted their family member at least once.

Three items assessed role or preference clarification. Overall, no (0%) patients expressed any preferences for family involvement; however in two consultations the patient indicated a desire for their family member to stop talking or become more passive. In one of these consultations, an elderly male patient indicated that his wife should stop answering for him, he stated “would you mind!” to his wife. In another consultation, a female patient indicated that her husband should
become more passive. She said “**excuse me, these are my questions!**”, and later in the consultation when the husband again interjected the patient stated “**you are not the doctor. Be quiet**”.

Two items assessed patient behaviours during the **information exchange** phase of decision-making. Eighteen percent of patients asked if their family member had any questions, whilst two (3%) patients provided information about the family member relevant to the decision. One patient, a female in her 60’s, provided information about her husband’s lifestyle. She said “**He [husband] plays golf on a Wednesday. So, if I have any treatment, could it not be on a Wednesday? He says it doesn’t matter, but I think it’s important that he plays golf**”. In another consultation, a female patient in her 50’s also provided information about her daughter. She said “**Can you pick any day that you want [for treatment]? Fridays, because [daughter] works**”.

Two items assessed patient behaviours during the **deliberation** phase of decision-making. Three (4%) patients asked for their family member’s preference or opinion during the consultation. One patient, a younger female, asked her partner about whether they should pursue fertility treatment prior to chemotherapy. She said “**I think [I want to see a fertility specialist]... do you want to?**”. There were no patient-family member disagreements about the decision in any consultations.

Two items assessed patient behaviours during **determination of a decision**. During the consultation, no patients deferred the decision to their family member or confirmed if their family member was happy with the decision.
Table 5.8: Patient behaviours during triadic consultations

<table>
<thead>
<tr>
<th>Item</th>
<th>Response</th>
<th>N[%]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall Communication</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrects or disagrees with family member (not related to decision)</td>
<td>Never</td>
<td>55 [77%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>11 [15%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>6 [8%]</td>
</tr>
<tr>
<td>Interrupts family member</td>
<td>Never</td>
<td>50 [69%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>12 [17%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>10 [14%]</td>
</tr>
<tr>
<td>Asks family member a question (not related to decision)</td>
<td>Yes</td>
<td>30 [42%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>42 [58%]</td>
</tr>
<tr>
<td>Answers for family member</td>
<td>Never</td>
<td>33 [46%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>39 [54%]</td>
</tr>
<tr>
<td>Speaks directly to family member (not a question)</td>
<td>Yes</td>
<td>20 [28%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>52 [72%]</td>
</tr>
<tr>
<td><strong>Preference Negotiation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indicates a desire for family member to stop talking/become more passive</td>
<td>Yes</td>
<td>2 [3%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>70 [97%]</td>
</tr>
<tr>
<td>Expresses a wish for active family involvement</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td>Voices preference for family member involvement in decisions</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td><strong>Information Exchange</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asks family member if they have any questions (related to decision)</td>
<td>Yes</td>
<td>13 [18%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>59 [82%]</td>
</tr>
<tr>
<td>Provides information about family member (related to decision)</td>
<td>Yes</td>
<td>2 [3%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>70 [97%]</td>
</tr>
<tr>
<td><strong>Deliberation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asks family member preference/opinion</td>
<td>Yes</td>
<td>3 [4%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>69 [96%]</td>
</tr>
<tr>
<td>Argues with family member about decision</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td><strong>Decision</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Defers decision to family member</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>9 [13%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>63 [88%]</td>
</tr>
<tr>
<td>Confirms family member is happy with decision</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>59 [82%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>13 [18%]</td>
</tr>
</tbody>
</table>
5.3.5 Family member behaviours

Sixteen items assessed family members’ overall consultation communication (non-decision related discussions) (see Table 5.9). The majority (77%) of family members contributed to the history taking stage of the consultation by recalling information about the patient at least once. Almost half (43%) of family members confirmed information provided by the patient, and 55% asked a non-decision related question. A small proportion (15%) of family members either apologised for speaking or asked for permission to speak. Some family members engaged in behaviours such as prompting patient questions (4%), summarising or repeating information for the patient (10%), and making optimistic or positive statements (13%). The content of the optimistic or positive statements varied, but several family members communicated positivity about fighting the cancer. The family member of a male patient showed positivity by stating “You do it as it comes along mate. Face it when and if it happens. We did that with [previous oncologist], we’ll do it again”. In some consultations, family members displayed partnership with the patient (10%), engaged in combined patient and family member talk (10%), or spoke directly with the patient (74%). However, around half family members engaged in potentially negative behaviours such as interrupting the patient (54%), interrupting the physician (42%), or answering for the patient (54%).

Two items assessed role or preference clarification. Although no family members expressed a desire to be actively involved in the consultation, one family member voiced their preference for involvement in the decision-making process. The sister of a female patient highlighted the preferred nature of her involvement and her preferences for information. She stated “I’m here to help support [patient] of course... But I think before any decisions can be made one way or the other you have to have all the information to make it a decision. I’m sure there’s positives of it [treatment] too. And that’s what I would like to hear”.

Ten items assessed family member behaviours during the information exchange phase of decision-making. A small proportion (18%) of family members provided information related to the decision. An example is the husband of a breast cancer patient who provided information about a friend who had died of advanced cancer. He stated to the physician “just to give you the insight into our worries about the side effects... a very good friend of mine [died of cancer]. The physician replied “That’s very different. If your friend’s had chemotherapy for advanced disease or recurrent disease and incurable disease, then the aim of treatment there is very different than for you [patient]”. Another example is a family member providing the physician with information from scientific studies. A
husband of a breast cancer patient stated “talking about all this, we listened recently to the results of a study where they were talking about chronic inflammation... increasing the risk of recurrence for breast cancer. Have you seen it?... I did print it out and was going to bring it along to you”. Additionally, most family members asked a question about the treatment decision (71%), and some more specifically discussed the risks and benefits of treatment (35%) or pain (6%). Fourteen percent of family members questioned the information provided by the physician. An example of this is the male partner of a breast cancer patient who, when discussing the use of a computer program to provide probabilities of cancer recurrence, stated “Well, be careful, because we’ve talked about it a lot, over the last month. As professionals, we sort of rely on information from experts and [patient] is in the situation where she will listen closely to you guys and, if you recommend it, she’ll do it”. He went on to ask “How accurate is this program?” and stated “I’d be interested to see the type of data that goes into it... you know, whether a lot of that data is based on results that you’ve recently had”.

Five items assessed family member behaviours during the deliberation phase of decision-making. Twenty one percent of family members expressed a treatment preference. The husband of a breast cancer patient who faced a decision about whether to receive chemotherapy stated to his wife “I think chemotherapy is the way to go”. A small proportion (7%) of family members helped highlight the patient’s preferences during the deliberation process; whilst 8% indicated a preference for further discussion about the decision outside of the consultation.

Five items assessed family member behaviours during determination of a decision. Within the consultation, a small proportion (6%) of family members highlighted that the patient is the ultimate decision-maker, making comments to the patient such as “It’s up to you” or “It’s your decision”. Almost one quarter (22%) of family members showed support of the patient’s decision, whilst only 2 (3%) family members showed disagreement with the decision.
<table>
<thead>
<tr>
<th>Item</th>
<th>Response</th>
<th>N [%]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall Communication</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apologises for speaking/asks for permission to speak</td>
<td>Yes</td>
<td>11 [15%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>61 [85%]</td>
</tr>
<tr>
<td>Recalls information about patient history</td>
<td>Never</td>
<td>16 [22%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>6 [8%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>50 [69%]</td>
</tr>
<tr>
<td>Shows partnership with patient</td>
<td>Yes</td>
<td>7 [10%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>65 [90%]</td>
</tr>
<tr>
<td>Corrects or disagrees with patient</td>
<td>Never</td>
<td>46 [64%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>17 [24%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>9 [13%]</td>
</tr>
<tr>
<td>Interrupts patient</td>
<td>Never</td>
<td>33 [46%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>14 [19%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>25 [35%]</td>
</tr>
<tr>
<td>Interrupts physician</td>
<td>Never</td>
<td>42 [58%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>15 [21%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>15 [21%]</td>
</tr>
<tr>
<td>Answers for patient (not related to decision)</td>
<td>Never</td>
<td>33 [46%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>15 [21%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>24 [33%]</td>
</tr>
<tr>
<td>Prompts patient questions (not related to decision)</td>
<td>Yes</td>
<td>3 [4%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>69 [96%]</td>
</tr>
<tr>
<td>Confirms information that patient provides</td>
<td>Yes</td>
<td>31 [43%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>41 [57%]</td>
</tr>
<tr>
<td>Summarises/repeats information for patient</td>
<td>Yes</td>
<td>7 [10%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>65 [90%]</td>
</tr>
<tr>
<td>Asks questions (not related to decision)</td>
<td>Never</td>
<td>32 [44%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>11 [15%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>29 [40%]</td>
</tr>
<tr>
<td>Asks questions about themselves</td>
<td>Yes</td>
<td>5 [7%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>67 [93%]</td>
</tr>
<tr>
<td>Asks patient a question</td>
<td>Yes</td>
<td>24 [33%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>48 [67%]</td>
</tr>
<tr>
<td>Patient and family member combined talk</td>
<td>Yes</td>
<td>7 [10%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>65 [90%]</td>
</tr>
<tr>
<td>Speaks directly to patient</td>
<td>Yes</td>
<td>53 [74%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>19 [26%]</td>
</tr>
<tr>
<td>Makes optimistic/positive statement</td>
<td>Yes</td>
<td>9 [13%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>63 [88%]</td>
</tr>
<tr>
<td><strong>Preference Negotiation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expresses desire to be actively involved in consultation</td>
<td>Yes</td>
<td>0 [0%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>72 [100%]</td>
</tr>
<tr>
<td>Voices preference for involvement in decisions</td>
<td>Yes</td>
<td>1 [1%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>71 [99%]</td>
</tr>
<tr>
<td>Item</td>
<td>Response</td>
<td>N[%]</td>
</tr>
<tr>
<td>---------------------------------------------------------------------</td>
<td>----------</td>
<td>-------</td>
</tr>
<tr>
<td><strong>Information Exchange</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides information/suggestion (related to decision)</td>
<td>Yes</td>
<td>13 [18%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>59 [82%]</td>
</tr>
<tr>
<td>Raises patient's previous reactions to treatments</td>
<td>Yes</td>
<td>4 [6%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>68 [94%]</td>
</tr>
<tr>
<td>Asks question about treatment or decision/seeks supplementary</td>
<td>Yes</td>
<td>51 [71%]</td>
</tr>
<tr>
<td>information</td>
<td>No</td>
<td>21 [29%]</td>
</tr>
<tr>
<td>Discusses the risks/benefits of treatment</td>
<td>Yes</td>
<td>25 [35%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>47 [65%]</td>
</tr>
<tr>
<td>Asks specific question about pain/treatment of pain</td>
<td>Yes</td>
<td>4 [6%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>68 [94%]</td>
</tr>
<tr>
<td>Asks about issues relating to themselves (related to decision)</td>
<td>Yes</td>
<td>1 [1%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>71 [99%]</td>
</tr>
<tr>
<td>Questions information provided by physician (related to decision)</td>
<td>Yes</td>
<td>10 [14%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>62 [86%]</td>
</tr>
<tr>
<td>Answers for the patient (related to decision)</td>
<td>Never</td>
<td>60 [83%]</td>
</tr>
<tr>
<td></td>
<td>Once</td>
<td>9 [13%]</td>
</tr>
<tr>
<td></td>
<td>More than once</td>
<td>3 [4%]</td>
</tr>
<tr>
<td>Prompts patient questions (related to decision)</td>
<td>Yes</td>
<td>1 [1%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>71 [99%]</td>
</tr>
<tr>
<td>Presents information back to patient (related to decision)</td>
<td>Yes</td>
<td>1 [1%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>71 [99%]</td>
</tr>
<tr>
<td><strong>Deliberation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expresses treatment preference</td>
<td>Yes</td>
<td>15 [21%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>57 [79%]</td>
</tr>
<tr>
<td>Expresses a general wish for treatment outcomes/aims</td>
<td>Yes</td>
<td>5 [7%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>67 [93%]</td>
</tr>
<tr>
<td>Indicates preference for further discussion outside consultation</td>
<td>Yes</td>
<td>6 [8%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>61 [85%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>5 [7%]</td>
</tr>
<tr>
<td>Helps articulate patient goals</td>
<td>Yes</td>
<td>1 [1%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>71 [99%]</td>
</tr>
<tr>
<td>Helps highlight patient preference</td>
<td>Yes</td>
<td>5 [7%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>67 [93%]</td>
</tr>
<tr>
<td><strong>Decision</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highlights that patient is ultimate decision-maker</td>
<td>Yes</td>
<td>4 [6%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>63 [88%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>5 [7%]</td>
</tr>
<tr>
<td>Confirms patient is satisfied with decision</td>
<td>Yes</td>
<td>3 [4%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>54 [75%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>15 [21%]</td>
</tr>
<tr>
<td>Shows agreement with, or support of, decision</td>
<td>Yes</td>
<td>16 [22%]</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>41 [57%]</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>15 [21%]</td>
</tr>
</tbody>
</table>
5.3.6 Tests of association between items

A number of exploratory tests were conducted to determine if participant characteristics (e.g. physician experience, patient illness severity, family member relationship type) were associated with a participants’ behaviours, or if one participant’s behaviours were associated with another participant’s behaviours. Tests were selected based on empirical considerations and also items with sufficient variability to warrant statistical testing. Generalised estimated equations (GEE), which accommodated correlations of observations within physician, were used to test associations.

5.3.6.1 Association between physician experience level and consultation behaviours

GEE analyses revealed a significant relationship between physician experience level and physician interruption of family members. Physicians with more than 10 years' experience were 1.79 times more likely to interrupt a family member than physicians with 10 years or less oncology experience (OR 1.793, \(p\leq.001\)). No other significant relationships existed between physician experience level and consultation behaviours (see Table 5.10).

Table 5.10: Results of physician oncology experience predicting physician behaviours

<table>
<thead>
<tr>
<th>Variable</th>
<th>Log-Odds (B)</th>
<th>Odds Ratio (OR)</th>
<th>95% CI Lower</th>
<th>95% CI Upper</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician social interaction with family member</td>
<td>1.326</td>
<td>3.767</td>
<td>.535</td>
<td>26.535</td>
<td>0.183</td>
</tr>
<tr>
<td>Physician asks Family Member a Question</td>
<td>.863</td>
<td>2.371</td>
<td>.306</td>
<td>18.368</td>
<td>0.409</td>
</tr>
<tr>
<td>Physician Interrupts family member</td>
<td>.584</td>
<td>1.793</td>
<td>1.340</td>
<td>2.399</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Physician engages in exclusive conversation with family member</td>
<td>.478</td>
<td>1.613</td>
<td>.440</td>
<td>5.916</td>
<td>0.471</td>
</tr>
<tr>
<td>Family member asks question about decision</td>
<td>.251</td>
<td>1.285</td>
<td>.848</td>
<td>1.950</td>
<td>0.237</td>
</tr>
<tr>
<td>Family member provides information about decision</td>
<td>.792</td>
<td>2.208</td>
<td>.923</td>
<td>5.285</td>
<td>0.075</td>
</tr>
<tr>
<td>Family member expresses treatment preference</td>
<td>-.376</td>
<td>.686</td>
<td>.219</td>
<td>2.149</td>
<td>0.518</td>
</tr>
</tbody>
</table>
5.3.6.2 Association between physician behaviours and family member behaviours

GEE analyses revealed a significant relationship between ‘physician interrupts family member’ and ‘family member corrects or disagrees with patient’. Physicians were 5.47 times more likely to interrupt a family member who had corrected or disagreed with the patient (OR=5.468, p=<.01). Additionally, physicians were 3.786 times more likely to interrupt the family member if the family member had interrupted the patient within that consultation (OR=3.786, p=<.01). However, no significant relationship existed between the variables ‘physician interruption of family member’ and ‘family member interruption of physician’ (see Table 5.11). Physicians were 5.42 times more likely to engage in an exclusive conversation with a family member who had interrupted the patient (OR=5.419, p=<.01) (see Table 5.12).

**Table 5.11: Results of physician interrupts family member predicting family member behaviours**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Log-Odds (B)</th>
<th>Odds Ratio (OR)</th>
<th>95% CI Lower</th>
<th>95% CI Upper</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family member corrects or disagrees with patient</td>
<td>1.699</td>
<td>5.468</td>
<td>1.493</td>
<td>20.031</td>
<td>0.01*</td>
</tr>
<tr>
<td>Family member interrupts patient</td>
<td>1.331</td>
<td>3.786</td>
<td>1.473</td>
<td>9.733</td>
<td>0.006*</td>
</tr>
<tr>
<td>Family member interrupts physician</td>
<td>0.469</td>
<td>1.599</td>
<td>.725</td>
<td>3.527</td>
<td>0.245</td>
</tr>
</tbody>
</table>

**Table 5.12: Results of physician engages in exclusive conversation with family member behaviours**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Log-Odds (B)</th>
<th>Odds Ratio (OR)</th>
<th>95% CI Lower</th>
<th>95% CI Upper</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family member interrupts patient</td>
<td>1.690</td>
<td>5.419</td>
<td>1.978</td>
<td>14.846</td>
<td>&lt;0.001*</td>
</tr>
</tbody>
</table>

5.3.6.3 Association between disease severity and consultation behaviours

GEE analyses revealed a significant relationship between patient disease severity and the family member recalling information. Family members were 2.2 times more likely to recall information for a patient with advanced disease (OR=2.201, p=<.01). No other significant relationships existed between patient disease stage and consultation behaviours (see Table 5.13).
Table 5.13: Results of patient disease stage (early vs. advanced) predicting patient or family member behaviours

<table>
<thead>
<tr>
<th>Variable</th>
<th>Log-Odds (B)</th>
<th>Odds Ratio (OR)</th>
<th>95% CI Lower</th>
<th>95% CI Upper</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient asks family member a question</td>
<td>.427</td>
<td>1.532</td>
<td>.660</td>
<td>3.557</td>
<td>0.321</td>
</tr>
<tr>
<td>Patient asks if family member has any questions</td>
<td>-.747</td>
<td>.474</td>
<td>.158</td>
<td>1.422</td>
<td>0.183</td>
</tr>
<tr>
<td>Family member recalls information</td>
<td>2.201</td>
<td>9.035</td>
<td>1.736</td>
<td>47.013</td>
<td>0.009*</td>
</tr>
<tr>
<td>Family member asks question about decision</td>
<td>.466</td>
<td>1.593</td>
<td>.771</td>
<td>3.295</td>
<td>0.209</td>
</tr>
</tbody>
</table>

5.3.6.4 Association between family relationship type and family member behaviours

No significant relationships existed between family relationship type and family member behaviours (see Table 5.14).

Table 5.14: Results of family relationship type (spouse vs. other) predicting family member behaviours

<table>
<thead>
<tr>
<th>Variable</th>
<th>Log-Odds (B)</th>
<th>Odds Ratio (OR)</th>
<th>95% CI Lower</th>
<th>95% CI Upper</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family member asks question about decision</td>
<td>.558</td>
<td>1.747</td>
<td>.643</td>
<td>4.748</td>
<td>0.274</td>
</tr>
<tr>
<td>Family member expresses treatment preference</td>
<td>-.142</td>
<td>.242</td>
<td>.028</td>
<td>2.099</td>
<td>0.198</td>
</tr>
</tbody>
</table>

5.4 Discussion

The analysis of audio-taped initial medical or radiation oncology consultations revealed that family involvement is widely variable. The extent that physicians and patients engaged with the family member, and the contributions of family members themselves, ranged from minimal to extensive. Variability also existed within consultations; the role a family member assumed at the start of the consultation was generally dynamic, not static. Most family members shifted role (e.g. from active to passive) at least once within the consultation. There were stages of the consultation where family members tended to become more active (e.g. information exchange) and other stages where family members were often passive (e.g. treatment logistics). This notion of within consultation variability is supported by other studies. Beisecker (1989) and Ellingson (2002) both reported that
family members serve multiple functions within a single encounter. Ellingson (2002) noted that some family members became more active when a particular issue was raised in a consultation, indicating an agenda of the family member.

It is unclear to what extent family members adopted a certain role to fulfil their own agenda or whether they were attempting to meet the perceived needs of the patient. However, previous research has highlighted that patient and family member expectations regarding level of family involvement are often mismatched. A study among geriatric patients found that they expected family members to assume a more indirect role (supporting, remembering information, facilitating communication) rather than an active or direct role (asking questions, providing information); whereas family members expected to play a more active role (Ishikawa et al., 2006). These findings suggest potential mismatch of expectations or confusion about what role to assume within the patient–family relationship. Such discrepancy was also highlighted by some patient-family pairs in Chapter 4. These findings indicate that it may be important to clarify and agree upon role preferences and expectations prior to, or at commencement of, the consultation. This was not done in any of the consultations in the current study. Namely, no physician ascertained why the family member had attended the consultation, established patient preferences for family involvement, or clarified the family member’s role in the consultation. Our results indicate that clinical practice does not reflect the strategies proposed by Speice et al. (2000), Mitnick et al. (2010) and in Chapters 2, 3 and 4 of this thesis. In ethical guidance endorsed by the American College of Physicians, Mitnick et al. (2010) recommended that physicians routinely clarify patient preferences regarding the nature and degree of family involvement in consultations. Speice et al. (2000) recommended that oncology health professionals ask role clarification questions in initial consultations such as [to patient] “What important things should I know about how you and your family members relate to each other” and [to family member] “How would you like to be involved in your loved one’s care”. Based on the results of our systematic review (Chapter 2), we suggested that physicians i) ascertain from the patient and/or family why the family member has accompanied the patient; ii) clarify and agree upon role preferences of patients and family members at commencement of the consultation; and iii) be aware of, and respect, the patient’s preferences for family involvement. Perhaps physicians are unaware of both the need for, and existence of, these strategies. Wider dissemination of clinical strategies is needed.

The results of our study also shed light on family involvement in treatment decision-making. Examination of the roles assumed by family members for the two decision-making phases
(information exchange; treatment deliberation and decision), showed that such roles are variable between triads and dynamic within consultations. Our study found fourteen different combinations of activity across the two decision-making phases, with family involvement ranging from passive (passive-passive) to dominant (dominant-dominant). Approximately half of family members held a consistent role across the two decision-making phases (e.g. active-active), while the other half shifted roles (e.g. active-passive). This indicates that there may be a greater range of family involvement than previously reported in the literature (e.g. Hilton, 1994; Krieger, 2014; Öhlén et al., 2006). Future theoretical frameworks of triadic decision-making need to incorporate the vast spectrum of roles, and consider including passive family involvement (e.g. physician-patient decision-making with family member as witness) and dominant family involvement (e.g. family-led triadic decision-making). Theoretical frameworks should also ensure that the dynamic nature of family involvement is accommodated, for example active family involvement in the information exchange phase and passive involvement in deliberation/decision phase.

Since development and application of the TRIO coding frame, Mazer, Cameron, DeLuca, Mohile, and Epstein (2014) published a transcript analysis of family involvement in advanced cancer consultations. Mazer et al. (2014) categorised family utterances according to a taxonomy of interactional control, whereby family members could speak on behalf of the patient in the consultations in a number of ways, ranging on a spectrum from: i) Pseudo-Surrogacy ("Speaking-as"); ii) Hear-say ("Speaking-for"); iii) Conflation of thoughts ("Speaking-with"); iv) Observation as an outsider and co-experiencing ("Speaking-about"); v) Facilitation ("Speaking-to"). Whilst the current study did not specifically code utterances using Mazer et al.’s (2014) taxonomy, both studies highlighted the ‘spectrum’ nature of family involvement ranging from passive, supportive, through to dominant.

In addition to the different triadic decision-making roles, very little is known about the behaviours of family members during the decision-making process. Prior to the current program of research, only one study had examined the behaviours of family members during each of the medical decision-making stages (e.g. information exchange, deliberation, decision). Hubbard et al. (2010) conducted interviews with cancer patients and family members and found that during the information exchange phase, family members may absorb information, relay information back to the patient, and pre-empt the patient’s decision-making needs. During the deliberation phase family members can stimulate thinking about the decision ‘behind the scenes’. Whilst the previous two chapters (Chapter 3; Chapter 4) have highlighted an array of behaviours for each stage of decision-
making, the current study is the first to detail the distinct contributions of family members, and the family relevant behaviours of patients and physicians, during medical decision-making based on analyses of cancer consultations.

Coding analyses revealed that during the information exchange phase most family members asked questions about the treatment or decision and a smaller proportion specifically discussed the risks or benefits of treatment. Some family members provided information to the physician, and a small proportion questioned information provided by the physician. Our study indicates that many family members are actively involved in the information exchange phase of decision-making, which mirrors the results of our interviews with health professionals (Chapter 3) and patients and family members (Chapter 4).

A smaller proportion of family members were actively involved in the deliberation phase. Some family members expressed their treatment preference or a general wish for treatment, and some helped highlight the patient’s preferences. These results align with the findings in Chapters 3 and 4; that overall, family members are less involved in the deliberation phase as they may self-censor their views, but some family members actively participate in the sharing of preferences. Whilst it was beyond the scope of this chapter to explore the nature of patient-family deliberation outside of the consultation, interviews with patients and family members indicated that in many families a large amount of deliberation takes place outside of the consultation (Chapter 4).

Of those family members involved in the decision phase of the consultation, the highest proportion showed support of, or agreement with, the patient’s decision. Very few family members showed disagreement with the decision made. This aligns with prominent ethical and legal approaches which advocate patient authority in decision-making and with the experiences of patients and family members in Chapter 4. It is possible that because the current study included initial consultations for adjuvant treatment only, the results do not capture the scenarios for conflict or anger highlighted by health professionals in Chapter 3, such as conflicting patient-family member treatment wishes when changing or ceasing treatment. Zhang and Siminoff (2003) found that a substantial proportion of family members of patients with advanced lung cancer reported disagreement about treatment decisions. The results of our study indicate that open displays of conflict and disagreement appear to be relatively uncommon in initial oncology consultations. Additionally, it may be that patient-family conflict and disagreement occurs more often outside the consultation away from the physician.
Indeed, there was little conflict, anger, or dysfunctional dynamics evident throughout any of the current consultations. In fact, a degree of humour was present in the two consultations where the patient indicated a desire for the family member to become more passive. Similarly, when patients or family members corrected or disagreed with one another, it often appeared to be a helpful correction rather than argumentative or confrontational disagreement. These results align well with the interviews (Chapter 3) where health professionals reported that conflict is uncommon and family members displaying problematic behaviours, such as aggression, during the consultation are the exception. Health professionals may find it reassuring that family involvement appears to have a mostly positive or neutral influence in initial oncology consultations.

One potential negative was the high rate of interruptions which occurred during consultations. Physicians interrupted the family member in 58% of consultations, patients interrupted their family member in 31% of consultations, family members interrupted the patient in 54% of consultations, and family members interrupted the physician in 42% of consultations. Generalised estimating equations revealed a significant relationship between physicians interrupting family members and family members interrupting the patient. Perhaps it is that physicians are more likely to interrupt family members who try to dominate the consultation. Interestingly, there was no significant relationship between physician and family member interruptions of each other. A significant relationship was also found between physicians interrupting family members and family members who corrected or disagreed with the patient. These results indicate that perhaps some physicians feel they should protect the patient’s rights to contribute when they perceive that the family member is dominating the consultation. This is reflective of the findings from Chapter 3, where physicians viewed the patient as the priority within the encounter. Analyses also revealed that more experienced physicians were more likely to interrupt the family member. Whilst it is unclear why more experienced physicians were more likely to interrupt the family member more, one possible explanation is that more experienced physicians feel they need to more actively protect the patient’s authority and rights within the consultation. Future research to understand the impact of physician experience on family involvement is warranted.

Perhaps the high rate of interruptions of, and by, family members might also indicate that family members are not being provided adequate opportunities to make contributions. Karnieli-Miller, Werner, Neufeld-Kroszynski, and Eidelman (2012) found, during triadic memory-clinic consultations, that when family members were explicitly assured that they would be given time for their own contributions or questions in the consultation, they were less likely to interrupt and this
resulted in smoother communication. By asking family members if they would like to comment or ask questions throughout the consultation, physicians may have the opportunity to improve the flow of triadic consultations.

Conversely, a small proportion of physicians engaged in exclusive conversations with family members during the decision-making process, potentially excluding the patient. This may indicate that some physicians and family members are engaging in a ‘coalition’ or ‘alliance’ within the triad. Analyses revealed a significant relationship between the items ‘physician engagement in exclusive conversation with the family member’ and ‘family member interrupts patient’. It is unclear why physicians are engaging in exclusive conversations with family members who interrupt the patient; however, physicians may need to be cognizant of their potential formation of coalitions with family members, particularly if they are at the cost of patient involvement.

Overall, there were a limited amount of negative interactions in the consultations; however there were also limited positive interactions, particularly initiated by the physician. Only 18% of physicians engaged in social interaction with the family member, and even less showed appreciation of the family member. This indicates that physicians may not be consistently building rapport with family members. Mitnick et al. (2010) recommended that physicians routinely validate the family member’s role, and explained that “acknowledgement of the caregiver contribution is vital to ongoing trust and continued collaboration providing patient care” (p. 257). Future clinician strategies/guidelines should specifically highlight how the physician can engage positively with the family member, whilst ensuring that the patient also feels included.

In addition, a minority of physicians asked the family member a question or invited family member questions. A consultation video-tape analysis by K. Boehmer et al. (2014), published after development and application of the TRIO coding frame, found similar results. K. Boehmer et al. (2014) coded 37 family medicine or endocrinology consultations were family members accompanied a patient and found that physicians did not frequently facilitate family participation in the consultation and most occurrences of family involvement were self-initiated rather than physician-initiated. It appears that our suggestion that physicians ‘encourage, welcome, and involve family members in consultations’ (Chapter 2) is not regularly applied in clinical practice. There are multiple potential reasons behind the lack of physician-initiated interaction. Given that many health professionals perceive that triadic encounters result in increased consultation time and complexity (Chapter 3), perhaps the importance of rapport building with family is lost in the busy clinical setting. Additionally, patient centredness is the current legal and ethical focus of Western
biomedicine (e.g. Gilbar, 2011; Kerridge et al., 2013) and many health professionals appear to struggle balancing patient autonomy with family involvement (Chapter 3; Gilbar, 2011). Perhaps some physicians are uncertain about what level of family engagement is appropriate given the current ethical and legal guidelines which emphasise patient autonomy, privacy, and confidentiality (Gilbar, 2011; Kerridge et al., 2013).

However, the results of the current study indicate that while physicians did not regularly engage family members, they were responsive to family member questions or comments. Indeed, no physicians ignored the family member's questions. Research has consistently shown that physicians hold positive attitudes towards family members (e.g. Beisecker & Moore, 1994; Speice et al., 2000) and physicians report that they welcome and encourage family input (Chapter 3). However, these self-reported behaviours do not align with the current results and perhaps some physicians are unaware that they do not actively engage with family members. This notion was highlighted by some nurses in Chapter 3, who believed that some oncologists were not aware of the potentially negative blocking or coalition building behaviours they engaged in during triadic consultations. One recommendation proposed by Speice et al. (2000) was that healthcare professionals assess their own attitudes and behaviours towards family members through a self-assessment questionnaire. This strategy could assist in overcoming a possible lack of self-awareness amongst some physicians.

The results of our study indicate that some family members may be anxious about being involved in the consultation. Fifteen percent of family members either apologised for speaking or asked permission to speak during the consultation. Morris and Thomas (2001) described a similar issue in their interview study. Some family members expressed reticence in entering the privileged physician-patient relationship, and some reported feelings of superfluousness or role uncertainty. These findings align with those in Chapter 4, where family members reported reverence towards the physician, a feeling of intruding on the physician-patient relationship, and a desire not to use up the physician’s time. These results further evidence the importance of health professionals building rapport, clarifying the family member’s role, and explicitly inviting family involvement.

As highlighted in previous interview studies (e.g. Chapter 3; Speice et al., 2000), family members are an important part of the multidisciplinary team and have the potential to provide valuable informational assistance to the patient and physician. In the current study, some family members recalled information about the patient’s medical history, confirmed information provided by the patient, and asked questions. These behaviours have been reported as useful by health
professionals in past studies (Beisecker & Moore, 1994; Chapter 3; Speice et al., 2000). Analyses revealed that family were more likely to recall information when the patient had advanced disease. These results align with the experiences of health professionals in the interview study (Chapter 3), who stated that family members are more involved when the patient is in greater need. The results of the current study and previous studies indicate that family members provide useful informational support to the patient.

In addition to the provision of informational support, health professionals in previous studies have indicated that family members provide important emotional support in the consultation (Beisecker & Moore, 1994; Speice et al., 2000). It is likely that much of this emotional support is non-verbal and therefore not captured in the consultation transcripts. However, the results of the current study highlight that a small proportion of family members engaged in verbal acts of support such as making optimistic or positive statements, or showing partnership with the patient. It is unclear whether the patients in the current study desired or appreciated these behaviours, however results from interview studies (Chapter 3; Chapter 4) indicate that provision of emotional support was greatly appreciated by patients and health professionals.

Many family member behaviours are considered helpful by physicians and patients (Chapter 3; Chapter 4); however consultation analyses reveal that some family members do not readily engage in helpful behaviours. Perhaps, prior to the agreement of family member roles, physicians could highlight the family member roles which are most commonly perceived as helpful. As with many of these strategies, it is important that physicians tailor this discussion to the individual patient and family member, rather than having a standard and prescriptive ‘patter’. These findings align with the strategy proposed based on the findings of our systematic review in Chapter 2: “Highlight helpful family behaviours. Family members may be unaware of, or confused about, what role they should assume. Health professionals could explain the different types of appropriate support they could offer (e.g. emotional, informational, logistical)”. Another strategy, proposed by Wolff et al. (2014), is that patients and family members complete a pre-consultation checklist designed to elicit and align patient and family member concerns to discuss with the physician and to also stimulate discussion about the family member’s role. Some of the items included “I would like my companion to i) Listen to what the doctor says, ii) Take notes, iii) Remind me to ask my questions…” In their pilot trial of the pre-consultation checklist among geriatric patients, Wolff et al. (2014) found that family members in the intervention group were more likely to be rated as helpful by the physician and patient compared to control group family members. Perhaps in addition to physician clarification of
roles during the consultation, patients and family members could complete a brief pre-consultation checklist highlighting helpful family member behaviours and stimulating discussion about role preferences. Further evaluation of the feasibility and effectiveness of these strategies in the oncology setting is needed.

5.4.1 Limitations

There are several limitations evident in the current study. The consultations included in this study were limited to initial medical or radiation oncology consultations, and therefore do not represent the involvement of family members throughout the entire cancer trajectory. Additionally, the physicians who agreed to participate in the two previous studies may have a greater interest in medical communication or informed decision-making. Thus, the findings may be biased to reflect the views of more interested and inclusive health professionals. Due to practical restrictions, only transcripts of audio-taped consultations were used, therefore para-verbal and non-verbal cues were unable to be utilised during coding. In addition, because of the use of consultation transcripts from previous studies no outcome data was available to examine the impact of family involvement on outcomes such as satisfaction or decisional regret.

Despite these limitations, the current study has a number of strengths. A new triadic coding system, with good reliability was developed to capture the actual behaviours of physicians, patients, and family members across consultation communication and decision-making. Additionally, this is the first study to code the family-relevant behaviours of all three parties within the triad. Although several studies have examined stakeholder attitudes towards triadic consultations and proposed consultation strategies, to date no studies have highlighted the actual behaviours of physicians, patients, and family members in triadic cancer consultations.

5.4.2 Clinical implications

Family involvement in cancer consultations is variable between consultations and dynamic within consultations. Remaining open to the different and changing styles of family engagement may be an important step for physicians to facilitate inclusive and productive triadic consultations. The results of our study revealed that physicians rarely engage in social interaction with family members or verbally show appreciation of their contributions. Engaging in positive behaviours with family members such as rapport building and validation of their important role could help clinicians to mitigate family member reticence about contributing to the consultation, and build a more effective physician-patient-family team.
This study found that no physicians engaged in role clarification with patients and family members, despite the variability of family involvement levels. By routinely clarifying patient (and potentially family member) preferences regarding the nature and amount of family involvement in consultations, physicians may reduce the potential for role confusion, role mismatch, and interruptions. Additionally, previous literature has found that family are perceived as an integral part of the extended multidisciplinary team and can engage in an array of helpful behaviours; however the results of this study indicate that some family members do not engage in these behaviours. By highlighting helpful family member roles when discussing role expectations and preferences, physicians may be able to enhance the benefits of family involvement in consultations and ultimately patients’ care. The feasibility and efficacy of a patient and family member pre-consultation role clarification checklist needs to be tested within the oncology setting.

Based on the high number of interruptions found in our study, it may be beneficial for physicians to reassure family members that they will have the chance to ask questions and make comments throughout the consultation. Results also indicate that physicians rarely ask family members a question or provide them with the opportunity to ask questions. Future strategies should aim to address these gaps in communication.

The current study indicates that the strategies developed by Mitnick et al. (2010), Speice et al. (2000) and from the systematic review (Chapter 2) and interviews in Chapters 3 and 4 are not regularly reflected in oncology clinical practice. Following development of a comprehensive strategies document, evaluation of the acceptability and effectiveness of triadic consultation strategies is needed.

The results of the current study confirm and clarify the qualitative findings from Chapters 3 and 4 that family involvement in the treatment decision-making process is variable between consultations and dynamic within consultations across the decision-making phases. Finally, the current study found a number of styles of triadic decision-making ranging from passive to dominant. The insight obtained through these consultation analyses will be utilised in the development of a theoretical framework depicting family involvement in decision-making. This framework is proposed in the following chapter.
Chapter 6:
A conceptual description of treatment decision-making capturing family involvement
6.1 Introduction

This chapter aims to utilise the insight gained from previous chapters to develop a draft conceptual framework depicting family involvement in decision-making.

The need for a framework is clear; despite the frequent involvement of family members in cancer consultations and decision-making, there is very limited conceptual description of family in the current decision-making literature. Whilst more recent ethical and conceptual publications have started to capture the input of others (including family) in the communication and decision-making process (e.g. Elwyn et al., 2014; Entwistle et al., 2010; Epstein & Street, 2011; Légaré et al., 2011), the majority of theoretical conceptualisations of decision-making (particularly shared decision-making) published to date have focused on the physician-patient dyad (see Makoul & Clayman, 2006).

This stands in contrast to empirical research which has found that a majority (49-84%) of cancer patients and family members (54-59%) report both preferring and experiencing family involvement in decision-making (Davison et al., 2002; Gilbar & Gilbar, 2009; Gonçalves et al., 2005; Pardon et al., 2010; Schäfer et al., 2006). Analyses of audio/video-taped medical consultations highlight that family regularly attend consultations, are often actively involved in communication (e.g. Chapter 5; Street & Gordon, 2008), and are often involved in the medical decision-making process (e.g. Clayman et al., 2005; Chapter 5; Mazer et al., 2014). Consultation analyses also highlight that family involvement in decision-making is variable and dynamic. Triadic (physician-patient-family) decision-making dynamics can vary within the same consultation over different stages of the decision, and can vary between triads, indicating that a variety of triadic decision-making dynamics may occur (Chapter 5).

Qualitative studies of triadic consultation participants' attitudes and experiences highlight similar variability. Chapters 3 and 4 revealed that family involvement in decision-making appears to vary on a spectrum from passive through to dominant involvement. Some participants noted that at times decision-making was controlled by one person, collaborative between two, or collaborative between three individuals. Hilton (1994) and Öhlén et al. (2006) similarly reported that family involvement in decision-making ranged from being passive to very active. Patients and family members in interviews reported in Chapter 4 discussed a variety of preferences for the extent of family involvement in decision-making, some indicating that they wanted the physician to lead decision-making, whilst others wanted their family to support or facilitate the patient's decision-
making, or for the family to share or lead decision-making. Several health professionals in Chapter 3 noted that they did not have a preferred style of family involvement, instead following the patient’s preferences for family involvement.

Stages of decision-making in triads

Whilst medical decision-making is commonly conceptualised as comprising three stages (information exchange, deliberation, decision) (e.g. Charles et al., 1997, 1999), qualitative analyses of participants’ experiences revealed that family members may be involved in up to five stages of decision-making (pre consultation information gathering, information exchange, deliberation, decision, post-decision deliberation), which may exist inside and/or outside of the consultation (Chapter 3; Chapter 4). Similar to the results obtained through consultation analyses (Chapter 5), participants in Chapters 3 and 4 indicated that family involvement levels may shift across the different stages of decision-making. Hubbard et al. (2010) found similar results, that family are often involved in the information exchange and deliberation phases of decision-making, inside and outside of the consultation.

Factors associated with family roles in decision-making

Participants in Chapters 3 and 4 indicated that the extent of family involvement in decision-making might be influenced by a complex array of characteristics (patient, family member, cultural, relationship, and decision). A number of studies have also pointed to the fact that some patient or family characteristics may impact on the extent of family involvement in decision-making (e.g. Beisecker & Moore, 1994; Hilton, 1994; Hobbs et al., 2015; Pardon et al., 2010; Sekimoto et al., 2004), while others have found that some patient characteristics do not impact on the extent of family involvement (Chapter 5; Street & Gordon, 2008). It appears that while there may be no single characteristic which predicts the level of family involvement, a complex array of factors may contribute towards the extent of family involvement.

Conceptual frameworks of triadic decision-making

Despite the common involvement of family in decision-making, there is very limited conceptual description of family in the current decision-making literature. Of the relevant empirical or theoretical papers which have proposed conceptual explanations of family involvement in decision-making, five have focused on describing typologies of family involvement, four have detailed the coalitions which can form in the triad, and two have proposed process models to explain the factors which may affect triadic interactions and the consequences of these interactions (for a detailed
examination of each conceptual explanation see Section 1.4.2 in Chapter 1). Whilst each conceptual explanation provides valuable insight into the nature of family involvement in decision-making, to date frameworks have not adequately acknowledged or built upon previous empirical or theoretical work and have not captured the complex interactions and dynamics of the three potential participants in the decision-making process.

*Ideal* or *preferred* triadic decision-making styles

Whilst frameworks have attempted to describe various aspects of triadic decision-making dynamics, to date there has been little prescription of *ideal* or *preferred* levels of family involvement in decision-making. Krieger (2014) noted that aligned patient and family decision-making preferences (e.g. when both the patient and family prefer the patient to make decisions independently, or when both patient and family prefer to make decisions collaboratively) may be preferable over misaligned decision-making preferences (e.g. when the patient wants to make decisions independently and the family want to collaborate). However limited other conceptual frameworks have proposed a preferred involvement level of family.

Various ethical discussion papers have, however, proposed that there are preferred involvement levels of family in decision-making. Some ethicists advocate individual patient autonomy with family providing support (e.g. Blustein, 1993; Mitnick et al., 2010), while others advocate that family deserve to be active and respected participants in the decision-making process (Hardwig, 1990; Ho, 2008; Levine and Zuckerman, 2000; Lindeman-Nelson, 1992). Whilst inclusion of family is gaining momentum in recent ethical publications (Gilbar, 2011) and in some legal and professional guidelines such as the Carers Recognition Act (Commonwealth Government of Australia, 2010), prominent Australian legal and professional frameworks continue to uphold the primacy of individual patient autonomy and authority with regards to patient privacy (New South Wales Government, 2002), informed consent, and engagement in decision-making (Australian Commission on Safety and Quality in Healthcare, 2008). Given the conflicting ethical and legal perspectives, and the fact that patient, family, and physician preferences for the style of family involvement vary widely, at this stage it appears that there may be no one ideal or preferred model of family involvement in decision-making.
**Aims**

In light of the previous empirical and conceptual work, this chapter aimed to propose a preliminary conceptual framework of decision-making capturing the dynamic and varied involvement of family members of cognitively competent adult patients.

Specifically, this framework aimed to depict seven of the main findings derived from this thesis and the wider evidence base regarding family involvement in decision-making. These findings included:

i) Decision-making stages may exist beyond the consultation

ii) There are a variety of triadic decision-making styles

iii) Triadic decision-making styles may rest on a spectrum

iv) Decision-making dynamics may be variable between triads

v) Decision-making dynamics may be variable within a triad over the illness experience

vi) Decision-making dynamics may be variable within the one decision

**Purpose of the framework**

This framework was designed to help explain the complex environment of family involvement in decision-making. It may prove to be useful as a guide for future research to describe the numerous styles of medical decision-making which may occur when family are present. It may act as the basis for further ethical and clinical discussions about appropriate/inappropriate styles of decision-making when family are involved in certain situations. It may also be a useful tool to educate health professionals about the myriad decision-making dynamics which are possible when family are involved. This framework was developed based on cancer treatment decision-making.

**6.2 Methods**

**6.2.1 Conceptual development**

Framework development was informed by a review of relevant empirical, conceptual, ethical, and legal perspectives on family involvement in decision-making. An initial conceptual framework was developed and drafts were iteratively reviewed by the candidate and two supervisors. Empirical examples of triadic decision-making dynamics derived from interviews with health professionals, patients, and family members (Chapter 3; Chapter 4) were applied to the framework to test its effectiveness in conveying triadic decision-making styles and behaviours.

**6.3 Results**
A conceptual framework of family involvement in decision-making is proposed. First the revised stages of decision-making underpinning the framework are explained and then seven ‘pure’ styles of decision-making are proposed. Whilst these ‘pure’ forms of decision-making styles help to map out the scope of family involvement and influence over the decision, they are not representative of what typically occurs. Therefore, the reality of triadic decision-making will then be discussed, where ‘intermediate’ styles will be highlighted. The varying nature of family involvement between and within triads will be detailed. Finally, some of the factors which are thought to influence the extent of family involvement will be highlighted.

6.3.1 Decision-making stages may exist beyond the consultation

The decision-making process, accommodating family involvement, could be subdivided into five stages (information gathering; information exchange; deliberation; decision; decisional monitoring). These stages, whilst informed by the Charles et al. (1997) and Charles, Gafni et al. (1999) framework, are predominantly derived from Chapters 3, 4, and 5 of this thesis. Figure 6.1 depicts that each of these stages may exist before, during, and after medical consultations. The dotted line between each of the stages represents the fluid, non-linear, and iterative dynamic of decision-making (rather than a linear progression through static stages), as in reality decision-making is a ‘messy and uncertain’ process (Elwyn et al., 2014). An overview of what each decision-making stage consists of is presented below:

- **Information gathering:** In this stage, individual/s (physician/patient/family member) recognise that there is more than one medical option available and may gather information about the possible options. A variety of sources may be used to gather information such as health professionals, family/friends, internet, media.
- **Information exchange:** Individual/s may share and discuss (medical, evidential and/or psychosocial) information relevant to the decision.
- **Deliberation:** Individual/s may form, express, and discuss treatment preferences.
- **Decision:** Individual/s choose an option to implement.
- **Post decision deliberation:** Individual/s reflect upon and evaluate the decision made. If the decision is reversible, they may change their minds. If it is irreversible, they may experience decisional regret.

Family members may be involved in any or all of these stages, and each of these stages may exist outside the consultation environment with the patient and/or family.
6.3.2 There are a variety of triadic decision-making styles

The most prominent models of decision-making, highlighted by Charles et al. (1997) and Charles, Gafni et al. (1999), include the paternalistic model (physician dominated), the informed model (patient dominated), and shared (physician-patient) decision-making model. In addition to these models of decision-making, Chapters 3, 4, and 5 of this thesis highlight that family may be involved in decision-making and their involvement may rest on a spectrum from passive to dominant.

Despite this being a ‘triadic’ framework, it is clear that decisions may in fact still be dominated by one individual, shared by two individuals, or include all three individuals (patient, physician, and family). Based on the previous chapters, empirical (e.g. Boehmer & Clark, 2001; Gilbar, 2011; Hilton, 1994; Öhlén et al., 2006) and theoretical work (e.g. Charles et al., 1997; Charles, Gafni et al., 1999; Degner & Beaton, 1987; Krieger, 2014; Rosow, 1981; Shapiro, 2001), seven ‘pure’ styles of decision-making when family are involved are proposed. These styles will be described in their ‘purest’ or ‘most extreme’ forms to highlight the total spectrum of styles possible. Miller and Brewer (2003) (p147) highlighted that “researchers construct concepts or ideas in their pure and essential form, mostly with the intent of then comparing them against the real world”. It is acknowledged that
in reality, these pure forms are unlikely to occur because the style of decision-making may shift throughout the decision-making stages and there are myriad intermediate decision-making stages, however the pure styles provide a basis for discussions about real world styles. They include:

- **Physician-led**: The physician has control over the entire decision-making process. The patient and family have no (or very limited) involvement in the decision.
- **Patient-led**: The patient has control over the entire decision-making process. The physician and family have no (or very limited) involvement in the decision.
- **Family-led**: The family member has control over the entire decision-making process. The physician and patient have no (or very limited) involvement in the decision.
- **Physician-patient shared**: The decision-making process is shared equally by the physician and patient. The family has no (or limited) involvement in the decision.
- **Physician-family shared**: The decision-making process is shared equally by the physician and family. The patient has no (or limited) involvement in the decision.
- **Patient-family shared**: The decision-making process is shared equally by the patient and family. The physician has no (or limited) involvement in the decision.
- **Shared triadic (physician-patient-family)**: The decision-making process is shared equally by all three participants (physician-patient-family) who have equal involvement in the decision.

It is proposed that these seven approaches can sit within a triangle (See Figure 6.2), where:

i) each of the points represents the dominance of an individual
ii) the midpoint between two points represents two individuals equally sharing a decision
iii) the centre of the triangle represents the point at which all parties share a decision (i.e. shared triadic decision-making)
These pure styles represent extremes of triadic interactions. It is acknowledged that in reality decision-making includes many intermediate styles of decision-making, found at any location within the triangle space. These intermediate locations will be discussed in the next section.

6.3.3 Decision-making styles rest on a spectrum

In reality, it is unlikely that these pure styles regularly occur. Rather, real decision-making involvement is likely to rest somewhere within the triangle as an 'intermediate' style. It is conceptualised that, in reality, decision-making when family is present rests on a triadic spectrum which can shift from dominant influence of one individual (triangle point) to complete triadic sharing of the decision (triangle centre) (See Figure 6.3). The triadic decision-making dynamics may rest in any position within this triangle.
6.3.4 Decision-making is variable between triads

As highlighted in Chapters 3, 4, and 5, decision-making dynamics may vary widely between different triads. In some cases the family member was very passive and the patient and physician shared the decision; in other cases the family member assumed an active role in the decision-making while the patient had limited involvement. Case examples are provided which highlight three different triadic dynamics (see Figure 6.4 and Box 6.1).
Figure 6.4: Triadic spectrum with case examples of decision-making between triads
Box 6.1: Case examples of triadic decision-making between triads

1. is plotted at a point which represents sharing of the decision between the patient and physician, and a small amount of family involvement. An example of this is where a patient who has advanced colorectal cancer is facing a decision of whether to receive chemotherapy or no treatment. The patient and his oncologist discuss medical information relevant to the decision and information about the patient’s lifestyle, preferences, and goals. The patient’s adult daughter states that she wants her dad to live as long as possible and prefers for treatment to be aggressive, but that she will support her father’s decision no matter what. The patient and physician have most influence over the decision, but the family member has a small amount of input into the decision-making process.

2. is plotted at a point which represents that the patient has greatest influence over the decision, followed by the family member then the physician. An example of this is where a young adult woman diagnosed with breast cancer is facing the decision of whether to delay treatment to undergo IVF to increase the chances of having a family in the future. Whilst the patient retains most of the decision-making control, she discusses it at length with her husband outside of the consultation who states that he wants to have children and would be very willing to undergo IVF with his wife. He researches the procedures and provides his wife with information, but also states it is ultimately her body and her decision. Whilst the couple discusses the decision with a physician, the patient and her husband do most of the information gathering and deliberating at home. Ultimately it is the patient who makes the decision to undergo IVF prior to chemotherapy, with some family involvement and only a small amount of physician involvement.

3. is plotted at a point which represents that the family member has greatest involvement in the decision-making, followed by the physician, and then the patient. An example of this is a patient who does not speak English who is diagnosed with prostate cancer. His son, who was educated in Australia and is fluent in English, speaks with the physician in all consultations and translates a small amount of the information for the patient. Whilst the patient wants to receive only alternative medicines, the family member does not convey this to the physician, and the physician and family member exchange information about the recommended treatments and research that the family member has gathered outside the consultation. The family member tells the patient that he must receive the recommended treatments, and the patient consents.

6.3.5 Decision-making is variable within a triad over the illness experience

In addition to between triad variability, this thesis has shown that decision-making is dynamic and moveable within the one triad over time. For example, several patients in Chapter 4 reported that their family’s involvement in decision-making evolved throughout the illness trajectory, where sometimes family were required to take a more active role in the decision-making process, and at other times they assumed a more passive role. To highlight the dynamics of decision-making styles within the one triad, a case example is provided (see Figure 6.5 and Box 6.2) where i, ii, iii, iv, and v represent different decision points within one patient’s illness trajectory.
Physician led

Physician-patient shared

Shared triadic

Patient-family shared

Family led

Figure 6.5: Triadic spectrum with case examples of decision-making within one triad over time

Box 6.2: Case example of influence within one triad over time

(i) A patient is diagnosed with breast cancer and is highly distressed when making an initial decision about surgery. The patient feels too distressed to be involved in decisions, so requests that her husband and the physician share the decision with the patient providing only limited input. (ii) After surgery, the patient gains more knowledge and confidence and begins to assume a more active role in the decision-making process about whether to receive chemotherapy. The patient, her husband, and the physician share this decision. (iii) After chemotherapy is finished, the patient faces the choice of whether to receive hormone therapy. She has strong feelings about this treatment and chooses to receive the treatment with limited input from her husband and physician. (iv) At a routine scan, cancer is found to have reoccurred and metastasised to the patient’s bones and lungs. Both the patient and her husband state that they are exhausted and want the physician to make the decisions about what treatment to receive. (v) The treatment is not successfully controlling the cancer and is having a number of unpleasant side effects, and the patient’s quality of life is deteriorating. Before consulting with the physician, the patient and her husband make the decision to cease treatment.
6.3.6 Decision-making is variable within the one decision

Up to this point, the ‘decision’ has been plotted at one point within the triangle. A single point has represented the overall influence over a decision or aggregate of all of the decision-making stages. However, as found in Chapters 3, 4, and 5, family involvement levels may shift between the different stages of decision-making. Styles used in the different stages of decision-making may rest at different areas within this triangle (See Figure 6.6). In Figure 6, the letters A, B, C, D and E are plotted at approximate areas on the triadic spectrum to represent different stages of decision-making within the one decision. A case example is provided in Box 6.3 to help explain how different styles of decision-making can occur at different stages of decision-making.

![Figure 6.6: Triadic spectrum with case examples of decision-making stages within the one decision](image)

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Box 6.3: Case examples of triadic influence across different stages of decision-making

A patient, has been diagnosed with prostate cancer. His wife, who is well educated and very computer literate researches information about possible treatments on the internet, and is active during the consultation when discussing possible treatments with the physician. However, the patient is adamant that he make the decision and has clear wishes and preferences. After the patient has made the decision (taking into account the information provided by his wife and physician), he and his wife continue to reflect on the decision and other possible treatments. Figure 6.6 depicts this case example where different stages of decision-making are plotted at approximate areas on the triangle:

A. represents information gathering where the family member actively researches and gathers information prior to the consultation, and the health professional also separately gathers relevant medical information prior to the consultation
B. represents information exchange where all three participants actively discuss information within the consultation (family member is slightly more dominant than patient) and then the patient and family discuss the information outside the consultation
C. represents deliberation where the patient expresses their wishes, the physician assumes a passive role, and the family member states that at the end of the day, it is up to the patient
D. represents decision where the patient makes the decision after considering the recommendations of the physician and the information provided by the family member
E. represents post decision deliberation where the patient and family member continue to discuss the decision after the consultation and reflect on how they each feel about the decision
6.4 Discussion

6.4.1 Practical applications of the framework

This conceptual framework may be useful in several ways. Firstly, the framework provides a description of the scope of triadic decision-making styles, and it may be a useful guide for further research in the area. The triangle could be conceptualised as a map to help understand the landscape of family involvement and influence. Utilising this map as a graphical and conceptual basis for further discussion and analysis of triads may be particularly fruitful. For example, it may form the basis of ethical and legal discussions debating whether some areas of the triangle are preferable in certain contexts (e.g. for patients with early stage dementia, for adolescent patients, for fertility treatment decision-making).

Secondly, as it provides a description of the various styles and stages of triadic decision-making, this framework could be used to educate physicians about the diverse and varying scope of family involvement and influence.

Thirdly, this framework highlights that in reality, there are many intermediate styles that lie between the seven ‘pure’ styles. The identification of intermediate styles which exist in between the pure styles increases options for physicians when they are discussing involvement with patients (and potentially family members). The point that decision-making styles may vary across the five stages of decision-making reinforces the importance of flexibility so that physicians are able to recognise and respond to the many varying and changing preferred styles of decision-making patients and family members may have.

The identification of influencing factors highlights that one factor (e.g. patient age or culture) is unlikely to solely influence the extent of family involvement; rather a complex web of factors are likely to influence decision-making styles.

Lastly, with further research and validation, a simplified form of the triangle may be useful in obtaining patient and/or family member preferences for triadic decision-making dynamics.

6.4.2 Conclusion

This chapter proposes an expanded conceptualisation of medical decision-making styles, accommodating the involvement of family members. This framework may help to guide future research in this area, and also to educate health professionals about the array of triadic decision-
making dynamics that are possible, inside and outside of the consultation. However, the framework in its current form has a number of limitations. Whilst it has started to depict some of the characteristics of triadic interactions, it does not yet adequately capture the complexity of family involvement in decisions. Whilst the above framework is a useful and important start, it is important to note that family involvement in decision-making is more complex and multifaceted than a single point of 'influence' on a triangle, and a wider view of who the family is, how they are involved, and how they influence decisions, will need to be adopted. The current framework does not capture the complex relationship dynamics between the parties in the triad (e.g. coalition formation, prior relationship dynamics), the many roles that family may assume (e.g. supportive, facilitative, persuasive), or the challenges inherent in triadic decision-making. The candidate will attempt to accommodate these insights in future iterations of the framework. Future iterations will also attempt to better account for Entwistle and Watt’s (2006) expanded conceptualisation of decision-making and involvement and Epstein and Street’s (2011) notion of the social embeddedness of decision-making.

This conceptual framework is an initial proposal in what is likely to be an ongoing and complex theoretical discussion. It will form the basis of iterative discussions with an expert advisory group comprising experts in medical decision-making and conceptual framework development, ethicists, clinicians, a medical law advisor and consumer representatives; each of whom will provide ongoing feedback and input throughout the framework development and review process. This work, however, is beyond the scope of the current thesis, and forms part of the candidate’s postdoctoral position.

In addition to informing development of this initial conceptual framework, Chapters 2, 3, 4, and 5 of this thesis have informed development of initial practical clinical strategies to assist health professionals to manage and enhance family involvement in cancer consultations. These strategies will be highlighted in the next chapter.
Chapter 7:
Draft strategies to manage and enhance family involvement in cancer consultations and decisions
7.1 Introduction

Many interventions have been designed to facilitate physician-patient communication (e.g. decision aids, question prompt lists, and communication skills training programs) (Laidsaar-Powell, 2012). Many of these interventions are increasingly recognising the important role and input of family members and accordingly may include sections relevant to family (e.g. Feenstra, Lawson, Harrison, Boland, & Stacey, 2015; Merckaert et al., 2013; Walczak et al., 2014). However, few targeted interventions, specifically designed to manage and enhance the family's involvement in communication and decision-making, exist. This is concerning given the results reported throughout this thesis. In Chapter 2, several studies reported challenges faced by physicians (Barone et al., 1999; Speice et al., 2000), patients (Kimberlin et al., 2004; Speice et al., 2000), and family members (Morris & Thomas, 2001; Sinfield et al., 2008) when family are involved in consultations. In the interviews in Chapter 3, health professionals reported facing many challenges when family are involved in consultations and decisions, such as concerns about patient privacy, negotiating conflicting patient-family treatment wishes, and managing dominant family members. In the interviews in Chapter 4, patients reported challenges such as feeling unable to speak freely about sensitive topics (e.g. sexuality, prognosis, coping) in front of their family member, having misaligned patient-family role or treatment preferences, or experiencing patient-family conflict. In addition, some patients and family members also reported negative physician behaviours including ignoring the family member, not adequately responding to family’s questions, or being condescending towards family. In Chapter 5, analyses of actual cancer consultations revealed that physicians rarely engaged in rapport building behaviours with family, did not elicit role preferences or negotiate family involvement levels, rarely asked family members questions, and regularly interrupted them. These findings indicate that physician communication with family members may be suboptimal.

In light of this evidence, it appears that tools to manage challenging situations which arise in triadic consultations and to enhance positive family involvement would be highly valued by patients, family members, and health professionals, and might lead to improved outcomes. Development of strategies to support positive and effective interactions during triadic consultations is particularly important given the high levels of distress experienced by family members during the cancer process (Sklentarova et al., 2015) and close relationship between family and patient wellbeing (Fang, Manne, & Pape, 2001). Therefore, facilitating and supporting positive and effective
communication in triadic consultations is not only important for the family member, but may also be beneficial for the patient.

A limited number of family-focused strategies have been published in the literature to date, targeting a number of different medical settings. Speice et al. (2000) proposed strategies for cancer consultations, including a physician self-assessment questionnaire to enable reflection upon attitudes and behaviours towards family members, and a number of questions for health professionals to ask patients and family members to ascertain role preferences and aid negotiation of roles. Lang et al. (2002) proposed a number of ‘core’ family interviewing skills to be used in routine primary care consultations when the family member communicates effectively and minimal differences exist between participants which include greeting and building rapport, identifying agendas, and respecting patient privacy and confidentiality. Lang et al. (2002) also proposed advanced skills for situations where the family exhibits ineffective communication, such as managing conflict. Burkhalter and Bromberg (2003) proposed a number of strategies for cancer consultations based on existing literature. Burkhalter and Bromberg (2003) proposed that a single physician-led family conference lasting 45-60 minutes can be a useful meeting to identify and discuss a number of issues. However, given the time constraints on current clinical practice, Burkhalter and Bromberg (2003) suggested that many of the principles of family conferences could be applied to general cancer consultations, including listening to family members’ concerns, observing family interactions, educating family members, and referring family members to relevant support services.

Mitnick et al.’s (2010) more recent ethical guidance paper, not targeting any specific medical setting, focused primarily on protecting patient autonomy (e.g. "Clinical encounters should be patient-centered, allowing for maximum appropriate patient autonomy and participation in decision-making") (p.256), advocated for clarification of patient preferences for the nature of family involvement, and also highlighted the importance of acknowledging respecting, and including family members in consultations. More recently, Baile et al. (2012) proposed strategies for building a therapeutic alliance with the family caregivers of cancer patients, signalled by the acronym PERKS: Preferences (determine patient preferences for caregiver involvement); Engagement (engage the caregiver, learn their names); Readiness for role (establish caregiver readiness for their role, provide clear information about caregiving demands); Knowledge and information (provide verbal information to the caregiver, and consider additional forms of information); and Support strategies (ensure that caregivers needs are met). Baile et al. (2012) proposed that building a
therapeutic alliance with the patient and family may result in a number of positive outcomes such as reduction in distress, increased compliance, improved satisfaction, enhanced psychological adjustment and improved decision-making. However each of these strategies remains untested.

The above strategies contain a number of limitations. Firstly, the legal and professional context in which existing strategies have been developed is unclear. This is problematic as family involvement is often limited by laws protecting patient autonomy. Next, most strategies do not adequately refer to the existing evidence base. For example Wolff and Roter (2010) published a letter to the editor regarding Mitnick et al.’s (2010) strategies highlighting the omission of many studies of central relevance, and that the recommendations made would be strengthened if they acknowledged the existing evidence base. Additionally, a number of the above strategies provide more general guidance about inclusion of family members, without including practical and concrete steps to improve interactions or to overcome common challenges arising in clinical practice.

Finally, it appears that there has not been widespread recognition or implementation of the previously published strategies. In Australia, strategies that have been more widely disseminated appear to be very general in nature, advocating acknowledgement and inclusion of family members, without clear guidance on how to do so. For example, the NSW Ministry of Health has developed the eCARERS training module, with the purpose of assisting NSW Health staff to identify, understand, and acknowledge carers. However, despite being an important step in the acknowledgement and support of family members, this module does not include strategies for health professionals to overcome specific challenges or facilitate positive family involvement, nor does it refer to the existing evidence base or any of the previously published strategies. Based on the above, there appears to be a need for current, specific, practical and evidence-based strategies to guide clinicians when interacting with family members in cancer consultations with competent adult patients. Such strategies will be proposed in the current chapter.

The strategies document proposed in the current chapter attempts to overcome many of the above limitations by clearly outlining the legal and professional context in which the strategies are proposed. Additionally, the current strategies document was developed based on a comprehensive systematic review (Chapter 2), interviews with health professionals (Chapter 3), interviews with patients and family members (Chapter 4), analyses of cancer consultation transcripts (Chapter 5), and a preliminary conceptual framework of family involvement in decision-making (Chapter 6). The strategies proposed in each of the previous chapters of this thesis have been synthesised. In addition, the current strategies document incorporates an array of previously published strategies.
and approaches (Baile et al., 2012; Burkhalter & Bromberg, 2003; Lang et al., 2002; Mitnick et al., 2010; Speice et al., 2000). See the method section for more detail.

Given the current national focus on better including and supporting family caregivers (e.g. National Carer Recognition Strategy, NSW Carers Strategy 2014-2019), development of comprehensive evidence based strategies may be a particularly useful and practical tool to help enact these system-wide calls for change.

**Aims**

This chapter aimed to utilise the findings from Chapters 2, 3, 4, 5, and 6, previously published strategies, and legal and professional publications to develop a draft set of practical strategies for oncology health professionals conducting cancer consultations where a family member is present. These strategies aimed to i) facilitate positive and effective family involvement in cancer consultations and decision-making (to the level desired by the patient/family member) and ii) overcome challenges of, and barriers to, family involvement in cancer consultations and decision-making.

**7.2 Method**

**7.2.1 Development of Draft Strategies**

Development of the draft strategies was informed by a review of relevant empirical, conceptual professional and legal perspectives on family involvement in medical consultations and decision-making. Strategies proposed in previous publications and throughout this thesis (Chapters 2, 3, 4, 5, and 6) were analysed and synthesised. Initial strategies were developed and iteratively reviewed by the candidate and two experts in medical communication. This document was conceptualised as a working paper, providing the evidence and rationale behind each proposed strategy. The final strategies document will be iteratively revised on the basis of expert multidisciplinary and consumer feedback, which is beyond the scope of this thesis, and will be re-written, formatted, and professionally designed and printed to appeal to a clinician audience.

**7.2.2 Context of Strategies**

Strategies were developed based on the current Australian legal and professional context in which patient autonomy is protected and patient rights to information, privacy, and informed consent are advocated (Kerridge et al., 2013). In Australia, family members have substantially fewer rights than
cognitively competent patients; however legislation and professional guidelines have recently started to acknowledge the importance of including and supporting the family, whilst maintaining the authority of the patient, such as the Carer Recognition Act (Commonwealth Government of Australia, 2010). To comply with current Australian legislation and professional guidelines, the proposed strategies will:

- Protect the patient’s rights to privacy and confidentiality
- Maintain patient provision of informed consent
- Facilitate positive family involvement and support which does not compromise the patient’s abovementioned rights

The proposed strategies are likely to be applicable in other Western countries, such as the UK and US, which also advocate for individual patient autonomy whilst recognising the family. For example, in the UK, the NHS constitution aspires “to put patients at the heart of everything it does... NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers where appropriate, will be involved in and consulted on all decisions about their care and treatment” (National Health Service, 2013)(p. 3).

The current strategies were developed based on cancer consultations and decision-making, however many of the strategies proposed are likely to be relevant in other medical settings where the patient is cognitively competent and a family member is present. For example, similar triadic dynamics and challenges have been described in diabetes (Rosland et al., 2011; Silliman et al., 1996), renal failure (Aasen, Kvangarsnes, Wold, & Heggen, 2012; de Rosenroll et al., 2012), primary care (Gilbar, 2011), and amyotrophic lateral sclerosis (Hogden, Greenfield, Nugus, & Kiernan, 2013) settings. Additionally, the current strategies have been developed for physicians, however many of the strategies may be relevant to nurses and other allied healthcare professionals.

7.2.3 Approach of the Strategies: Balancing the Needs of the Patient and Family

The current Western legal, ethical, and professional climate advocates that the patient should remain the physician’s primary focus. However, the patient’s family (who are usually their primary caregivers at home) may desire active involvement in the consultation and decisions, and may require information and support. Health professionals may face the sometimes challenging task of balancing the patient’s priority status with the needs of the family. Often health professionals will be in a position to cater to both, as most patients prefer family involvement and appreciate when
physicians include and support their family; and most family members respect and support the patient’s autonomy. In some cases, active, or even dominant, family involvement may be appropriate if it is preferred by the patient. However, some family members may detract from the patient’s autonomy and silence the patient’s voice, and their level and type of involvement may conflict with the patient’s preferences.

The challenge, and opportunity, for health professionals is to determine where the patient and family member ‘sit’ and to tailor their communication and strategies accordingly. The proposed document provides suggestions of strategies for:

i. preparing for family involvement
ii. establishing and negotiating family involvement
iii. including and supporting the family member
iv. managing common challenges which may arise when family members are present

By being aware of the patient’s and family’s dynamics and preferences, health professionals may pick and choose the most fitting strategies from their ‘strategies toolbox’ for each situation they may be faced with.

7.3 Results

Four categories of strategies were identified, including: i) preparing for family involvement; ii) establishing and negotiating family involvement; iii) including and supporting the family member; and iv) managing challenging situations. See Box 7.1 for a summary of all strategies.
Box 7.1: Overview of proposed strategies

<table>
<thead>
<tr>
<th>Preparing for family involvement</th>
<th>Establishing and negotiating family involvement</th>
<th>Include and support family members</th>
<th>Manage challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Critically examine the consultation environment</td>
<td>7. Clarify patient and family preferences for family involvement</td>
<td>11. Connect with the family member</td>
<td>17. Be aware of family dynamics</td>
</tr>
<tr>
<td>3. Highlight that family attendance is welcome</td>
<td>8. Provide family member role education</td>
<td>12. Reassure family that they will have the opportunity to contribute</td>
<td>18. Guide dominant family members’ behaviour</td>
</tr>
<tr>
<td>4. Be open to alternative forms of family involvement</td>
<td>9. Facilitate open negotiation of family involvement</td>
<td>13. Acknowledge and affirm the family member’s important role</td>
<td>19. Communicate calmly and productively with family members displaying anger</td>
</tr>
<tr>
<td>5. Consider conducting a family meeting</td>
<td></td>
<td>14. Refer family to support services if needed</td>
<td>20. Appoint a family spokesperson</td>
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<td></td>
<td></td>
<td>15. Provide family with information or refer to appropriate sources</td>
<td>21. Encourage use of a professional interpreter</td>
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<td>22. Explore family requests for non-disclosure with empathy and flexibility</td>
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<td>23. Retain patient privacy while attempting to meet the family’s information needs</td>
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<td></td>
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<td>24. Create opportunities to speak with the patient privately</td>
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<td></td>
<td></td>
<td>25. Negotiate conflicting treatment wishes</td>
</tr>
</tbody>
</table>
7.3.1 Preparing for family involvement

This category includes strategies to be considered prior to commencement of an initial consultation with a patient and family member.

7.3.1.1 Self-assessment

Physicians may lack awareness of their own behaviours towards family members (Chapter 3). Similar findings are apparent in the dyadic evidence base, where physicians have displayed over-optimistic self-assessments of their communication (e.g. Ford, Fallowfield, & Lewis, 1994). Speice et al. (2000) recommended that physicians complete a self-assessment of their own attitudes and behaviours towards family members. Whilst there has been no systematic evaluation of Speice et al.’s (2010) self-assessment tool, other medical communication self-assessment tools are increasingly being used to encourage physicians to reflect on their clinical practice, compare their knowledge and skills to clinical guidelines, and seek feedback from peers (e.g. Hudelson, Perron, & Perneger, 2011; Silver, Campbell, Marlow, & Sargeant, 2008). Reviews by Davis et al. (2006) and Eva and Regehr (2005) on physician communication self-assessment tools suggested that such tools should be well structured, based on standard measures and guidelines, and incorporate relevant theory such as Schön’s reflection-in-action phase of the reflective learning cycle. A revised validated family involvement self-assessment tool, which acknowledges the latest research on family involvement and self-assessments, is needed.

- **Strategy 1: Complete a self-assessment of attitudes and behaviours**
  Physicians should consider completing a self-assessment of their own personal and professional perspectives of family involvement in medical consultations to identify areas of strength and opportunities for improvement.

7.3.1.2 Consultation room setup

Having a consultation room set up in a way that accommodates family members may demonstrate inclusiveness (Chapter 3; Chapter 4). The theoretical model for family meetings by Fineberg, Kawashima, and Asch (2011) highlighted that environmental factors should be considered, including i) appropriate room size in proportion to participant numbers; ii) sufficiency and configuration of seating; iii) promotion of participants’ comfort (e.g. comfortable chairs); and iv) awareness of power dynamics (e.g. health professional standing over family participants, family sitting away from the patient).
• **Strategy 2: Critically examine the consultation environment**

Critically examine the consultation room environment to ensure that patients and family members feel welcome, comfortable and included.

7.3.1.3 **Encourage family attendance**

Overall, patients prefer family attendance at consultations (Beisecker et al., 1997; Huang et al., 1999; Kimberlin et al., 2004; Repetto et al., 2009), particularly if bad news is being disclosed or important treatment decisions are being discussed (Chapter 4; Eggly et al., 2006). Some patients report not inviting their family to attend because they do not want to be a burden on their family (Chapter 4) and some family members report regret that they were not present at consultations, particularly if bad news was delivered (Chapter 4; Srirangam et al., 2003). This recommendation is depicted within a number of breaking bad news guides, such as the consensus guidelines for medical practitioners by Girgis and Sanson-Fisher (1995) which states: “Encourage a second person to be present if appropriate. Being confronted with bad news is a potentially stressful experience for people and they may recall little of what they have been told. Having a family member or friend with them may be a great support, but it is the patient’s choice” (p. 15).

Prior to the consultation, health professionals (or the reception staff making appointments) should consider highlighting to the patient that family members are welcome to attend consultations, and that family involvement can benefit both the patient and family. Encouraging family attendance (without distressing the patient) may be particularly important if bad news (such as the cancer diagnosis or recurrence) might be delivered or important treatment decisions may be discussed. For example, when arranging an appointment, a reception staff member could say “it is standard practice that we encourage all patients to bring a family member or friend when the results of tests are being discussed”. Whilst no studies have examined the effectiveness of medical reception staff’s encouragement of family attendance, Atri et al. (1997) found that educating reception staff on the importance of breast screening and then having them make patient follow up calls to encourage breast screening improved uptake.

However, patients should not feel forced to attend with family as some do not want family involvement. Ultimately, it should be the patient’s choice, and their wishes should be respected.

• **Strategy 3: Highlight that family attendance is welcome**

Encourage family attendance, especially when there is the potential for bad news to be delivered or if an important treatment decision may be discussed. This strategy may be
carried out by the reception staff managing consultation appointments. However, if the patient does not desire family involvement, this should be respected.

7.3.1.4 Alternative forms of family inclusion

Work commitments, family commitments, and physical distance from the consultation/clinic are common barriers to family attendance (Chapter 4). Mitnick et al. (2010) recommended that “physicians should recognise that geographically distant caregivers may face unique challenges” (p. 257). Possible strategies to maintain family involvement include teleconferencing with the family or audio-taping the consultation for the family (Chapter 3). Baile et al. (2012) similarly suggested that audio-taped consultations or consultation summary letters can be a useful source of information for family. Whilst these strategies have not been specifically developed to promote family inclusion in medical consultations, Knox, Butow, Devine, and Tattersall (2002) in their study of audiotaped consultations found that patients provided with an audiotaped consultation commonly reported that family members found it very beneficial. Additionally, Van Ast and Larson (2007) found that teleconferencing with rural caregivers to provide information and training for the care of patients was well accepted by both carers and facilitators and enabled high levels of understanding and information retention.

- **Strategy 4: Be open to, and facilitate, alternative forms of family involvement**
  Consider alternative forms of family involvement, such as teleconferencing, consultation summary letters, or audiotaping the consultation, if the family is unable to physically attend the consultation.

7.3.1.5 Family meetings

Limited consultation time can reduce family engagement and the physicians’ ability to address complex issues such as family dynamics (Chapter 3; Speice et al., 2000). Burkhalter and Bromberg (2003), Powazki (2011), and Speice et al. (2000) advocated for routine inclusion of family meetings at the start of care or at difficult times throughout the cancer experience. Family meetings (or ‘family conferences’) are meetings usually attended by the patient, family members and one or a number of members of the multidisciplinary healthcare team (e.g. oncologist, oncology nurse, social worker). Family meetings can have a range of functions including facilitating communication, enhancing family inclusion, sharing information, and negotiating decisions. They can be used to discuss a range of topics such as diagnosis, prognosis, treatment options, and end-of-life decisions (Fineberg et al., 2011). Family meetings can facilitate continuity of care and also may provide a
forum to discuss patient and family needs and address any problematic family dynamics. Girgis and Sanson-Fisher’s (1995) consensus guidelines for breaking bad news recommended that medical practitioners “Encourage family meetings to discuss issues which arise over time” (p. 19). In the palliative care setting, Gueguen, Bylund, Brown, Levin, and Kissane (2009) advocated for family meetings for at risk families, such as those with poor family cohesion, communication and conflict resolution, and proposed a communication skills training module for family meetings in the palliative setting. Similarly, Hudson, Quinn, O’Hanlon, and Aranda (2008) developed clinical practice guidelines for palliative care family meetings, and in a pre-post pilot study of the guidelines found that family meetings led to a significant increase in family members having their care needs met (Hudson, Thomas, Quinn, & Aranda, 2009). However as Hudson et al.’s (2008) and Gueguen et al.’s (2009) guidelines are specific to the palliative care setting, development and evaluation of family meeting guidelines which apply to a wider cancer setting may be appropriate.

- **Strategy 5: Consider conducting a family meeting**
  Consider conducting a family meeting with patients and their family members at the start of care or any other difficult time points, particularly if challenging family dynamics are apparent.

### 7.3.2 Establishing and Negotiating Family Involvement

Family members may attend the consultation for a range of reasons (e.g. to obtain information, to provide support, to express their own wishes), and may have a specific agenda (Chapter 4). Alternatively they may be unsure of what role to assume or whether their involvement is useful to the patient (Chapter 4, Morris & Thomas, 2001). Some patients and family members may have mismatched family involvement preferences and information needs (Chapter 4, Beisecker et al., 1997; Glasser et al., 2001; Ishikawa et al., 2006). These findings indicate a need for clarification of agendas and preferences and subsequent negotiation of family involvement.

#### 7.3.2.1 Establishing agendas

As highlighted in the systematic review in Chapter 2 “family may attend for a range of reasons, which may differ from the patient’s wants and needs”, after which the following strategy was proposed “ascertain from the patient and/or the family why the family member has accompanied the patient to the consultation”. Lang et al. (2002) proposed a similar strategy that physicians should first clarify the agenda of the patient, then ask the family member why they have attended and if there is anything additional they would like to discuss.
• **Strategy 6: Clarify agendas and reasons for attending**

After clarifying the patient’s reasons for attending the consultation and agenda, health professionals should consider ascertaining why the family member has attended and if there is anything additional they would like to discuss.

### 7.3.2.2 Role clarification

Health professionals should also consider clarifying the patient’s and family member’s preferences for the nature and extent of family involvement. While the patient is often considered to hold priority status, many health professionals, patients, and family members perceive that the family also have a right to be involved (Chapters 3 and 4). We propose that whilst the patient’s involvement preferences are of paramount importance, the family member’s preferences for their own level of involvement should also be considered.

A recommendation from Chapter 4 was that health professionals clarify the nature of the patient-family relationship (that is, what is the relation of the family member to the patient, such as husband, child or friend). One family member appreciated when a physician asked “how does this work” in reference to the quality of the patient and family relationship (such as whether they get on, whether one tends to make the decisions for the other, etc). Similarly Speice et al. (2000) proposed that physicians ask “*What important things should I know about how you and your family members relate with each other?*” (p. 111) and Omole, Sow, Fresh, Babalola, and Strothers (2011) proposed that health professionals “*identify the relationship between the patient and the family member*” (p. 782). Additionally, Mitnick et al. (2010) and Baile et al. (2012) recommended that physicians determine patient preferences for the nature and degree of family involvement. Speice et al. (2000) proposed that health professionals ask patients and family members how the family should be included in the patient’s care, how the health professionals should communicate with the family, and how the patient and family communicate with one another. Omole et al. (2011) and Edwards and Chapman (2004) proposed that the role of the family in decision-making should also be clarified. Despite similar recommendations from a number of studies and strategy papers, consultation analyses in Chapter 5 revealed that no physicians established the family member’s reason for attending or clarified patient or family member preferences for family involvement.

We propose that health professionals could have a discussion with the patient clarifying a number of aspects of family involvement. Given the sensitive nature of these questions and potential for
social desirability or coercion to influence answers, it may be beneficial if health professionals privately clarify the patient’s preferences. Health professionals could explore:

i. **The functioning and quality of the patient-family relationship (e.g. what is the relationship between the patient-family, how do they get on, how do they tend to make decisions?)**

ii. **How the patient wants their family to be involved in the consultation (e.g. do they have any preferred roles?)**

iii. **If the patient permits health professionals to discuss their health with family members separately**

iv. **If there is anything the patient does not want to discuss in the presence of their family member**

v. **How would the patient like their family member to be involved in any medical decisions**

Next, it is proposed that health professionals clarify the family member’s involvement preferences. Although preferable, it may not be feasible to ask these questions privately. Health professionals might consider exploring the family member’s involvement preferences, for example asking:

i. **How would you like to be included in consultations? What would you like your role to be?**

ii. **How/to what degree would you like to be involved in medical decisions?**

It is important to note that there is no one preferred role or decision-making style, it should be based on individuals’ preferences and situation (Chapter 3; Chapter 4; Chapter 6). Preferences and needs may evolve over the course of the illness (Chapter 6), so health professionals should consider regularly checking in with patients and family members regarding their involvement preferences.

- **Strategy 7: Routinely clarify patient and family preferences for family involvement**
  If possible, privately clarify the patient’s preferences for the nature and extent of family involvement in consultations and decisions and ascertain information sharing preferences. Clarify the family members’ preferences for their own involvement in consultations and decision-making. As needs may change over time, patient and family preferences should be routinely clarified.

### 7.3.2.3 Role education

Many family member behaviours are considered helpful by physicians and patients (see Chapters 3 and 4); however interviews with family members revealed that some were confused about what role to assume (Chapter 4). If patients and family members do not have clear preferences for family
involvement, health professionals could highlight a number of helpful roles (based on Chapters 2, 3 and 4) that family can assume in the consultation and wider care process, including:

- **Informational support:** Providing information, asking questions, prompting the patient to ask questions, taking notes, ensuring that the patient understands the information presented in the consultation, acting as a memory aid or ‘second pair of ears’.
- **Emotional support:** Comforting the patient verbally (e.g. “I love you and I am with you”) and/or nonverbally (e.g. holding patient’s hand).
- **Logistical support:** Driving the patient to the consultation, carrying scans, completing paperwork, arranging prescriptions, assisting with arranging appointments.
- **Patient advocate:** Ensuring that the patient is receiving the best care and raising issues with physician that the patient may not feel confident to discuss themselves.
- **Family liaison:** Communicating information discussed in the consultation with the wider family.
- **Pre/Post-consultation support:** Discussing information/emotions with the patient prior to, and/or after, the consultation.

If treatment decisions are being considered and the patient and family do not have clear preferences for the family’s involvement, health professionals could inform patients and family members about the array of triadic decision-making styles (such as those derived from Chapters 3 and 4), which include:

- **Physician led:** The physician makes the decision on behalf of the patient and family
- **Patient led with family support:** The patient makes the decision, based on their own wishes and the information provided by the physician. The family member’s role is to support the patient’s wishes.
- **Patient led with family facilitation:** Family member assists the patient’s decision-making process by providing informational support, engaging in discussions, and acting as a sounding board. The family are actively involved, but the patient retains decision-making authority.
- **Collaborative/shared triadic decision-making:** The patient and family (and potentially physician) share the decision-making equally, each providing and discussing information and preferences and coming to consensus.
- **Family-led:** The family member makes decisions on behalf of the patient (*note: this decision-making style may not align with laws and professional guidelines advocating individual patient autonomy*).

Alternatively, the physician could highlight the wide scope of family involvement using the triangle figure proposed in Chapter 6. However, further revision and evaluation of the conceptual framework is needed before the triadic decision-making triangle is implemented as a tool in clinical practice.

- **Strategy 8: Provide family member role education**
  If patients and family members do not have clear involvement preferences for the family member, consider providing education about the array of roles family members can assume both in the general consultation and more specifically in decision-making.

### 7.3.2.4 Role negotiation

Once preferences for the nature and extent of the family’s involvement are ascertained, health professionals may need to facilitate a negotiation process, particularly if the involvement preferences of the patient and family are disparate. It may be appropriate to gain patient permission prior to engaging in open negotiation.

Ethical and practical strategies proposed for end-of-life mediation may be useful in this setting. Bowman (2000) highlighted steps including i) summarising parties’ preferences; ii) generating and exploring options; iii) conducting joint discussions; and iv) reaching a final agreement. Health professionals will need to gently navigate this process with respect and empathy (Bowman, 2000). Whilst legally the patient’s preferences are usually considered paramount, ethically it may not be appropriate to compel a family member to be involved beyond the extent they are comfortable with.

- **Strategy 9: Facilitate open negotiation of family involvement**
  Clarify the involvement preferences of the patient and family member. If the preferences are disparate, facilitate an open negotiation where exploration of options is discussed.

### 7.3.3 Include and Support Family Members

Patients and family members report appreciating health professionals’ attempts to connect with the family member (Chapter 3; Chapter 4; Morris & Thomas, 2001; Speice et al., 2000). However,
Chapter 5 revealed that few of these connections were made in clinical practice. In fact, health professionals may engage in potentially unhelpful behaviours such as excluding the family member, making them feel unwelcome or superfluous, or ignoring signs of family distress (Chapter 3; Chapter 4; Morris & Thomas, 2001; Speice et al., 2000). Therefore, this category includes strategies to acknowledge and include the family member in the consultation.

7.3.3.1 Build rapport

Patients and family members appreciate when health professionals welcome and build rapport with the family member (Chapter 4; Sinfield et al., 2008; Speice et al., 2000). Specific physician behaviours include shaking the family member's hand, learning their name, asking the family member about themselves, and remembering information about the family member (Baile et al., 2012; Chapter 3; Chapter 4; Lang et al., 2002). A number of these behaviours appear to rarely occur in clinical practice (Chapter 5).

- **Strategy 10: Welcome and build rapport with the family member**
  Make the family member feel welcome and included in the consultation. Specific behaviours include shaking the family member's hand, learning their name, and asking them about themselves.

7.3.3.2 Connect throughout the consultation

Patients and family members appreciate when health professionals engage with the family throughout the consultation (Chapter 4; Sinfield et al., 2008). Specific behaviours include making eye contact with the family member, answering the family member's questions, and providing them with relevant information. However, it is also important that the patient remains the focus of the consultation and the physician does not form a coalition with the family to the point of excluding the patient (Baile et al., 2012; Chapter 3; Chapter 4).

- **Strategy 11: Connect with the family member**
  Whilst ensuring that the patient remains the primary focus, include the family member throughout the consultation. Make eye contact with the family member, provide them with information, and adequately respond to their questions.

7.3.3.3 Give opportunities

There were a high number of interruptions of, and by, family members coded in audiotaped consultations, as reported in Chapter 5. This may indicate that family members are not being
provided adequate opportunities to make contributions. Explicitly reassuring family members that they will be given time for their own contributions and questions in the consultation may result in less interruptions and smoother communication (Karnieli-Miller et al., 2012).

- **Strategy 12: Reassure family that they will have the opportunity to contribute**
  Reassure the family member that they will be given time to make contributions and ask questions. Ensure that adequate time is provided for this.

### 7.3.3.4 Acknowledge and affirm

Some patients and family members appreciated when health professionals showed respect for the family member, acknowledged the impact of the illness on the family, and affirmed their important role in the process (Chapter 4; Kimberlin et al., 2004). Pennbrant (2013) advocated for physicians to adopt a respectful demeanour towards the family member that does not make them feel subordinated or unwelcome. This may be particularly important because some family members indicated anxiety or reticence about being involved in the consultation (Chapter 4; Chapter 5). Mitnick et al. (2010) recommended that health professionals should recognise the value of family members and routinely validate their role. Omole et al. (2011) suggested that physicians recognise the impact of the patient’s health on the family member. However, it appears this rarely occurs in clinical practice (Chapter 5).

- **Strategy 13: Acknowledge and affirm the family member’s important role**
  Treat the family member with respect, acknowledge the impact of the illness on the family member and affirm their important role.

### 7.3.3.5 Support

Family members caring for a loved one with a serious illness such as cancer may experience clinical levels of anxiety and depression (Hodges et al., 2005), reduced quality of life, high levels of stress and burnout, and poor physical health (Wilkinson, 2010). Health professionals should recognise and acknowledge emotions expressed by the family member (Omole et al., 2011), be alert for signs of distress in the family, and suggest appropriate referrals such as to psychologists, social workers, or support groups (Baile et al., 2012; Chapter 3; Mitnick et al., 2010).

- **Strategy 14: Refer family to support services if needed**
  Acknowledge family emotions and remain alert for signs of distress among family members. Refer family members to appropriate support services if needed.
7.3.3.6 Educate

Family members report unmet information needs, particularly regarding prognosis, details about illness progression, and at-home care provision (e.g. Chapter 4; Sklenarova et al., 2015; Soothill et al., 2001). Burkhalter and Bromberg (2003) and Baile et al. (2012) recommended that health professionals provide information and education to the family member if approved by the patient. If physicians do not have patient approval to provide the family with information, they could refer family to other reliable information sources such as cancer care nurses, the Cancer Council helpline, or information booklets for cancer carers (e.g. the Cancer Council’s ‘Caring for someone with cancer’ booklet) (Chapter 4).

- **Strategy 15: Provide family with information or refer to appropriate sources**
  Family members may have unmet information needs and may require information. If unable to provide information to family members, physicians could refer family to an appropriate source such as cancer care nurse or cancer authority helpline.

7.3.4 Manage Challenging Situations

Health professionals, patients, and family members report that an array of challenges may arise in consultations involving family members (Barone et al., 1999; Chapter 3; Chapter 4; Kimberlin et al., 2004; Morris & Thomas, 2001; Sinfield et al., 2008; Speice et al., 2000). Strategies to assist in overcoming these challenges are proposed below.

7.3.4.1 Inconsistent attendance

Consistent family attendance throughout the illness experience appears to be preferable over several different family members attending or family only attending once the patient has become very unwell. These family members may not have an accurate understanding of the illness, treatments, and reasons behind decisions (Chapter 3; Chapter 4). Similarly Speice et al. (2000) recommended that health professionals conduct interactions with the patient and family together as much as possible. If the patient desires family involvement, health professionals should consider encouraging consistent family attendance early in the illness trajectory. This may also include proposing alternative methods of family involvement if there are barriers to attendance (see Strategy 4 in section 7.3.1.4).
• **Strategy 16: Encourage early and consistent family attendance**

If the patient desires family involvement, encourage their family member to attend as many consultations as possible. Discuss and attempt to overcome any barriers to family attendance.

### 7.3.4.2 Problematic family dynamics

It may be helpful if health professionals are attuned to the relationship dynamics between the patient and their family member (Burkhalter & Bromberg, 2003; Chapter 3), and observe patients and family members for signs of conflict or coercion (Omole et al., 2011). If problematic dynamics are suspected, health professionals could consider administering a scale to assess patient-family communication and conflict. Siminoff et al. (2008) developed the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) which includes patient and family specific measures to be administered separately. It measures the level and types of communication concordance and discordance between patients and caregivers and could act as a screening tool to assess family risk for communication problems (Siminoff et al., 2008). It also includes items assessing the patient’s and family members’ approach to decision-making. The importance of assessing, and potentially intervening, is underscored by Siminoff et al.’s (2008) findings that higher CCAT-PF discrepancy scores are correlated with greater patient depression, lower patient-family wellbeing, and lower family cohesion. If negative dynamics are observed or patient-family discrepancies are found, it may be beneficial if physicians meet with the patient and/or family member separately. The physician may also consider referring the patient and family member to a social worker or family therapist for counselling.

• **Strategy 17: Be aware of family dynamics**

Health professionals should observe family dynamics and be aware of any signs of conflict or coercion. They may consider administering the CCAT-PF to patients and family members if family conflict/discordance is suspected. A private meeting with the patient/family could be arranged and/or referral to a social worker or family therapist provided, if the patient and family are considered at risk of conflict.

### 7.3.4.3 Dominant family members

 Whilst some family members speaking for the patient may helpfully articulate the patient’s own needs and values and provide welcome corrections or comments, other family members engaging in similar behaviours (e.g. speaking for, correcting, or interrupting the patient) may silence or
reduce the patient’s autonomy (Chapter 5; Clayman et al., 2005; Mazer et al., 2014). Some family members may also dominate decisions; potentially resulting in inadequate accommodation of the patient’s own wishes (Chapter 3). Physicians may face the difficult task of ascertaining if the family’s dominance is welcome and appreciated by the patient, or is silencing the patient and their own wishes.

As a first step, if inappropriate dominance is suspected, physicians could find opportunities to speak with the patient alone without the family member present to ascertain the patient’s views about their family members’ involvement and the patient’s own preferences for decisions (Chapter 3). Within the consultation, if the family is assuming an inappropriate level of dominance, physicians could consider reminding the family of the goal of helping the patient and guiding family into a supportive rather than dominant role (Mazer et al., 2014). Physicians could provide direction to the dominant family member about their involvement, for example asking them to withhold comments or questions until the physician or patient has finished speaking, using humour to gently highlight the family member’s behaviour, or suggest helpful supportive behaviours such as helping the patient to recall information and providing emotional support to the patient. Physicians could also consider speaking privately with the family member about the nature of their involvement (Chapter 3; Speice et al., 2000). Finally, the physician may consider referring the patient and/or family member to a social worker or family therapist if problematic dynamics persist.

- **Strategy 18: Guide dominant family members’ behaviour**
  If inappropriate family dominance is suspected, physicians could speak with the patient privately to ascertain their preferences for any decisions and family involvement preferences. Within the consultation, the physician may guide dominant family members into a more supportive role by highlighting that the patient is the focus and recommending some supportive family roles such as informational and emotional support.

7.3.4.4 **Aggressive or angry family members**

Whilst family members displaying aggression, anger, or defensiveness are considered to be uncommon, these issues may arise on occasion and are often considered by physicians to be difficult to manage (Chapter 3; Kimberlin et al., 2004; Rosland et al., 2011). For family members displaying anger, Boudreaux (2010) and Lown (2007) proposed that first gaining an understanding of the family members’ underlying feelings (e.g. reasons for anger) can help physicians diffuse difficult situations. Lown (2007) titles this the ‘differential diagnosis of anger’ and proposes a
number of reasons for family anger in the clinical setting (e.g. physical or psychological discomfort, negative information, negative emotions, healthcare system issues, relationship issues with physician). Lown (2007) suggested communication strategies to use in these situations such as positive communication (e.g. calm and slow voice, open posture), reflection of family's feelings, validation of the family's emotions, respect for the family's role, offering support for the family member, and building a partnership with the family to overcome issues. The physician may consider referring the family member to a social worker or counsellor if their anger persists, or inviting one of these allied health professionals into the consultation with the family member. When dealing with an agitated person, health professionals should consider their own safety as a key priority.

- **Strategy 19: Communicate calmly and productively with family members displaying anger**

  For family members displaying anger, attempt to understand family member's perspective, remain calm, use positive communication strategies, offer help, and build a partnership with the family member. Consider referral to social worker or counsellor if anger persists.

### 7.3.4.5 Numerous family members

Numerous family members attending a single consultation may be overwhelming for the physician and counterproductive for an effective consultation (Chapter 3). If a large number of family members want to attend the consultation, the physician could consider apologising and acknowledging the limited space in the consultation room, requesting that fewer family members enter the consultation room, and asking that the family nominate one or two spokespeople to be in consultations and liaise with health professionals (Burkhalter & Bromberg, 2003; Chapter 3). A family meeting could also be arranged (see Strategy 5 in section 7.3.1.5).

- **Strategy 20: Appoint a family spokesperson**

  When numerous family members attempt to enter the consultation, acknowledge the limited space and ask for one or two family spokespeople to be nominated. Consider arranging a family meeting for all members.

### 7.3.4.6 Managing family member acting as interpreter

Family members may assume the role of interpreter for culturally and linguistically diverse (CALD) patients. Health professionals report concern that in these situations the patient may not receive accurate and complete information (Chapter 3). Analyses of consultation audiotapes by Butow et al.
(2011) evidence this concern, revealing that family interpreters had a higher rate of non-equivalent interpretations than professional interpreters and appeared more likely to hide diagnoses and prognoses. A systematic review by Karliner, Jacobs, Chen, and Mutha (2007) found that use of professional interpreters was associated with improved clinical care when compared to ad hoc interpreters (including family). Leanza, Boivin, and Rosenberg (2010) also identified specific risks of working with family interpreters in comparison to professional interpreters, including that family interpreters were more likely to impose their own agenda and control the consultation process. In Chapter 3, health professionals suggested that physicians (or perhaps the medical receptionists arranging appointments) should actively find out if the patient is non-English speaking and encourage and arrange use of a professional interpreter either in person or over the telephone. However, patient and family resistance, low uptake, and limited availability of professional interpreters remains an ongoing issue (Ginde, Sullivan, Corel, Caceres, & Camargo, 2010). If professional interpreters are unavailable or unwelcome and the family act as the interpreters, physicians should attempt to connect with the patient and may consider using intercultural communication skills when communicating with the patient such as the use of gestures and pictures to aid understanding (Paternotte, van Dulmen, van der Lee, Scherbier, & Scheele, 2014).

- **Strategy 21: Encourage use of a professional interpreter**
  Patients with a family member interpreting information may be less likely to receive accurate and complete information. Health professionals (or medical receptionists arranging appointments) should encourage and arrange use of professional interpretation services.

### 7.3.4.7 Requests for non-disclosure of diagnosis

Family occasionally request that the diagnosis of cancer not be disclosed to the patient (Chapter 3; Speice et al., 2000). A strategy proposed in Chapter 3 was to acknowledge that according to Australian law the patient must know their diagnosis in order to provide informed consent. Similarly, Speice et al. (2000) proposed that physicians should openly state that they cannot treat the patient as long as the family will not allow the patient to know about their illness. However, Hallenbeck and Arnold (2007) proposed that “a common pitfall is to respond to requests to non-disclosure with a categoric we cannot do that, the patient must be told the truth” (p. 5031) and McCabe, Wood, and Goldberg (2010) acknowledged that disclosure of diagnosis to the patient is a relatively recent development and that non-disclosure is considered ethically and culturally
appropriate in many parts of the world. Hallenbeck and Arnold (2007) proposed that physicians adopt a more inquisitive, empathic, and flexible approach when faced with requests for non-disclosure. They suggest the following steps: i) take a deep breath and do not overreact; ii) find out the family’s reasons for requesting non-disclosure; iii) respond empathically to the family’s distress; iv) talk to the family about what the patient would want; v) find out how the patient normally functions in the family unit; vi) explain your position and the explanatory model favouring disclosure; and vii) negotiate with the family member about an approach to talking with the patient. McCabe et al. (2010) similarly proposed that physicians i) spend time developing an understanding of the family’s point of view; ii) understand the patient’s true preferences for receiving information; iii) take an incremental approach to resolving requests for nondisclosure; and iv) continue to work with and include the family at key time points, when there is new information to be conveyed and when there are decisions to be made. Whilst it is important that physicians adhere to the legal requirements of informed consent, they could adopt a more flexible, empathic, and gentle approach to disclosure.

- **Strategy 22: Explore family requests for non-disclosure with empathy and flexibility**
  
  Based on the suggestions of Hallenbeck and Arnold (2007) and McCabe et al. (2010), consider exploring with empathy why the family is requesting non-disclosure of diagnosis, ascertain the patient’s preferences for receiving information, negotiate with the family member regarding an approach to talking with the patient that is sensitive to the patient’s and family’s wishes, and continue to work with and include the family.

### 7.3.4.8 Requests for patient information

Family may request information about the patient without their consent (Chapter 3; Chapter 4), however provision of patient information without consent conflicts with Australian legal and professional guidelines (Kerridge et al., 2013), and also with some patient preferences (Chapter 4; Petronio et al., 2004).

Physicians need to be aware of both the family’s need for information and the patient’s rights to privacy and confidentiality. It may be helpful to addresses this issue early by asking the patient if they consent to separate physician-family conversations. If the patient does not agree, family could be reminded of the patient’s legal rights to privacy and directed to more general information sources, such as the Cancer Council helpline (Chapter 3). The physician may also suggest that the patient and family discuss their information preferences privately with one another.
• **Strategy 23: Retain patient privacy while attempting to meet the family's information needs**
  
  Seek patient permission for separate physician-family conversations. If the family request information and patient permission has not been obtained, acknowledge the legal protection of patient privacy and direct the family member to more general information sources.

7.3.4.9 **Discussing sensitive information**

Some patients feel unable to share or enquire about sensitive information with the physician due to the presence of a family member (e.g. sexuality, fertility, mental health, prognosis) (Barone et al., 1999; Chapter 4). Private patient-physician time should be incorporated into consultations to give patients the opportunity to speak with the physician alone. Physicians could highlight that sensitive information needs to be discussed and ask the family member to step outside the room for a short time. Alternatively, the physician could use opportunities to speak privately with the patient about sensitive issues, such as during a physical examination, which is done without the family member present (Chapter 2; Chapter 3; Lang et al., 2002).

• **Strategy 24: Create opportunities to speak with the patient privately about sensitive information**
  
  Patients may want to discuss sensitive information (e.g. sexuality, mental health, prognosis) without their family present. Request time to speak with the patient alone or use naturally occurring opportunities when alone with the patient to discuss any sensitive issues.

7.3.4.10 **Managing conflicting treatment wishes**

One of the most common challenges raised by health professionals in Chapter 3 was negotiating conflicting treatment wishes of the patient and family. Although only a few patients and family members raised this in Chapter 4, other studies have reported that conflicting treatment wishes are common (e.g. Zhang & Siminoff, 2003). Some common conflicts include when the patient and/or family hold strong views about which treatment to receive or not receive (for example alternative therapies), delaying treatment, or ceasing treatment. The need to appropriately manage family conflict is evidenced by Zhang et al. (2010) who found that perceived family disagreement was associated with depression in cancer patients and their family caregivers.

When faced with conflicting treatment wishes, health professionals could firstly assess patient and family understanding of important information, as there may be a misunderstanding or erroneous
beliefs (Chapter 3). Next, health professionals could conduct open and detailed discussions about the benefits and costs of each option (i.e. decision analyses) and reframe each individuals' position in ways that allow the other person to understand and appreciate viewpoints (Chapter 3; Lang et al., 2002). If consensus is unable to be achieved, it may be advisable to arrange for the patient and family member to speak with a different health professional, such as another physician for a second opinion, with a nurse to discuss treatments in more detail, or with a social worker to help resolve differences. If conflict continues, physicians should openly acknowledge that patient wishes are paramount and facilitate the patient's open expression of preferences (Chapter 3).

- **Strategy 25: Negotiate conflicting treatment wishes**
  Assess patient and family understanding, clearly discuss benefits and costs of options, and reframe conflicting viewpoints. If consensus is unable to be achieved, arrange for the family and patient to seek another health professional's opinion and/or openly acknowledge that patient wishes are paramount.

### 7.4 Discussion

The current strategies were designed to facilitate positive family involvement and provide an array of practical strategies to manage challenges found in cancer consultations involving family members. These strategies attempt to overcome a number of limitations found in the strategies proposed to date. They acknowledge and were developed to comply with current Australian medical law and professional guidelines (Kerridge et al., 2013), are based on rigorous examination of the evidence base through completion of a systematic review (Chapter 2), two large qualitative studies (Chapters 3 and 4), analyses of actual physician behaviours in cancer consultations (Chapter 5) and are informed by a newly proposed theoretical framework of family involvement in decision-making (Chapter 6). Existing strategies proposed in the evidence base and strategies proposed throughout this thesis have been synthesised. To the candidate’s knowledge, these are the most comprehensive triadic consultation strategies developed to date.

The current strategies are preliminary in nature, and will undergo further evaluation. This process is beyond the scope of this thesis and forms part of the candidate’s postdoctoral research program. First, the current ‘working paper’ strategies will be evaluated by a core expert advisory group comprising three physicians (one medical oncologist, one haematologist, one primary care physician), an ethicist, an expert in medical law, two consumer representatives (a patient and family member), a social worker, and two psycho-oncology researchers. The candidate has also
established links with the Carers Portfolio of the NSW Ministry of Health, and a policy expert has agreed to join the expert advisory group. Feedback will be incorporated through an iterative review process. The revised strategies will be presented for discussion and feedback at a focus group with a larger stakeholder committee (n=20) including academics, health professionals and ethicists. The strategies will be revised based on the focus group feedback and will then undergo further evaluation through an online consensus process using the Delphi method (Keeney, Hasson, & McKenna, 2011). For the consensus process, 200 international experts (n=100 academic experts in medical communication and/or decision-making; n=100 health professionals) will be invited to participate in the consensus process, in which experts will rate their agreement/disagreement with each of the strategies in up to three rounds of surveys. Once consensus is reached and the strategies are finalised, the document will be re-written for a health professional audience and will include examples of wording to be used when implementing each strategy in the clinical context and a number of exercises such as a revised self-assessment and clinical vignettes (informed by Heru and Drury’s (2006) psychiatric training module). The strategies will be professionally designed and printed. The strategies document will form part of a pre-post evaluation of a triadic clinical skills training module with ten oncologists from five tertiary hospital sites in the greater Sydney area.

The current strategies were developed for cancer consultations where competent adult patients attend with an adult family member. However, there are a number of other challenging situations where physicians may desire guidance regarding family involvement. For example, family involvement in clinical trial decisions, consultations involving adolescent patients and their parents, consultations where patients have impaired cognitive capacity such as an intellectual disability or early stage dementia, or settings where the couple are considered to be a treatment unit, such as in fertility treatments. The applicability of the current strategies document should be explored across medical settings.

The comprehensive set of strategies described in this chapter was based on existing empirical literature and strategies. These strategies aim to assist physicians in preparing for family involvement, negotiating family roles, including and supporting the family, and managing common challenges which arise in triadic consultations. These strategies will undergo comprehensive expert review before being tested in a pre-post study with oncology physicians.
Chapter 8:
Final Discussion
8.1.1 Overall comment on thesis

This thesis has explored the complex, multifaceted, and dynamic nature of family involvement in cancer consultation communication and decision-making. Through a rigorous and diverse program of research examining the existing evidence base, experiences and attitudes of each participant in the triad, and their behaviours during cancer consultations, a comprehensive understanding of family involvement has been obtained. To date, medical communication has primarily focused on the physician and patient- this thesis contributes to a clearer and more inclusive ‘360 degree view’ of cancer consultations and decisions.

The systematic review reported in Chapter 2 highlighted that the majority of the evidence base was comprised of descriptive studies exploring the characteristics of triadic consultations and accompanied patients or focusing qualitatively on preferences for family involvement. However, few studies explored deeper concepts such as the nature and impact of family on decision-making, health professional attitudes and practices towards family, and family behaviours within actual consultations. These findings were utilised to inform the subsequent direction of the thesis.

Chapter 3 described a qualitative study examining oncology physicians’ and nurses’ attitudes towards, and experiences of, family involvement in consultations. This chapter highlighted that health professionals largely held positive attitudes towards family involvement, and viewed family members as a helpful resource to clinicians and supportive companion to patients. Health professionals described an array of family behaviours and roles both inside (e.g. information gathering and provision, emotional support, patient advocacy) and outside of the consultation (e.g. pre-consultation preparation support, family liaison, decision-making sounding board). However, most health professionals, although appreciative of family involvement, advocated that the patient remain the priority within the consultation and retain authority over decisions.

Chapter 4 described a qualitative study of cancer patients’ and family members’ attitudes and experiences towards family involvement. The reported contributions of family members were numerous and diverse, and included provision of emotional and information support and facilitation of patient decision-making. Several novel challenges of being a family member attending consultations were also highlighted, including the stress felt by family members acting as the messenger to the wider family, difficulties and conflict which arose when assisting patients with treatment decision-making, and feelings of discomfort or distress when ignored or disrespected by health professionals. Many patients and family members reported preferences for the family
member to assume an “ancillary” or “collaborative” role in decision-making, however many also acknowledged that family are heavily impacted by the patient's illness and deserve some level of involvement in the decision-making process. Finally, patients and family members proposed a number of strategies for health professionals to facilitate positive communication when family members are present.

Chapter 5 reported the development and application of the 80 item TRIO coding system. Results revealed that the role of family members varied considerably both within the one consultation, and between different consultations. Coding analyses showed that although oncologists were responsive, they rarely proactively engaged with family members, including building rapport or asking family members questions. Family members were typically more involved in the information exchange phase of decision-making rather than the later stages of deliberation or deciding on a treatment to implement.

An initial conceptual framework was proposed (Chapter 6), using a triangle to expand the conceptualisation of medical decision-making styles beyond the physician-patient dyad. The triangle was also used to graphically represent a number of important theoretical findings from Chapters 2-5, including the variety of decision-making styles resting on a spectrum, and variability of decision-making dynamics between different triads, within the one triad over time, and within the one decision. The initial conceptual framework will form the basis of ongoing theoretical discussions.

Finally, in Chapter 7, the findings from Chapters 2-5 informed proposal of practical strategies for health professionals to prepare for family involvement in consultations, establish and negotiate family involvement, facilitate family inclusion and support, and manage the common triadic consultation challenges.

This thesis has examined family involvement from multiple perspectives across a number of methodologies. Within the qualitative chapters (Chapter 3; Chapter 4), the attitudes and experiences of health professionals, patients, and family members were obtained, and many of the findings were consistent across participants. Analyses of cancer consultations (Chapter 5) provided a more objective view of the triad. Reassuringly, many of the findings from this chapter were consistent with reports obtained from Chapters 3 and 4. For example, the dynamic nature of family involvement within the consultation was reported by physicians and also found in consultation analyses. The variability of family involvement between different triads ranging from passive to
dominant was found in both interviews and analyses, pointing to a spectrum of decision-making styles. The lack of conflict or disagreements found in the consultation analyses aligned with the reports of physicians, patients, and family members. Additionally, physicians’ attitudes that the patient should remain the priority were reflected both in interviews and consultation analyses. Several family members described reticence to impose on the privileged physician-patient relationship and feelings of submissiveness to the physician (see Chapter 4), and this notion was also found in the consultation analysis where a proportion of family members apologised or asked permission before speaking (Chapter 5). Finally, family members’ provision of informational support described in stakeholder interviews (Chapter 3; Chapter 4) was captured in the consultation analysis reported in Chapter 5, where family members often recalled information about the patient’s history, confirmed information provided by the patient, and asked questions. This triangulation of findings (Fenech Adami & Kiger, 2005) has contributed to a rich and full exploration of family involvement and enhances confidence in many of the findings discussed throughout the thesis.

By examining both attitudes (Chapter 3; Chapter 4) and behaviours (Chapter 5), a number of interesting contradictory findings were also obtained. For example, when interviewed, many physicians reported that they engage in a number of inclusive behaviours with family members, such as learning and using their name, building rapport, and providing family with the opportunity to ask questions. However, consultation analyses revealed that physicians made limited attempts to welcome, build rapport with, or include the family. This is surprising given the mostly positive views of physicians in our qualitative study, however perhaps in the busy clinical setting the pro-family views of physicians are not clearly conveyed. Additionally, whilst the importance of family role education, clarification, and negotiation was highlighted by interview participants in Chapters 3 and 4, consultation analyses revealed that no physician engaged in these behaviours. These findings indicate that family involvement (to the level preferred by the patient and family) in clinical practice may be suboptimal and strategies to improve triadic interactions may be beneficial.

An interesting finding revealed in this thesis is the challenges faced by family members. Family members typically assume a number of roles inside and outside of the consultation, and these are mostly appreciated by the patient and physician. However many of these roles may raise specific challenges for family members themselves. For example, some family members found attending consultations to be confronting and liaising with the wider family to be stressful. Self-censoring their opinions was at times frustrating and conflict during the decision-making process was
upsetting. However despite these challenges, and the high levels of carer distress reported in the cancer literature (e.g. Hodges et al., 2005), very little support was reportedly offered to family members in the consultation. Additionally, in the health professional interviews reported in Chapter 3, many physicians considered family members to be a ‘resource’ or ‘part of the multidisciplinary team’. These beliefs that the family member is there to help the physician may be contributing to a high degree of expectation and low level of support offered to the family. A number of strategies in Chapter 7 have been proposed to assess for family distress and provide avenues for support.

An additional challenge faced by some family members was obtaining information from the physician. Many family members interviewed (Chapter 4) reported unmet information needs, and this has also been highlighted in the wider evidence base (e.g. Sklenarova et al., 2015). Perhaps it is this desire for information that contributed to the high number of interruptions by family members detected in the consultation analyses reported in Chapter 5. In the interviews (Chapter 4), some family members indicated a desire to speak with the physician privately, often to obtain information about the patient’s prognosis and disease progression. A number of health professionals also raised this issue, but often felt it was inappropriate to speak privately with the family without patient consent, given the legal protection of patient privacy. A relevant strategy was included in Chapter 7 for physicians to ascertain patient’s information sharing preferences early to facilitate private physician-family discussions (if desired). However without patient consent, physicians are usually not legally allowed to provide this important information to family. Further ethical and legal discourse is needed to consider the rights of the family (who are likely to be the patient’s primary caregivers at home) to access important information.

The apparent struggle between the authority of the patient and the rights of the family emerged at several points throughout this thesis. Whilst the authority of the patient was advocated by most health professionals, patients, and family members in the interviews reported in Chapters 3 and 4, the impact of cancer on the family and rights of the family to be involved in the decision-making process were also highlighted- more often by patients and family members than by clinicians. It may be that the current legal and professional focus on the patient as an individual impacts on clinicians’ greater emphasis on patient autonomy versus family involvement in decision-making. Greater ethical and legal clarification regarding the difficult balance between individual patient autonomy and the rights of the family is needed.
The findings of this thesis contribute to a more complete understanding of medical decision-making. Most patients reported in interviews (Chapter 4) that they approached decision-making as an interdependent process, inextricably linked with their family. This finding provides evidence for a relational conceptualisation of autonomy (Entwistle et al., 2010), where the patient’s autonomy is located within and influenced by interpersonal relationships, such as with their family. These findings are also relevant to the emerging theoretical fields of shared mind (e.g. Epstein & Peters, 2009; Epstein & Street, 2011) and collaborative deliberation (Elwyn et al., 2014) which acknowledge the importance of the patient’s wider social network when making decisions.

Additionally, this thesis also provides evidence for the dynamic and non-linear conceptualisation of decision-making, discussed by Epstein and Street (2011). As highlighted in the conceptual framework of family involvement in Chapter 6, decision-making may be a fluid, non-linear, and iterative process which exists before, during, and after a consultation between several participants.

Further insight into the nature of family involvement in decision-making has also been obtained. Family involvement appears to vary widely between triads, with both the interviews and consultation analyses pointing to a spectrum of triadic decision-making styles ranging from passive to dominant. Family involvement in decisions also appears to be dynamic within the one triad. Findings from Chapters 3 and 4 indicate that the nature and extent of family involvement in decision-making may change throughout the illness trajectory. Additionally, results from Chapters 3, 4 and 5 indicated that the extent of family involvement may also vary across the stages of decision-making within the one decision. Each of these findings has been captured in the novel conceptual framework of family involvement in decision-making, proposed in Chapter 6. This framework provides much needed conceptual clarity to the field and represents an important step to better understanding and communicating the variable and complex decision-making dynamics which can occur when family are involved. The proposal of ‘pure styles’ of triadic decision-making, and plotting of these styles onto a triangle, may facilitate future ethical and normative discussions about where the influence of family could or should sit within the triangle space, based on different scenarios (e.g. patients with early stage dementia, adolescent patients) and across cultures.

The findings of this thesis indicate that the family's involvement in decisions may be positioned within the wider context of the family's involvement in the consultation and care. The informational/emotional support that family may provide, the relationship dynamics between the patient and family and the family's interactions with the wider social circle all may shape and form part of the family members’ involvement and influence in decision-making. Each of these findings
will be integrated into subsequent iterations of the conceptual framework of family involvement in decision-making.

Throughout this thesis, a number of challenges related to triadic consultations have been highlighted, such as issues of patient privacy, family role confusion, dysfunctional family dynamics, and conflicting patient-family treatment wishes. Participants highlighted a number of strategies to manage and enhance family involvement during the interviews reported in Chapters 3 and 4; however consultation analyses revealed that few of these strategies are applied in clinical practice. The strategies proposed in Chapter 7 will form the basis of guidelines for health professionals, with the aim of facilitating positive family involvement and overcoming potential challenges. These strategies will undergo a rigorous process of expert feedback, a consensus process with international experts using the Delphi method (Keeney et al., 2011), and finally, as part of a larger training module, the strategies will be tested in a pre-post evaluation with oncology clinicians.

8.1.2 Limitations

Methodological considerations have been outlined in previous chapters. However a number of limitations of the thesis as a whole require acknowledgement. Firstly, given the exploratory nature of the thesis, the scope of Chapters 2, 3, 4, and 5 was broad. For example, in the interviews and consultation analyses reported in Chapters 3, 4, and 5, patients of all cancer types and stages were included, as were any family member (e.g. spouse, sibling, adult child). Therefore, the findings of this thesis may be more general in nature and may not have captured some of the intricacies of specific sub-groups. Future research may benefit by using this thesis as a basis to explore the more specific experiences of sub groups, such as triadic decision-making during disease recurrence or clinical trial participation, or the experiences of adult children attending with an elderly parent. Due to practical limitations, the attitudes and behaviours of patients and family members from culturally and linguistically diverse (CALD) backgrounds who did not speak English were unable to be captured in interviews or consultation analyses. It is likely that these participants would have provided different perspectives compared to Caucasian patients and family members, given the high level of family involvement in medical decisions in many cultures such as China (Cong, 2004), Japan (Akabayashi, 2006), and Pakistan (Aslam, 2005). Given that Australia is a multicultural society with a large number of residents from CALD backgrounds, it is important that the views of these patients and family members are obtained in future research.
Whilst the experiences of health professionals, patients, and family members provided insight into what occurs outside of the consultation, this thesis has primarily focused on triadic communication and decision-making within the consultation. As such, studies examining only the patient-family dyad were excluded from the systematic review and objective analyses of patient-family communication and decision-making outside the consultation were not able to be obtained. Future research should attempt to further uncover the at-home decision-making dynamics of the patient and family. Finally, as acknowledged throughout this thesis the health professionals willing to participate in this research (Chapters 3 and 5, and to recruit patients and family members for the interviews reported in Chapter 4) may have a greater interest in medical communication or family involvement. The findings of this thesis may be biased to reflect the views of more interested and inclusive health professionals. However, this further evidences the need for development, evaluation, and dissemination of clinical strategies in light of the thesis findings.

8.1.3 Strengths

This thesis has a number of strengths. By capturing a variety of participants’ perspectives and employing a number of different methodologies, a comprehensive and rich view of triadic communication and decision-making has been obtained. A major strength of this thesis is the deep exploration of novel aspects of family involvement in communication and decision-making. It includes the first systematic review of quantitative and qualitative studies of triads, which subsequently informed the direction and scope of the thesis to ensure that unexplored areas of family involvement were examined and clarified. The large qualitative study, which included 85 participants, provided both diversity and depth of perspectives and examined a number of novel areas such as family involvement in decision-making, challenges of family involvement, practical strategies to overcome challenges, and the barriers and facilitators to positive family involvement. The development of a novel and comprehensive triadic coding frame, capturing 80 distinct behaviours, and subsequent application of the coding frame to 72 initial medical or radiation oncology consultations provided insight into many unexplored aspects of triadic communication and decision-making.

An additional strength of this thesis is the conceptual and clinical significance of the findings. For example, the systematic review, interviews and consultation analyses reported in Chapters 2, 3, 4, and 5 have led to the development of a preliminary conceptual framework (Chapter 6) and draft clinical strategies document (Chapter 7), which have the potential to impact future research, practice, and policy.
8.1.4 Future research

Continued development, review and validation/evaluation of the triadic coding frame (Chapter 5), conceptual framework (see Chapter 6) and clinical strategies (see Chapter 7) was beyond the scope of this thesis and forms part of the candidate’s postdoctoral research program at The University of Sydney. Specifically, the TRIO coding frame will be validated through its application to audio-taped cancer consultations where participation in a clinical trial is discussed between the physician, patient, and family member. Additionally, the candidate and another researcher plan to apply an adapted version of the TRIO coding frame to audio-taped psychiatric consultations where treatment decision-making for bipolar disorders is discussed with patients and family members. The proposed conceptual framework will undergo a process of iterative review with an expert advisory group comprising experts in medical decision-making and conceptual framework development, ethicists, clinicians, a medical law advisor and consumers. The clinical strategies will be presented for feedback at a focus group with academic and clinical experts and, after revision, will undergo further evaluation through an online consensus process using the Delphi method (Keeney et al., 2011) with approximately 200 academic and clinical experts. The final strategies document will form part of a triadic communication skills training module. The feasibility, acceptability, and efficacy of the module will be tested in a pre-post pilot study with 10 oncologists.

A number of gaps in our understanding of family involvement in communication and decision-making remain. Firstly, this thesis and indeed a large proportion of previous triadic communication studies focus on the cancer setting. Research is needed in other areas where significant treatment decisions are made, such as diabetes care, cardiovascular care, orthopaedics, and fertility treatments. Additionally, further research is needed to more clearly understand the factors affecting the extent of family involvement, such as clinical characteristics (illness type/severity, nature of decision) and patient/family characteristics (such as age, education, culture). Of particular importance is the impact of culture on family involvement in decision-making. Despite Australia being a multicultural nation, legal and professional guidelines advocate for individual patient autonomy, which may be in conflict with cultural norms of some CALD patients and their families (e.g. Huang et al., 1999). Future research should assess the attitudes and behaviours of patients and family members from an array of ethnically diverse cultures and attempt to develop strategies for family involvement which are sensitive to the needs and cultural norms of CALD patients and families. Additionally, few studies have examined outcomes as a result of family involvement in consultations or decisions, such as how the extent of family involvement in
decisions impacts on patient and family member satisfaction with the decision. Perhaps future research could examine both patient and family outcomes such as satisfaction, quality of life, mental health, and decisional regret.

Whilst clinician-led strategies were proposed in this thesis, a number of alternative avenues for improving family involvement in consultations and decisions also appear feasible. For example, newly developed patient/family role and preference assessment tools are showing promise. Wolff et al. (2014) developed a pre-consultation information preference checklist designed to elicit and align patient and family perspectives regarding health concerns to discuss with the physician, and a role clarification checklist, provided to patients to help simulate thought and discussion about the family member’s role in the visit. These tools were evaluated by the majority of participants as easy and useful and led to more patient-centred communication and better patient understanding.

Whilst developed for use in routine medical visits for elderly patients, use of an adapted version for the cancer setting may prove useful. One tool specifically developed for the cancer setting is Siminoff et al.’s (2008) Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) which assesses communication concordance and discordance between patients and caregivers and their approaches to decision-making. The CCAT-PF could act as a screening tool to be used in clinical practice to assess risk for communication problems between the patient and family member.

Furthermore, role education could be provided to patients and family members prior to the consultation in the form of a preparation package. A patient and family decision coaching tool, developed by Feenstra et al. (2015) may be a beneficial tool for the cancer setting. Similar to a decision-aid, this tool provided information about a number of diabetes treatment options and accommodated both adolescent diabetic patient’s priorities and the family's priorities. It aimed to assist patients and family members to identify and address their decision-making needs. Whilst this patient-family decision-making tool was deemed feasible and acceptable, large scale evaluation of its efficacy has not yet been published. A preparation package could also include information about relevant support services that family members can access. Additionally, family members in our study regularly assumed a supportive role during the decision-making process. Given that the use of professional decision-making coaches can result in more informed and engaged patients (Veroff, Ochoa-Arvelo, & Venator, 2013), perhaps family members could be also provided with some of these coaching skills, to assist them when they are supporting the patient’s decision-making. By combining communication skills training for clinicians with coaching for patients and family
caregivers (e.g. via preparation packages and question prompt lists), communication may be further enhanced through the preparation of all key stakeholders in the triad.

Further, opportunities also exist for other health professionals. As highlighted throughout Chapter 7, clerical staff, nurses, psychologists, and social workers play an important role in including and supporting family members. Future interventions could be developed specifically for these multidisciplinary team members.

A number of findings of this thesis point to a need for more systemic change in regard to family involvement in cancer consultations and decisions. Whilst family provide the majority of at-home care for the patient and are usually significantly impacted by medical decisions; ethical, legal, and professional guidelines largely focus on the autonomy of the patient, and may view the family with a level of suspicion (Gilbar, 2011). The recent recognition of family caregivers in legislation represents a positive step towards family-inclusive clinical practice, however in light of the findings of this thesis and other studies (Gilbar, 2011; Öhlén et al., 2006), further reflection on the appropriateness of legal and professional guidelines is needed. Clayman and Morris (2013) argued that for patients to truly experience patient-centred care, researchers and clinicians need to better engage with the family members that patients choose as their partners in the illness journey. System-wide changes that may be considered include standard screening for family caregivers at risk of distress or burnout, clear referral pathways for family members in need, and greater system-wide recognition and respect for family members.

In summary, this thesis improves our understanding of patient, family, and health professional experiences of, and actual behaviours within, cancer consultations involving family. It highlights the dynamic and multifaceted nature of family involvement in decision-making and raises a number of conceptual, ethical, and practical issues regarding the accommodation of family in consultations and decisions. Further empirical and theoretical work is needed to comprehensively understand, and potentially enhance, family involvement in the cancer consultation and decision-making process.
References


Epstein, R., & Gramling, R. (2013). What is shared in shared decision making? Complex decisions when the evidence is unclear. *Medical Care Research and Review, 70*(1 suppl), 94S-112S.


Appendices
Appendix A
Systematic Review Tables
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Country</th>
<th>Quality Rating</th>
<th>Approach, Design &amp; Method</th>
<th>Sample &amp; Setting</th>
<th>Measures specific to results Key: (+)/(-)= validated/ unvalidated measure</th>
<th>Results</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clayman M, Roter D, et al</td>
<td>2005</td>
<td>USA</td>
<td>100%</td>
<td>Design: Cross-sectional Method: Questionnaires, analysis of videotaped consultation</td>
<td>Sample: n= 93 patients (aged &gt; 65 years) NB: all matched patient-family member pairs</td>
<td>Patient (+) Demographics, reason for visit (+) Medical Outcomes Study Short Form SF-36 Family member (+) Demographics, relationship to patient and reason for accompaniment Consultation analysis (+) Roter Interaction Analysis System&lt;br&gt;<strong>Key</strong>: (+)/(-)= validated/ unvalidated measure</td>
<td>– Family members: spouse (46%); adult child (36%); other relatives (13%); friends (3%)&lt;br&gt;– Compared to male family members, female family members were more likely to facilitate patient involvement (p&lt;.06) and engage in autonomy-detracting behaviours in the medical visit (p&lt;.05)&lt;br&gt;– Family members of sicker patients compared to family members of healthier patients were more likely to engage in behaviours such as facilitating patient involvement (p&lt;.05) and patient understanding (p&lt;.05)&lt;br&gt;Family member behaviours coded as autonomy-enhancing or -detracting:&lt;br&gt;Autonomy-enhancing behaviours:&lt;br&gt;– 79% of family members clarified or expanded patient history&lt;br&gt;– 50% of family members asked questions of the physician&lt;br&gt;– 33% of family members introduced medical topics that were not initially discussed by either the physician or patient&lt;br&gt;Autonomy-detracting behaviours:&lt;br&gt;– 21% of family members answered for the patient&lt;br&gt;– 11% interrupted the patient&lt;br&gt;– 10% of family members discussed their own health problems&lt;br&gt;– Most family members (52%) engaged in enhancing behaviours and no autonomy detracting behaviour</td>
<td>Sicker patients were more likely to have family members who engaged in facilitating behaviours. Female compared to male family members were more verbal, more likely to facilitate patient involvement, but also displayed more autonomy detracting behaviours in the medical visit.</td>
</tr>
<tr>
<td>Eggly S, Harper FWK, et al</td>
<td>2011</td>
<td>USA</td>
<td>100%</td>
<td>Design: Cross-sectional Method: Analysis of video-recorded consultations</td>
<td>Sample: n= 109 patients NB: included only those self-identified as White American or Black American</td>
<td>Patient (+) Adapted version of the Karmanos Information Seeking Analysis System</td>
<td>– Most family members identified as a spouse (41%) or adult child (21%)&lt;br&gt;– Patients who were accompanied versus those who were unaccompanied did not differ with regard to age, t(107)=.99; sex, χ2(1)=.075; education χ2(2)=.023, or annual household income, χ2(5)=5.9. However, White patients were more likely than Black patients to have a family member with them (86% versus 40%) χ2(1)=23.64, p&lt;.000&lt;br&gt;– Patients with family members asked an average of 10.86 questions per interaction, compared to the average of 9.5 questions asked by patients who were alone&lt;br&gt;– The presence versus absence of family members was not a significant predictor of the total frequency of patient questions (p&lt;.39)</td>
<td>Age, sex, education and annual household income were not associated with accompaniment status. Family member presence did not decrease the number of questions asked by patients.</td>
</tr>
<tr>
<td>Ishikawa H, Hashimoto H, et al</td>
<td>2005a</td>
<td>Japan</td>
<td>100%</td>
<td>Design: Cross-sectional Method: Pre- &amp; post-visit questionnaires; analysis of audio-taped consultation</td>
<td>Sample: n= 145 patients (age &gt; 65 years) NB: included only those self-identified as White American or Black American</td>
<td>Patient (+) Pre-visit: Demographics and health status (SF-8; unvalidated translation) (+) Post-visit: Modified version of Patient-Centeredness Scale (+) Roter Interaction Analysis System&lt;br&gt;<strong>Key</strong>: (+)/(-)= validated/ unvalidated measure</td>
<td>– 43% of patients were accompanied&lt;br&gt;– Accompanied patients were significantly older (p&lt;.001), less educated (p&lt;.05), and in poorer health than unaccompanied counterparts (p&lt;.01)&lt;br&gt;– Patient contribution to the medical dialogue was significantly lower when a family member was present (p&lt;.001). This difference remained after controlling for potential confounders including age, gender, educational level and health status</td>
<td>Accompanied patients were older, less educated and had poorer health than unaccompanied patients. Accompanied patients talked less in the medical encounter than unaccompanied patients. The presence of a family member did not significantly increase the consultation length.</td>
</tr>
</tbody>
</table>
## Table 1. Patient, Family member, and Consultation Characteristics (Studies ordered by Quality Rating)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Quality Rating</th>
<th>Approach, Design &amp; Method</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Ishikawa H, Roter DL, et al&lt;sup&gt;17&lt;/sup&gt;</td>
<td>100%</td>
<td>Design: Cross-sectional Method: Pre- and post-visit questionnaire; analysis of audio-taped consultation</td>
<td>Sample: n= 145 patients (age &gt; 65 years) n= 63 family members NB: all matched patient-family member pairs</td>
<td>(+) Demographics and health status (SF-8; unvalidated translation) (+) Family member’s age, gender, relationship to patient (+) Roter Interaction Analysis System</td>
<td>– Compared to dyadic consultations, physicians used relatively less partnership-building behaviours (p&lt;.05) and positive talk in triadic consultations (p&lt;.05)</td>
<td>Physicians in triadic consultations provided more psychosocial information and less partnership-building and positive talk than physicians in dyadic consultations.</td>
</tr>
<tr>
<td>Japan</td>
<td>2005b</td>
<td></td>
<td>Geriatric clinic affiliated with university hospital. Medical Discipline: Geriatrics</td>
<td></td>
<td>– Family member composition: female (75%); wives (33%), husbands (18%), daughters (25%), sons (8%), daughters-in-law (8%), and other (8%) Percentage contribution to verbal activity during a consultation: - Physicians - 49% - Patients - 29% - Family members - 22% - In 41% of consultations, the family member was more verbally active than the patient. In 5% of consultations, the family member did not speak at all</td>
<td>Family members were mostly female and the patient’s spouse. Physicians were most verbally active, followed by the patients and then family members.</td>
</tr>
<tr>
<td>Ishikawa H, Roter DL, et al&lt;sup&gt;13&lt;/sup&gt;</td>
<td>100%</td>
<td>Design: Cross-sectional Method: Questionnaires, analysis of audio-taped consultation</td>
<td>Sample: n= 63 patients (age &gt; 65 years) n= 63 family members NB: all matched patient-family member pairs</td>
<td>(+) Patient demographics and health status (SF-8; unvalidated translation) (+) Family member’s age, gender, relationship to patient (+) Roter Interaction Analysis System</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Japan</td>
<td>2006</td>
<td></td>
<td>Geriatric clinic affiliated with university Medical Discipline: Geriatrics</td>
<td></td>
<td>– 31% of patients were accompanied at most or all visits – 36% of patients reported that they are never accompanied</td>
<td>A third of patients reported being accompanied regularly to consultations.</td>
</tr>
<tr>
<td>Rosland A, Piette J, et al&lt;sup&gt;20&lt;/sup&gt;</td>
<td>100%</td>
<td>Design: Cross-sectional Method: Questionnaire</td>
<td>Sample: n= 439 diabetic and heart failure patients n= 88 physicians Response Rate: Patients= 59% Physicians = 73% Setting: Patients and physicians affiliated with a University healthcare system Medical Discipline: Primary care</td>
<td>(+) Patient demographics (+) Health Literacy: Short Test of Functional Health Literacy in Adults (+) Self rated health status (+) Depressive symptoms: Patient Health Questionnaire-2 (+) Family structure and functioning: the Family APGAR (+) Family member participation in primary care visits</td>
<td>– Independent patient correlates of accompaniment included: - being married/partnered ([OR]:3.1; CI: 1.9-7.1) (p&lt;.001) - high satisfaction with family function ([OR]:2.4; CI: 1.4-4.2) (p&lt;.01) - low health literacy ([OR]:2.9; CI: 1.4-5.7) (p&lt;.01) - no college education ([OR]:2.4; CI: 1.4-4.1) (p&lt;.01) - higher levels of depression symptoms ([AOR]:1.3; CI: 1.1-1.6) (p&lt;.01) - functional limitations ([AOR]:1.9; CI: 1.1-3.4) (p&lt;.05)</td>
<td>Accompanied patients were more likely to be married/partnered, satisfied with their family functioning, have lower health literacy, lower education, higher levels of depressive symptoms and functional limitations.</td>
</tr>
<tr>
<td>USA</td>
<td>2011</td>
<td></td>
<td></td>
<td></td>
<td>– Accompanied patients were generally older (p&lt;.05) less physically functional (p&lt;.01), more likely to require family member assistance with activities of daily living (p&lt;.01) and diabetes management (p&lt;.001) – 45% of family members responded that they always or usually accompany the patient to the doctor. 47% of those family members talk to the doctor when attending the consultation – Treatment was the most frequent discussion topic in accompanied consultations (48%), followed by test results (47%), preventive strategies (41%), and prognosis (31%)</td>
<td>Accompanied patients were older, less physically functional, and required more family member assistance with daily activities. Just under half of family members reported accompanying the patient to a medical encounter, mostly to discuss treatment, tests, and preventive strategies.</td>
</tr>
<tr>
<td>Silliman R, Bhatti S, et al&lt;sup&gt;30&lt;/sup&gt;</td>
<td>100%</td>
<td>Design: Cross-sectional Method: Questionnaire</td>
<td>Sample: n= 357 family members identified by elderly diabetic patients Response Rate: 82% Setting: Three primary care sites in USA Medical Discipline: Diabetes</td>
<td>(+) Patient and family member sociodemographics, clinical characteristics, family involvement in patient care, and participation in medical encounters</td>
<td>– Accompanied patients were generally older (p&lt;.05) less physically functional (p&lt;.01), more likely to require family member assistance with activities of daily living (p&lt;.01) and diabetes management (p&lt;.001) – 45% of family members responded that they always or usually accompany the patient to the doctor. 47% of those family members talk to the doctor when attending the consultation – Treatment was the most frequent discussion topic in accompanied consultations (48%), followed by test results (47%), preventive strategies (41%), and prognosis (31%)</td>
<td>Accompanied patients were older, less physically functional, and required more family member assistance with daily activities. Just under half of family members reported accompanying the patient to a medical encounter, mostly to discuss treatment, tests, and preventive strategies.</td>
</tr>
</tbody>
</table>
### Authors
**Glasser M, Prohaska T, et al**

**Country**: USA  
**Year**: 1992

**Design**: Longitudinal  
**Method**: Interviews at initial visit, one week after visit and three months after initial visit  
**Sample**: n = 50 family members  
**Setting**: Medical clinic  
**Medical Discipline**: Geriatrics  
**Response Rate**: 71%  
**Results**: Of the 529 patients who visited the geriatric medical clinic, 193 (36%) patients were accompanied. The majority of accompanied patients were female (72%), widowed (62%) and most were between 76 to 90 years of age (70%). Most family members were female (80%) and younger than the patient. All family members were family members; 25 (50%) were the patient’s daughter, 15 (30%) were the patient’s spouse.

### Authors
**Beisecker AE**

**Country**: USA  
**Year**: 1988

**Design**: Cross-sectional  
**Method**: Pre-visit demographic questionnaire, tape recording of interaction, post-visit interview and opinion survey  
**Sample**: n = 106 patients  
**Setting**: Outpatient clinics  
**Medical Discipline**: Rehabilitation  
**Response Rate**: 81%  
**Results**: Overall, 35% of patients were accompanied to the consultation by a family member. Percentage of patients who brought a family member according to age; 17 to 25 years old = 69%, 25 to 59 = 20%, Over 60 = 57%.

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**Table 1. Patient, Family member, and Consultation Characteristics (Studies ordered by Quality Rating)**

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<th>Results</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glasser M, Prohaska T, et al</td>
<td>1992</td>
<td>95%</td>
<td>Design: Longitudinal Method: Interviews at initial visit, one week after visit and three months after initial visit</td>
<td>Sample: n = 50 family members</td>
<td>(-) Demographics interview</td>
<td>Of the 529 patients who visited the geriatric medical clinic, 193 (36%) patients were accompanied. The majority of accompanied patients were female (72%), widowed (62%) and most were between 76 to 90 years of age (70%). Most family members were female (80%) and younger than the patient. All family members were family members; 25 (50%) were the patient’s daughter, 15 (30%) were the patient’s spouse.</td>
<td>The majority of family members were female, most were daughters accompanying mothers or mothers-in-law and wives accompanying their husbands.</td>
</tr>
<tr>
<td>Prohaska T, Glasser M</td>
<td>1996</td>
<td>95%</td>
<td>Design: Longitudinal (3 time points; before medical visit, within one week of visit, 10 – 12 weeks after initial visit) Method: Face-to-face or telephone interview and/or written survey</td>
<td>Sample: n = 136 (aged &gt; 60 years) NB: 129 completed all three stages of data collection</td>
<td>(-) Demographics, reasons for visit, accompaniment status and medical issues</td>
<td>50% of patients were accompanied. Reported relationship with family member; spouse (41%), other family members (35%) and non-family members (25%). Accompanied patients were usually accompanied by the same person across medical visits. No significant differences by accompaniment status for patients’ age, race, marital status, family income, and self-rating of health. Unaccompanied patients had more years of formal education than accompanied patients (p&lt;.05). Accompanied patients were more likely to be female (45%) compared to unaccompanied patients (19%) (p&lt;.001). Unaccompanied patients were more likely to report that they understood their medical problems and/or what procedures were done (p&lt;.05).</td>
<td>Half of the patients were accompanied by a family member. The majority of family members were the patient’s spouse. Accompanied patients tended to be less educated and female. Accompanied patients tended to be less likely to understand the medical problems and procedures and desired more health care assistance from others than unaccompanied patients.</td>
</tr>
<tr>
<td>Schilling L, Scatena L, et al</td>
<td>2002</td>
<td>95%</td>
<td>Design: Cross-sectional Method: Questionnaire administered immediately after consultation</td>
<td>Sample: n = 121 unaccompanied patients n = 115 accompanied patients (in examination room) n = 57 physicians</td>
<td>(-) Patient/Family member: Patient/family member characteristics. Patients rated overall health, relationship to family member and reasons for accompaniment. (-) Physician: Visit type, complexity of the encounter, family member’s influence and helpfulness during the medical encounter</td>
<td>Family members accompanied 16% of patients into the examination room. Family member composition: Overall, 93% were family members; specifically, 55% were classified as spouse/partner. Patients who were older, less well educated and whose cases had a greater medical or social complexity were more likely to be accompanied (p&lt;.001). Physician rating of greater medical or social complexity was the only significant predictor of accompaniment (OR, 1.7; 95% CI, 1.4-2.1).</td>
<td>Family members and partners were often the family members. Patients whose cases were more medically or socially complex were more likely to have a family member.</td>
</tr>
<tr>
<td>Beisecker AE</td>
<td>1988</td>
<td>91%</td>
<td>Design: Cross-sectional Method: Pre-visit demographic questionnaire, tape recording of interaction, post-visit interview and opinion survey</td>
<td>Sample: n = 106 patients</td>
<td>(-) Demographic questionnaire</td>
<td>Overall, 35% of patients were accompanied to the consultation by a family member. Percentage of patients who brought a family member according to age; 17 to 25 years old = 69%, 25 to 59 = 20%, Over 60 = 57%.</td>
<td>Curvilinear relationship between age and the presence of a family member, younger and older patients brought family members to consultations more often than those aged 25 to 59.</td>
</tr>
</tbody>
</table>
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</thead>
<tbody>
<tr>
<td>Labreque M, Blanchard C, et al.</td>
<td>1991</td>
<td>91%*</td>
<td>Design: Cross-sectional Method: Analysis of audio-taped consultation, post-consultation interview</td>
<td>Sample: n=473 patients Response Rate: 46% Setting: University-based oncology practice Medical Discipline: Oncology</td>
<td>(-) Revised Physician Behaviour Checklist; Includes behaviours such as: addressed patient, describes future tests or treatments and provides verbal support</td>
<td>Accompanied and unaccompanied patients did not differ in sex or age. Family member composition: spouses (65%), children (10%), other relatives (including, siblings and parents) (6%), unknown (19%). Accompanied patients were more likely to have poorer performance status (p&lt;.001) and be undergoing active treatment (p&lt;.001). Accompanied visits were on average 3 minutes longer than unaccompanied visits (p&lt;.001)</td>
<td>No significant difference between the age and sex of accompanied and unaccompanied patients. Spouses most often accompanied patients. Accompanied patients tended to be more symptomatic. Physicians spent more time with patients who had a family member present.</td>
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<td>Baker PS, Yoels WC, et al.</td>
<td>1997</td>
<td>92%*</td>
<td>Design: Cross-sectional Method: Analysis of audio-taped medical consultations</td>
<td>Sample: n=36 triadic medical encounters (patient &gt; 60 years) Response Rate: N/A Setting: Clinic at urban university medical centre Medical Discipline: Geriatrics</td>
<td>(+) Transcripts analysed using a coding system (Verbal Exchange Initiation System)</td>
<td>86% of family members were female. Patients instigate laughter twice as often as family members. The patient was sometimes excluded from the topic of laughter: The patient was excluded 62% of the time when the family member instigated the laughter. The patient was excluded 25% of the time when the physician instigated the laughter</td>
<td>Most family members were female. Family members are not passive observers, and are often involved in laughter within a triadic consultation.</td>
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<tr>
<td>Eggly S, Penner LA, et al.</td>
<td>2006</td>
<td>90%*</td>
<td>Design: Cross-sectional Method: Self-report questionnaire and analysis of video-recorded medical consultations</td>
<td>Sample: n=28 interactions where ‘bad news’ were discussed Response Rate: N/A Setting: Multi-disciplinary outpatient oncology clinics at two cancer centres Medical Discipline: Oncology</td>
<td>(+) Demographics, familial relationship, knowledge and attitudes about cancer Analysis and Coding Global ratings of the interpersonal relationships: Global judgment section of Karmanos Accrual Assessment System, derived from the Moffitt Accrual Assessment System; 14 items rated on a 7 point rating scale, addressed the interpersonal relationship between the patient and physician or family members and physician</td>
<td>In consultations where “bad news” were discussed 86% of patients had at least one family member. Out of 38 family members, 17 were adult children, 13 were spouses, 1 parent, 1 friend, 3 classified as other and remaining were unknown. Family members asked significantly more questions per interaction than patients (m=16.86 vs. m=9.92, p&lt;.05). Treatment was the most frequent question topic (32% of patient questions and 48% of family member questions), followed by diagnostic testing, diagnosis, and prognosis. The frequency of questions asked was unrelated to patient or family member gender, race/ethnicity, marital status, relationship with family members, or gender concordance/discordance between patient and family member. The frequency of questions asked by the patients had a significant negative correlation with age (p&lt;.05), positive correlation with the level of education (p&lt;.05), and positive correlation with self-reported knowledge of science (p&lt;.05). Ratings of “trust” were positively correlated with the number of family member questions (p&lt;.05). The “closer” the relationship between the family members and the physicians, the fewer questions patients asked (p&lt;.05)</td>
<td>Family members frequently accompanied patients in consultations where “bad news” was discussed. Family members asked significantly more questions than patients. The younger and more educated asked more questions. The length of the consultation was significantly related to the number of questions asked by the family member and how much trust was in the family member-physician dyad. Family members asked more questions if they trusted the physicians more and if they perceived the physician to be less conversationally dominant in the consultation.</td>
</tr>
<tr>
<td>Street RL, Gordon HS</td>
<td>2008</td>
<td>90%*</td>
<td>Design: Cross-sectional Method: Quantitative analysis of audio-taped consultations; self-administered surveys</td>
<td>Sample: n=48 unaccompanied newly diagnosed lung cancer patients N=84 accompanied newly diagnosed lung cancer patients with n=84 family members Response Rate: 69% Setting: Thoracic surgery and (+) SF-12 Health Status</td>
<td>(+) Verbal analysis of doctor-patient-family member communication (+) SF-12 Health Status</td>
<td>Of accompanied patients, 82% bought one family member. No significant differences found between accompanied and unaccompanied patients on education, age, mental health status, and physical health status. No significant differences found between accompanied and unaccompanied visits on length of consultation, physician control of conversation, or physician’s use of facilitative communication</td>
<td>The presence of a family member was not associated with longer consultations, differences in physician’s facilitative communication, or control of the consultation. There were differences in the communication pattern of accompanied patients and their family members.</td>
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</tbody>
</table>
Table 1. Patient, Family member, and Consultation Characteristics (Studies ordered by Quality Rating)

| Authors                      | Year | Quality Rating | Approach, Design & Method                                                                 | Sample & Setting                                                                 | Measures specific to results Key: (+)(-) = validated/unvalidated measure | Results                                                                 | Summary                                                                 |
|------------------------------|------|----------------|------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------|-------------------------------------------------------------------------|-------------------------------------------------------------------------|
| Shields CG, Epstein RM, et al | 2005 | 88%            | Design: Randomised controlled trial Method: Random assignment of patients to 'accompanied' or 'unaccompanied' condition. Analysis of audiotaped consultations | Sample: n=30 patients (aged > 65); 13 (43%) accompanied condition; 17 (57%) unaccompanied condition | (+) Measure of Patient Centred Communication; 3 components measuring the degree to which the physicians elicited: 1. Patient symptoms, expectations, and functioning 2. Psychosocial aspects of the patient (e.g. family, work) 3. Involvement of patient in treatment plan | - Unaccompanied patients expressed more negative feelings than accompanied patients and their family members (p=.03)  - Patients talked more (p<.001), were more active participants (p=.04), and were more assertive than their family members (p=.001)  - Family members were more active participants when the physicians’ communication was more facilitative (e.g. partnership building, supportive talk) (p=.003) | There were few systematic differences found between accompanied and unaccompanied visits. |
| Glasser M, Prohaska T, et al  | 2001 | 86%            | Design: Cross-sectional Method: Pre- and post-visit self-administered questionnaires      | Sample: n=185 patients (aged > 60 years) n=48 caregivers                           | Patient  (-) Frequency and importance of accompaniment, demographics, health characteristics, patient satisfaction (+) Durham Geriatric Research, Education and Clinical Centres Scale - assess depression symptoms (11 items) (+) Dartmouth COOP Charts- assess quality of life Family member  (-) Perceptions of patient medical issues, reasons for accompaniment, and health characteristics | - 39% of patients were accompanied, 92% were accompanied by one person  - 47% of patients were most often accompanied by their spouse, followed by their daughter/daughter-in-law (29%). 76% of accompanied family members were accompanied by the same person most or all of the time  - Accompanied patients were more likely to be female (p=.008) and have lower incomes (p=.035) than unaccompanied patients  - Non significant trends showed that accompanied patients may be more likely to be non-white (p=.067). No significant difference in age or educational level was found between accompanied and unaccompanied patients  - 57% of accompanied patients reported health as fair or poor compared to 31% of unaccompanied patients (p=.001)  - 38% of accompanied patients reported more symptoms of depression compared to 15% of unaccompanied patients (p=.001) | Accompanied patients tended to be female, have lower income and be in poorer health. Accompanied and unaccompanied patients did not differ in age or educational level. Most often the same family member accompanied the patient to medical visits. |
| Wolff JL, Roter DL           | 2008 | 86%            | Design: Cross-sectional Method: Face-to-face interviews unrelated to any particular consultation | Sample: n=11 487 community-dwelling Medicare beneficiaries aged > 65 years Response Rate: Not stated Setting: Community Medical Discipline: None  (-) Accompaniment status- whether usually accompanied. demographics, health and disability status, family member’s relationship to patient | - 39% of participants reported being accompanied on medical visits; 53% were spouses, 32% adult children, 7% other relatives, 5% roommates, neighbours or friends and 3% were other nonrelatives  - Accompanied participants reported were older, attained less education, suffered poorer health, had more chronic illnesses and were more disabled than their unaccompanied counterparts | Accompanied patients tended to be older, less educated, in poorer health, had more chronic illnesses and more disabled than unaccompanied patients. Most family members were spouses, followed by adult children. |
Table 1. Patient, Family member, and Consultation Characteristics (Studies ordered by Quality Rating)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Country</th>
<th>Quality Rating</th>
<th>Approach, Design &amp; Method</th>
<th>Sample &amp; Setting</th>
<th>Measures specific to results Key: (+)/(-) = validated/ unvalidated measure</th>
<th>Results</th>
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</thead>
</table>
Response Rate: 78% Setting: Single participating oncology centre Medical Discipline: Oncology | (-) Partner’s experience of the patient’s diagnosis, subsequent medical consultations, and their involvement in medical decision-making (33 items) | – 48% of partners were present in the consultation at the time the diagnosis was given
74% of partners attended subsequent medical consultations once they were aware of the diagnosis | Nearly half of the partners were absent from the consultation when the diagnosis was given. Once partners were made aware of the diagnosis, the majority attended subsequent medical consultations. |
| Greene MG, Majerovitz SD, et al15 | 1994 | USA     | 82%k          | Design: Cross-sectional Method: Audiotaped consultation | NB: Secondary analysis of previous data set Sample: n= 15 dyadic first visits n= 15 triadic first visits n= 19 physicians NB: dyadic visits were matched on gender and race of both patients and physicians in triadic visits Response Rate: Patients = 80% Physicians = 95% Setting: Primary care hospital-based group practice in urban teaching facility Medical Discipline: General practice Audiotapes coded with the Multi-dimensional Interaction Analysis (MDIA) scoring system. (+) Functional Status Questionnaire | – In 14 out of 15 (93%) triadic consultations, the family members were female
– No significant difference in consultation length between triadic and dyadic visits
– Accompanied patients had poorer functional status than unaccompanied patients (p<.001). No significant difference in psychological status
– Patients in triads were rated to be less assertive and expressive than patients in dyads (p=.001)
– No difference in the number of physician-raised topics between triads and dyads. Patients raised fewer topics in triadic encounters than dyadic encounters (p=.04). No significant difference in number of medical and psychosocial topics raised
– Physicians’ responsiveness (i.e. quality of question asking, information-giving and supportiveness) did not differ between triadic and dyadic medical encounters
– There was significantly less joint decision-making in triads than dyads (p<.01) | Most family members were female. Accompanied patients compared to unaccompanied patients were more unwell physically, but not psychologically. Length of consultation did not increase with the presence of a family member, however there was less joint decision making in triadic consultations. Patients in triadic encounters raised fewer issues than those in dyadic encounters. Physicians’ responsiveness to topics raised did not differ between triadic and dyadic medical encounters. |
| Brown JB, Brett P, et al14 | 1998 | Canada  | 82%k          | Design: Cross- sectional Method: Questionnaires completed by physicians of 100 consecutive patients | Sample: n= 8 physicians (800 questionnaires) Response Rate: Not stated Setting: 3 academic and 5 community-based practices Medical Discipline: General practice | (-) Patient’s demographics, medical characteristics, accompaniment status, physician’s perceptions of family member and of the consultation (12 item) | – 19% of adult patients were accompanied
– Elderly patients were most frequently accompanied. Accompanied patients were more likely to have acute problems rather than chronic problems
– Accompanied patients were most frequently accompanied by one person (74%).
– 73% of family members were female
– 24% of family members were spouses | Elderly patients were frequently accompanied and the accompanying person was most often a female. |
| Botelho RJ, Lue B, et al11 | 1996 | USA     | 64%k          | Design: Cross- sectional Method: Self-administered questionnaire | Sample: n= 457 patients Response Rate: Estimated to be at least 55% Setting: Family medicine centre (urban training unit practice) Medical Discipline: General practice | (-) Demographics, accompaniment status and preference for a family member | – 25% of patients were accompanied by a family member (percentage excludes patients under the age of 18)
– Lower educational level (p<.01), higher emotional involvement scores (p=.004) and being married (p=.001) significantly predicted accompaniment
– Accompanied patients were mostly accompanied by a spouse (40%), a friend (27%), daughter (16%) or mother (9%) | Patients with lower educational level, higher emotional involvement and those that were married were more likely to be accompanied. The spouse most often accompanied the patient. |
<table>
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<tr>
<th>Authors</th>
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<th>Sample &amp; Setting</th>
<th>Measures specific to results Key: (+)/(-)= validated/unvalidated measure</th>
<th>Results</th>
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<tbody>
<tr>
<td>Beisecker AE, Moore WP&lt;sup&gt;1&lt;/sup&gt;</td>
<td>1994</td>
<td>90%&lt;sup&gt;p&lt;/sup&gt;</td>
<td>Design: Cross-sectional Method: Semi structured face-to-face interviews</td>
<td>Sample: n = 12 oncologists (6 medical, 4 surgical and 2 radiation)</td>
<td>(-) Perceptions of cancer patients/family members within medical encounters</td>
<td>Physicians noted that most family members were the patients' spouses, followed by parents, siblings and adult children. Family members were most often present in the consultation to determine a treatment plan, immediately after the cancer recurred and further decisions needed to be made and when the patient reached the terminal stage. Parents were family members and, mostly accompanied patients. Family members most often present during consultations where there is a change in the patient’s condition and/or decisions need to be made.</td>
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<tr>
<td>USA</td>
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<td>Tertiary medical facility Response Rate: 100% (purposive sampling) Medical Discipline: Oncology</td>
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<td>Main DS, Holcomb S, et al&lt;sup&gt;11&lt;/sup&gt;</td>
<td>2001</td>
<td>80%&lt;sup&gt;p&lt;/sup&gt;</td>
<td>Design: Multimethod comparative case study Method: Direct observation of clinical encounters, detailed field notes</td>
<td>Sample: n = 1600 patient encounters n = 50 clinicians</td>
<td>(-) Structured observational checklists, unstructured dictated field notes and interviews of staff regarding the delivery of preventative services and their perspectives on practice processes</td>
<td>− 96% of family members were family members. − Family members were mostly wives (29%), daughters (19%), and husbands (19%); − Elderly patients were most likely accompanied by wives and daughters, in these consultations frequent questions were asked by family members about information exchange and collaboration occurred between providers and family members. Most family members were family members, and mostly females.</td>
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<td>USA</td>
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<td>18 family practices Response Rate: N/A Setting: Family Medical Discipline: General practice</td>
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<td>Barone AD, Yoels WC, Clair JM&lt;sup&gt;19&lt;/sup&gt;</td>
<td>1999</td>
<td>75%&lt;sup&gt;n, p&lt;/sup&gt;</td>
<td>Design: Cross-sectional. Method: Structured face-to-face interviews</td>
<td>Sample: n = 18 geriatricians NB: Geriatrician data included Response Rate: 75% Setting: University based Centre for Aging Medical Discipline: Geriatrics</td>
<td>(-) Structured open-ended interview questions on physicians’ views concerning family members and their effects on medical visits</td>
<td>Geriatricians estimated that 55% of geriatric patients were accompanied by a family member. − 72% of the geriatricians stated that daughters were the most common family members to accompany the patient. Most geriatric consultations include a family member. Daughters most often accompanied geriatric patients.</td>
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<td>Petronio S, Sargent J, et al&lt;sup&gt;10&lt;/sup&gt;</td>
<td>2004</td>
<td>6.5%&lt;sup&gt;n, j, n, p&lt;/sup&gt;</td>
<td>Design: Cross-sectional Method: Semi-structured survey</td>
<td>Sample: n = 96 university students (mean age 22) Response Rate: Not stated Setting: University Medical Discipline: Various</td>
<td>(-) Demographic characteristics, attitudes towards consultations [on a scale of 1 (strongly agreed) to 6 (strongly disagreed)]</td>
<td>81% of participants reported accompanying their relatives more than their friends to physician visits. Family members usually accompany their family members rather than friends to medical visits.</td>
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<tr>
<td>Beisecker A, Brecheisen M, et al&lt;sup&gt;18&lt;/sup&gt;</td>
<td>1997</td>
<td>90%&lt;sup&gt;p&lt;/sup&gt;</td>
<td>Design: Cross-sectional Method: Individual semi-structured telephone interviews</td>
<td>Sample: n = 18 heterogeneous cancer patients accompanied to oncology consultation n = 17 family members NB: 7 matched pairs Response Rate: Not stated Setting: Cancer support groups and university clinic Medical Discipline: Oncology</td>
<td>(-) Family members influence on consultation and relationships, family member helpfulness, and coalition formation. 6-point scale ranking of occurrence of family member roles, helpfulness, and the amount of change in the medical encounter when a family member was present</td>
<td>Patients reported main family member’s relationship; spouse (50%); parent (17%); other relative (11%), child (11%) and friend (11%); 71% of family members were female. The primary family member was unavailable, only half of the patients chose an alternative family member. Patients reported that they were accompanied to medical visits mostly at the beginning of treatment (72%), when test results were discussed (72%), or when treatment decisions had to be made (61%). The main family member was a spouse, and mostly female. Patients were most often accompanied to important consultations such as the beginning of treatment, test results, or when treatment decisions were needed.</td>
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<tr>
<td>Beisecker AE&lt;sup&gt;13&lt;/sup&gt;</td>
<td>1989</td>
<td>74%&lt;sup&gt;n, l, n, p&lt;/sup&gt;</td>
<td>Design: Cross-sectional Method: Pre-visit demographic questionnaire, tape recording of interaction, post-visit interview and opinion survey</td>
<td>Sample: n = 21 elderly patients (aged &gt; 60 years) NB: 12 triadic and 9 dyadic interactions</td>
<td>(-) Interaction analysis of tape recorded consultation</td>
<td>− No significant difference was found between the length of accompanied and unaccompanied consultations; − The majority of comments were made by the doctor to the patient (28%) and by the patient to the doctor (29%); − Family member’s activity mainly occurred during history and feedback sections of the consultation, rather than the physical examination. The presence of a family member did not lengthen the interaction, which suggests that the presence of a family member may reduce the interaction time between the doctor and patient. The family member was an initiator and recipient of a moderate amount of communication with the doctor.</td>
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<td>USA</td>
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<td>N/A Setting: Outpatient clinic Medical Discipline: Rehabilitation</td>
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Table 1. Patient, Family member, and Consultation Characteristics (Studies ordered by Quality Rating)

Note: Score of 1 or 0 on the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Item number from quantitative [QN] and qualitative [QL] studies quality rating checklist)

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<th>Item</th>
<th>Description</th>
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<tr>
<td>a</td>
<td>Question description [QN 1; QL 1]</td>
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<tr>
<td>b</td>
<td>Study design [QN 2; QL 2]</td>
</tr>
<tr>
<td>c</td>
<td>Study context description [QL 3]</td>
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<tr>
<td>d</td>
<td>Theoretical/empirical connection [QL 4]</td>
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<td>e</td>
<td>Sampling strategy [QN 3; QL 5]</td>
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<td>f</td>
<td>Subject characteristics reported [QN 4]</td>
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<td>g</td>
<td>Data collection methods [QN 5, 6, 7; QL 6]</td>
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<td>h</td>
<td>Means of assessment reported [QN 8]</td>
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<td>i</td>
<td>Sample size [QN 9]</td>
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<td>j</td>
<td>Data analysis [QN 10; QL 7]</td>
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<td>k</td>
<td>Estimate of variance reported [QN 11]</td>
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<td>l</td>
<td>Controlled for confounding [QN 12]</td>
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<td>m</td>
<td>Results reported in sufficient detail [QN 13]</td>
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<td>n</td>
<td>Verification procedure to establish credibility [QL 8]</td>
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<td>o</td>
<td>Conclusions supported by the results [QN 14; QL 9]</td>
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<td>p</td>
<td>Reflexivity of the account [QL 10]</td>
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<td>Authors</td>
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| Ishikawa H, Roter DL, et al¹⁴ | 2006 | 100%           | Design: Cross-sectional Method: Pre- and post-visit questionnaire; analysis of audio-taped consultation | Sample: n= 145 patients (age > 65 years)  
**Method:** Geriatric clinic affiliated with university hospital.  
**Medical Discipline:** Geriatrics  
**Response Rate:** 87%  
**Setting:** Geriatric clinic affiliated with university hospital.  
**Medical Discipline:** Geriatrics | (+) Family member’s role:  
Patient expectation and family member intention (6 items, 3 point Likert scale, 1 = ‘not at all’ to 3 = ‘always’). Divided into 2 subscales, indirect and direct roles)  
(−) Family member’s role:  
Patient expectation and family member intention (6 items, 3 point Likert scale, 1 = ‘not at all’ to 3 = ‘always’). Divided into 2 subscales, indirect and direct roles) | - Highest rated role by both patient and family member was ‘remember what the physician told’  
- Male patients those who had a poorer health status expected their family members to assume a more direct role (p<0.05)  
- Family member’s intention of a more active role was higher when the patient had poorer health (p<0.05) and when the family member was the primary caregiver and not the spouse (p=0.05) | Patients expected their family members to assume a more indirect role, while family members anticipated a direct role.  
Primary caregivers and those looking after patients in poorer health took on a more active role. Similarly, those in poorer health expected their family members to play a more active role. |
| Ishikawa H, Roter DL, et al¹⁴ | 2005b| 100%           | Design: Cross-sectional Method: Pre- and post-visit questionnaire; analysis of audio-taped consultation | Sample: n= 63 patients (age > 65 years)  
**Method:** Questionnaires, analysis of audio-taped consultation  
**Response Rate:** 83% (pairs)  
**Setting:** Geriatric clinic affiliated with university hospital.  
**Medical Discipline:** Geriatrics | (+) Family member’s role:  
Patient expectation and family member intention (6 items, 3 point Likert scale, 1 = ‘not at all’ to 3 = ‘always’). Divided into 2 subscales, indirect and direct roles)  
(−) Family member’s role:  
Patient expectation and family member intention (6 items, 3 point Likert scale, 1 = ‘not at all’ to 3 = ‘always’). Divided into 2 subscales, indirect and direct roles) | - Patients expected their family members to assume more of an indirect role than direct communication role (indirect score mean=6.82; direct score mean=5.84, p=0.002).  
- Family members anticipated playing a greater role than patients had expected [indirect score mean = 7.22 (SD=2.19); direct score mean = 7.48 (SD=1.98)] | Patients expected their family members to assume a more indirect role, while family members anticipated a direct role. |
**Response Rate:** 82%  
**Setting:** 3 primary care sites  
**Medical Discipline:** Diabetes | Sample: n= 357 family members of elderly diabetic patients  
**Method:** Quantitative Studies  
**Response Rate:** 95%  
**Setting:** 3 primary care sites  
**Medical Discipline:** Diabetes | (+) Family member participation in medical encounters  
Most common reasons for accompaniment/discussion with the doctor were to:  
- Get own questions answered (86%)  
- Help patient ask questions (74%)  
- Provide information the patient forgot (61%)  
- Make sure the doctor listens to the patient (48%)  
- Provide information that the patient is reluctant to give (28%) | Family members often had their own questions for the doctor, but also wanted to support the patient, ensure the doctor listened to the patient, and ensure that the patient provided the required information. | Providing transportation was the main role of the family member, followed by physical and emotional support. |
### Table 2. Family member Roles (Studies ordered by Quality Rating)

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<tr>
<th>Authors</th>
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<th>Results</th>
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<tr>
<td>Schilling LM, Scatena L, et al</td>
<td>2002</td>
<td>95%</td>
<td><strong>Design:</strong> Cross-sectional Method: Self-administered questionnaire immediately after visits.</td>
<td>Sample: n = 121 unaccompanied patients n = 115 accompanied patients (in examination room) n = 57 physicians</td>
<td>(-) Patient/family member: Reasons for accompaniment</td>
<td>Patients and family members Family member roles most endorsed by patients and family members (37-58%): - Transportation - Provide company and emotional support - Help with communication concerns to the doctor - Help remember physician’s advice and instructions - Express concerns regarding the patient to the physician Family member roles moderately endorsed by patient and family members: - Help make decisions (patient-35%; family member-28%) Family member roles least endorsed by patients and family members (4-13%) - Help with language barriers - Help with insurance/ payment forms <strong>Physicians:</strong> Physicians reported that family members engaged in active behaviours such as clarifying or expanding history (65%), supporting or encouraging the patient (65%), asking questions or requesting explanations (48%), discussing concerns about the patient’s symptoms/problems (45%), making evaluation or treatment requests (17%) and taking notes (13%)</td>
<td>Patients and family members thought that the presence of a family member was helpful for a range of reasons including practical, social and emotional support and to facilitate communication.</td>
</tr>
<tr>
<td>Street RL, Gordon HS</td>
<td>2008</td>
<td>90%</td>
<td><strong>Design:</strong> Cross-sectional Method: Analysis of audiotaped consultations; self-administered surveys</td>
<td>Sample: n = 48 unaccompanied newly diagnosed lung cancer patients n = 84 accompanied newly diagnosed lung cancer patients with n = 84 family members Setting: Thoracic surgery and oncology clinics within a large Medical Centre Response Rate: 69% Medical Discipline: Oncology</td>
<td>(-) Verbal analysis of doctor-patient-family member consultation communication Family members’ divided into three categories (according to total contribution patient + family member activity) - Observer: &lt;40% - Partner: 40–60% - Advocate: &gt;60% (+) SF-12 - Health Status</td>
<td>Family member participation were coded as follows: - 49% Observer - 18% Partners - 33%-Advocates and surrogates The role that the family member played did not vary as a function of the patient’s age, education, race, physical and mental health status or the physicians’ use of facilitative communication.</td>
<td>Family member roles varied along a passive to active spectrum, with half of the family members coded as passive observers. Their roles were not influenced by the patient’s age, education, race, physical and mental health status or the physicians’ use of facilitative communication.</td>
</tr>
<tr>
<td>Glasser M, Prohaska T et al</td>
<td>2001</td>
<td>86%</td>
<td><strong>Design:</strong> Cross-sectional Method: Pre- and post-visit self-administered questionnaires</td>
<td>Sample: n = 185 patients (aged&gt; 60 years) n = 48 caregivers Setting: 3 general practice and 1 geriatric practice Medical Discipline: General Practice and Geriatrics</td>
<td>Patient &amp; Family member (-) List reasons for accompaniment</td>
<td>Most common reasons for accompaniment were: - Transportation (68%) - General assistance (50%) - Ensuring essential information was provided (34%) - Emotional support (34%)</td>
<td>Transportation is the most common reason for accompaniment, followed by general assistance, ensuring essential information was provided and emotional support.</td>
</tr>
<tr>
<td>Wolff JL, Roter DL</td>
<td>2008</td>
<td>86%</td>
<td><strong>Design:</strong> Cross-sectional Method: Face-to-face interviews unrelated to any particular consultation</td>
<td>Sample: n = 11 487 community-dwelling Medicare beneficiaries aged&gt; 65 years Setting: Community</td>
<td>(-) Reasons for accompaniment (9 items)</td>
<td>Family member roles included; - Assisting with logistics such as transportation (52%) - Recording physician comments and instructions (44%) - Communicating information about the patient to physician (42%)</td>
<td>The roles of the family member mostly include transportation, facilitating in communication and providing moral support.</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Country</td>
<td>Quality Rating</td>
<td>Approach, Design &amp; Method</td>
<td>Sample &amp; Setting</td>
<td>Measures specific to results</td>
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<tr>
<td>Ellingson LL</td>
<td>2002</td>
<td>USA</td>
<td>90%</td>
<td>Cross-sectional</td>
<td>Secondary analysis of previous data set</td>
<td>Analysis of ethnographic field notes &amp; transcribed consultations using grounded theory</td>
<td>Roles carried out by family members</td>
</tr>
<tr>
<td>Beisecker AE, Moore WP</td>
<td>1994</td>
<td>USA</td>
<td>90%</td>
<td>Cross-sectional</td>
<td>Participants not stated</td>
<td>Physician’s perceptions of family role in consultation</td>
<td>11 out of 12 (92%) physicians perceived support to be the main role of the family member.</td>
</tr>
<tr>
<td>Brown JB, Brett P et al</td>
<td>1998</td>
<td>Canada</td>
<td>68%</td>
<td>Cross-sectional</td>
<td>Questionnaires</td>
<td>Physician’s perceptions of family role in consultation</td>
<td>69% of physicians described the role of the family member as ‘patient advocates’.</td>
</tr>
</tbody>
</table>

**Qualitative Studies**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Country</th>
<th>Quality Rating</th>
<th>Approach, Design &amp; Method</th>
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<td>USA</td>
<td>90%</td>
<td>Cross-sectional</td>
<td>Participants not stated</td>
<td>Physician’s perceptions of family role in consultation</td>
<td>Providing support and comfort; calming patients; offering moral support; providing information; facilitating logistics of visit; serving as patient’s advocate</td>
<td>Physicians thought that the main roles of the family member were support, information gathering, and information sharing.</td>
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<td>Brown JB, Brett P et al</td>
<td>1998</td>
<td>Canada</td>
<td>68%</td>
<td>Cross-sectional</td>
<td>Questionnaires</td>
<td>Physician’s perceptions of family role in consultation</td>
<td>69% of physicians described the role of the family member as ‘patient advocates’.</td>
<td>Generally, physicians perceived that family members were supportive and that they assumed the advocate role in the consultation.</td>
</tr>
</tbody>
</table>

**Table 2. Family member Roles (Studies ordered by Quality Rating)**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
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<th>Approach, Design &amp; Method</th>
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<th>Results</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Speice J, Harkness J, et al</td>
<td>2000</td>
<td>80%</td>
<td>USA</td>
<td>Design: Cross-sectional Method: Focus groups</td>
<td>Sample: n= 96 patients (various stages of cancer treatment, many breast cancer patients n= 40)</td>
<td>Structured focus group discussions regarding family member involvement in cancer consultations.</td>
<td>Patients reported that when family members were involved, they were helpful in asking questions, recalling details, gathering information, taking notes, and reporting symptoms and behaviours that patients may have forgotten or were hesitant to share. Patients thought that family members served as a resource for comfort and emotional support, and to help make critical decisions about treatment.</td>
<td>Patients reported that family members were helpful by providing informational support, emotional support and helped to decide on treatment. Patients and family members may need to renegotiate roles as the illness changes.</td>
</tr>
<tr>
<td>Petronio S, Sargent J, et al</td>
<td>2004</td>
<td>65%</td>
<td>USA</td>
<td>Design: Cross-sectional Method: Semi-structured survey</td>
<td>Sample: n= 96 university students (mean age 22)</td>
<td>(-) Semi-structured survey focused on the perceptions regarding informal healthcare advocates e.g., role during medical interviews</td>
<td>Roles of the participants as derived by the authors included: clarification, correction and refutation (i.e., when the family member or friend perceived that the patients gave misleading information) and also altruistic supporter (when family members or friend viewed that they accompanied the patient because of loyalty helpfulness or supportiveness)</td>
<td>Informal healthcare advocates appear to provide clarification, correction, refutation and altruistic support to family members during medical interviews.</td>
</tr>
<tr>
<td>Beisecker AE, Brecheisen MA, et al</td>
<td>1997</td>
<td>90%</td>
<td>USA</td>
<td>Design: Cross-sectional Method: Individual semi-structured telephone interviews unrelated to any particular consultation</td>
<td>Sample: n= 18 heterogeneous cancer patients n= 17 family members NB: 7 were matched patient-family member pairs</td>
<td>(-) Rank on a 6-point scale according to frequency of family member roles (1 = did not occur at all to 6 = occurred all of the time)</td>
<td>Patients and family members perceived the main roles of family members to be: – provide support and family membership – help increase understanding – ask questions – provide transportation</td>
<td>The main roles filled by family members were to support, help increase understanding, ask questions and provide transportation.</td>
</tr>
<tr>
<td>Beisecker AE</td>
<td>1989</td>
<td>74%</td>
<td>USA</td>
<td>Design: Cross- sectional Method: Pre-visit demographic questionnaire, tape recording of interaction, post-visit interview and opinion survey. NB: Secondary analysis of previous data set</td>
<td>Sample: n= 21 elderly patients (aged&gt; 60 years) NB: 12 triadic interactions and 9 dyadic interactions</td>
<td>(-) Interaction analysis of tape recorded consultation</td>
<td>Through observation of the interactions, three family member roles were used by researchers to describe role functions: Watchdog: Provided information for the doctor; Elaborated patient information; Clarified and obtained information from the doctor Significant other: Provided the doctor with feedback about their behaviour; Often caused the doctor to switch from addressing the patient to directing comments to the family member Surrogate patient: Took over the patient’s role; Interrupted the patient, answered questions for the patient and provided unrequested information; Family member acted as voice and advocate for the patient</td>
<td>The role of the family member is not homogenous and may serve different functions for the patient and doctor.</td>
</tr>
</tbody>
</table>
Table 2. Family member Roles (Studies ordered by Quality Rating)

Note: Score of 1 or 0 on the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Item number from quantitative [QN] and qualitative [QL] studies quality rating checklist)

| a | Question description [QN 1; QL 1] |
| b | Study design [QN 2; QL 2] |
| c | Study context description [QL 3] |
| d | Theoretical/empirical connection [QL 4] |
| e | Sampling strategy [QN 3; QL 5] |
| f | Subject characteristics reported [QN 4] |
| g | Data collection methods [QN 5, 6, 7; QL 6] |
| h | Means of assessment reported [QN 8] |
| i | Sample size [QN 9] |
| j | Data analysis [QN 10; QL 7] |
| k | Estimate of variance reported [QN 11] |
| l | Controlled for confounding [QN 12] |
| m | Results reported in sufficient detail [QN 13] |
| n | Verification procedure to establish credibility [QL 8] |
| o | Conclusions supported by the results [QN 14; QL 9] |
| p | Reflexivity of the account [QL 10] |
### Table 3. Attitudes of Patients, Family members and Physicians Toward Family member Involvement (Studies ordered by Quality Rating)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Quality Rating</th>
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<th>Approach, Design &amp; Method</th>
<th>Sample &amp; Setting</th>
<th>Measures specific to results</th>
<th>Results</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repetto L, Piselli P, et al 37</td>
<td>2009</td>
<td>86% b, l</td>
<td>Italy</td>
<td>Quantitative Design: Cross-sectional</td>
<td>n= 598 cancer</td>
<td>(-) Information on diagnosis,</td>
<td>87% of patients thought that their families were their main</td>
<td>Most patients thought that family patients and the</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td>Method: Structured</td>
<td>patients with a newly</td>
<td>treatment related side-effects,</td>
<td>source of support in the disease experience and 79% wanted</td>
<td>members supported them and  they wanted to have family members to</td>
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<td></td>
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<td></td>
<td></td>
<td>interviews</td>
<td>diagnosed neoplasm or disease</td>
<td>and prognosis disclosure;</td>
<td>participate in the oncology consultation</td>
<td>participate in oncology consultations.</td>
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<tr>
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<td>progression (aged&gt; 65 yrs)</td>
<td>patients communication</td>
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<td></td>
<td>Response Rate: 96%</td>
<td>preferences and satisfaction</td>
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<td>Setting: 47 non-academic</td>
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<td>medical centres</td>
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<td>Medical Discipline: Oncology</td>
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</tr>
<tr>
<td>Botelho RJ, Lue B, et al 33</td>
<td>1996</td>
<td>64% m</td>
<td>USA</td>
<td>Quantitative Design: Cross-sectional</td>
<td>n= 457 adult patients</td>
<td>(-) Preference for a family</td>
<td>30% of unaccompanied patients wished that a family</td>
<td>Many patients supported being accompani</td>
</tr>
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<td></td>
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<td></td>
<td>Method: Self-administered</td>
<td>(estimation)</td>
<td>member and 4 items from the</td>
<td>member or friend had accompanied them to the visit. Of</td>
<td>ed by a consultation. Patients who wished someone</td>
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<td></td>
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<td></td>
<td>questionnaire</td>
<td>Setting: Family medicine</td>
<td>Family Emotional Involvement</td>
<td>those who wished someone had accompanied them, 44%</td>
<td>had accompanied them mostly expressed a desire for a family</td>
</tr>
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<td></td>
<td></td>
<td>centre (urban training unit)</td>
<td>and Criticism Scale</td>
<td>expressed a preference for their spouse, 20% preferred a</td>
<td>member, in particular a spouse, to accompany them to their visit.</td>
</tr>
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<td>Medical Discipline: General</td>
<td></td>
<td>friend</td>
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<td></td>
<td></td>
<td>practice</td>
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<tr>
<td>Sinfield P, Baker R, et al 40</td>
<td>2008</td>
<td>75% g, n, p</td>
<td>UK</td>
<td>Qualitative Design: Cross-sectional</td>
<td>n= 10 female partners</td>
<td>(-) Open ended questions were</td>
<td>Partners felt it was important to accompany patients when</td>
<td>Partners are generally involved in oncology consultations and focus</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td>Method: Semi-structured interview</td>
<td>of prostate cancer patients</td>
<td>asked about all phases of their</td>
<td>attending hospital for further tests even though they had not</td>
<td>on supporting the patient. They thought it was important they</td>
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<td></td>
<td>NB: Study included prostate</td>
<td>partners’ care (e.g. initial</td>
<td>been invited or encouraged to be involved by the family</td>
<td>attend consultations. They appreciated an invitation to</td>
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<td></td>
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<td>cancer patients, but patient</td>
<td>presentation, diagnosis,</td>
<td>physician or the hospital</td>
<td>attend the consultation, as some partners felt they were a</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td>data not relevant for this</td>
<td>treatment decision-making)</td>
<td>Most partners felt pleased they had attended hospital to</td>
<td>burden to the physician.</td>
</tr>
<tr>
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<td>review</td>
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<td>support the patient and reported positive (e.g. welcoming</td>
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<td></td>
<td>Response Rate: Not stated</td>
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<td>nature of staff) and negative (e.g. feeling excluded or</td>
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<td>Setting: Two urology</td>
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<td>ignored during consultations) experiences</td>
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<td></td>
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<td>outpatient clinics and two</td>
<td></td>
<td>Partners felt it was important to hear information first-hand</td>
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<td></td>
<td>cancer charities</td>
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<td>from the specialist because it made it easier to participate</td>
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<td></td>
<td>Medical Discipline: Oncology</td>
<td></td>
<td>in subsequent discussions. They wanted to support the patient</td>
<td></td>
</tr>
<tr>
<td>Morris SM, Thomas C 39</td>
<td>2001</td>
<td>75% n, p</td>
<td>UK</td>
<td>Qualitative Design: Cross-sectional</td>
<td>n=47 heterogeneous cancer patients (purposive sampling)</td>
<td>(-) Guided interview schedule</td>
<td>Carers felt they needed an invitation from patients to be involved. They</td>
<td>Carers felt that their involvement was important, and appreciated</td>
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<td></td>
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<td>Method: Questionnaires with an invitation for an</td>
<td>(e.g. narrative, reflections on experience, exploration of social</td>
<td>(e.g. narrative, reflections on experience, exploration of social</td>
<td>the opportunity to be involved in consultations. Carers placed a</td>
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<td>in-depth interview (joint</td>
<td>network and support)</td>
<td>network and support)</td>
<td>continuing autonomy and independence</td>
<td>greater importance on access to information than patients.</td>
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<td>patient &amp; carer or separate interviews)</td>
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<td>Carers appreciated that health professionals included them</td>
<td></td>
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<td></td>
<td>Response Rate: Patients = 51%; Carers = 48%</td>
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<td>Carers found it difficult when they were actively excluded and at</td>
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<td>Setting: Four hospitals</td>
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<td>times felt ‘superfluous’ in the consultation.</td>
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<td>Medical Discipline: Oncology</td>
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<td>Carers wanted to be involved and informed, and at times</td>
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<td>were uncertain about their role in the medical setting</td>
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<td>Carers rated the importance of information about</td>
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<td>‘medication and side-effects, treatment plans, and what to</td>
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<td>expect’ higher than the patients did</td>
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<tr>
<td>Medical Discipline</td>
<td>Setting</td>
<td>Response Rate</td>
<td>Sample</td>
<td>Study aim</td>
<td>Sample size</td>
<td>Approach</td>
<td>Design</td>
<td>Method</td>
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<tr>
<td>Geriatrics</td>
<td>University based</td>
<td>75%</td>
<td>100 geriatricians</td>
<td>Attitudes towards attending consultations on a scale of 1 (strongly agreed) to 6 (strongly disagreed)</td>
<td>n = 96 university students (mean age 22)</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured survey</td>
</tr>
<tr>
<td>Oncology</td>
<td>Oncology team</td>
<td>90%</td>
<td>12 oncologists (6 medical, 4 surgical and 2 radiation)</td>
<td>Perceptions of cancer patients' family members within medical encounters, description of family members</td>
<td>n = 12 oncologists (purposive sampling)</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured face-to-face interviews</td>
</tr>
<tr>
<td>Geriatrics</td>
<td>Large Midwestern university</td>
<td>65%</td>
<td>18 geriatricians</td>
<td>Attitudes towards attending consultations on a scale of 1 (strongly agreed) to 6 (strongly disagreed)</td>
<td>n = 96 university students (mean age 22)</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured survey</td>
</tr>
<tr>
<td>Oncology</td>
<td>Radiation</td>
<td>90%</td>
<td>96 oncologists</td>
<td>Perceptions of cancer patients' family members within medical encounters, description of family members</td>
<td>n = 12 oncologists (purposive sampling)</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured face-to-face interviews</td>
</tr>
</tbody>
</table>

**Table 3. Attitudes of Patients, Family members and Physicians Toward Family member Involvement (Studies ordered by Quality Rating)**

<table>
<thead>
<tr>
<th>Family members believed that they were helping both the patient and physician in providing better medical care to the patient.</th>
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<th>Family members believed that they were helping both the patient and physician in providing better medical care to the patient.</th>
</tr>
</thead>
<tbody>
<tr>
<td>They also did not view it as a burden to accompany their family or medical visits, they did not mind helping in medical encounters and believed that they did not frequently intervene in the physician-patient dialogue.</td>
<td>Oncologists generally preferred the involvement of a family member, especially if they had a positive attitude, were knowledgeable, or were aware of the patient’s wishes. Some physicians detected that the age and gender of the family member can influence their level of involvement in the consultation.</td>
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</tr>
</tbody>
</table>

**Studies examining the attitudes of physicians only**

<table>
<thead>
<tr>
<th>Beisecker AE, Moore WP</th>
<th>90%</th>
<th>Qualitative</th>
<th>Cross-sectional</th>
<th>Semi-structured face-to-face interviews.</th>
<th>Sample: n = 12 oncologists (purposive sampling)</th>
<th>Oncologists appreciated family members who understood patient values’ desires</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ellingson LL</td>
<td>90%</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Observational; ethnographic field notes</td>
<td>NB: Secondary analysis of previous data set</td>
<td>Oncology team members felt that the involvement of a family member generally did not shift the focus of their communication away from the patient</td>
</tr>
<tr>
<td>Barone AD, Yoels WC, Clair JM</td>
<td>75%</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Structured face-to-face interviews</td>
<td>Sample: n = 18 geriatricians</td>
<td>Geriatricians preferred patients to provide personal and medical information, but if they perceived the information to be insufficient they then asked family members. They valued and sought family members’ input as they can provide rich amounts of required information. Some geriatricians preferred to speak privately with</td>
</tr>
<tr>
<td>2004 USA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1994 USA</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1999 USA</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
**Table 3. Attitudes of Patients, Family members and Physicians Toward Family member Involvement (Studies ordered by Quality Rating)**

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Authors</th>
<th>Year</th>
<th>Design</th>
<th>Base</th>
<th>Sample</th>
<th>Methods</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ishikawa H, Roter DL, et al</td>
<td>Japan</td>
<td>100%</td>
<td>2006</td>
<td>Quantitative Cross-sectional</td>
<td>100%</td>
<td>Sample: n = 63 patients (age &gt; 65 years)</td>
<td>(–) Physician’s perceptions of family member and of the consultation</td>
<td>Physicians thought that the family member’s involvement was supportive to the patient (83%) and to the doctor (70%). For adults who were accompanied by a spouse, physicians reported that family member involvement was generally positive (82%) or neutral (14%). A very small proportion of family members (4%) had a negative impact on the consultation. Patients expected their family members to take on a more active role rather than an active role. While, family members intended to take on a more active role than what patients expected. Patients thought that verbally active family members were more helpful than less verbally active family members.</td>
</tr>
<tr>
<td>Schilling LM, Scatena L, et al</td>
<td>USA</td>
<td>95%</td>
<td>2002</td>
<td>Quantitative Cross-sectional</td>
<td>95%</td>
<td>Sample: n = 121 unaccompanied patients</td>
<td>(++) Patient/family member characteristics</td>
<td>The majority of patients and family members thought that the presence of a family member was helpful. Over half of physicians thought the presence of a family member was helpful. Over half of patients and family members thought family member positively influenced physician and patient understanding. A small but important minority of unaccompanied patients would appreciate the involvement of a family member.</td>
</tr>
<tr>
<td>Beisecker AE, Brecheisen MA, et al</td>
<td>USA</td>
<td>99%</td>
<td>1997</td>
<td>Qualitative &amp; Quantitative Cross-sectional</td>
<td>99%</td>
<td>Sample: n = 18 heterogeneous cancer patients accompanied to an oncology consultation.</td>
<td>(++) Patient/family member influence on consultation and relationships, family member helpfulness, and coalition formation</td>
<td>Patients thought that they should decide whether or not to bring a family member. They perceived that it was helpful to have a family member present. Family members thought that they were more active and their</td>
</tr>
</tbody>
</table>
### Table 3. Attitudes of Patients, Family members and Physicians Toward Family member Involvement (Studies ordered by Quality Rating)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Design</th>
<th>Method</th>
<th>Approach</th>
<th>Sample</th>
<th>Setting</th>
<th>Medical Discipline</th>
<th>Patients</th>
<th>Family member</th>
<th>Healthcare Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Huang X, Butow P, et al</td>
<td>1999</td>
<td>Cross-sectional</td>
<td>Focus group or individual telephone interviews</td>
<td>-</td>
<td>n = 36 Chinese-Australian cancer patients n = 12 relatives</td>
<td>3 major teaching hospitals and a Chinese cancer support group</td>
<td>Oncology</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Glasser M, Prohaska T, et al</td>
<td>2001</td>
<td>Cross-sectional</td>
<td>Pre- and post-visit self-administered questionnaires</td>
<td>-</td>
<td>n = 185 patients (aged &gt; 60 years) n = 48 caregivers</td>
<td>3 general practice and 1 geriatric practice</td>
<td>Oncology</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Speice J, Harkness J, et al</td>
<td>2000</td>
<td>Cross-sectional</td>
<td>Focus groups</td>
<td>Structured focus group discussions regarding family member involvement in cancer consultations</td>
<td>n = 96 patients (various stages of cancer treatment, mostly breast cancer, n = 40)</td>
<td>8 academic cancer centres</td>
<td>Oncology</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**Notes:**
- Patients' and family members' views about information delivery and perceived impact of cancer
- Frequency and importance of accompaniment, demographics, health characteristics, patient satisfaction
- Perceptions of patient medical issues, reasons for accompaniment, and health characteristics
- Patients emphasised the importance of inviting family members and valued the efforts providers made to get to know family members
- Providers acknowledged that learning family members’ names and showing empathy/physical contact were important in welcoming and involving patients and family members
- Providers thought it was important to talk with family members about their understanding and expectations regarding the illness. They ensured that other family members who were not present in the consultation felt included
- Providers acknowledge that family members’ involvement is important to the emotional well-being of the patient
- Most patients wanted their family to be informed of their illness, so that family members can advise doctors about the best method of delivering information to patients and can also contribute to the emotional and practical support for the patient. Family members also thought that they should support the patient by advising the doctor about how they should communicate information to the patient. Need for further work comparing and contrasting the attitudes and needs of different ethnic groups in Australia.
- Overall, patients valued the involvement of family members in the consultation. Patients valued the physicians effort to include their family members in the decision making process. Providers recognised the importance of family members’ contribution to the consultation and treatment decision making process. They also were aware of some of the difficulties associated with the involvement of family members.
| Kimberlin C, Brushwood D, et al. | 2004 | USA | **Approach:** Qualitative | **Design:** Cross-sectional | **Method:** Focus group and interview | **Sample:** n= 22 cancer patients; n= 16 family members | **NB:** unmatched patient-family member pairs | **Response Rate:** Not stated | **Setting:** Recruited through affiliation with cancer centres/hospice and through newspaper advertisement | **Medical Discipline:** Oncology | **Patient** | **Family member** | **Note:** Score of 1 or 0 on the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Item number from quantitative [QN] and qualitative [QL] studies quality rating checklist) |
|---------------------------|-----|-----|----------------|----------------|----------------|----------------|-----------------|----------------|----------------|----------------|----------------|----------------|----------------|----------------|
|                           |     |     |                  |                |                |                | (a) Barriers to communication; positive and negative communication behaviours; suggestions for patients, family members, and providers to improve communication |                  |                |                  |                  |                  | **Patients preferred the family member to be involved and thought that family members were helpful when communicating with providers** | **Family members expressed a preference that physicians acknowledge their important role in caring for the patient. Family members preferred to be involved in the consultation, but felt that at times they were unwelcome** |  |
|                           |     |     |                  |                |                |                |                  |                  |                |                |                  |                  |                  |                  |
|                           |     |     |                  |                |                |                |                  |                  |                |                |                  |                  |                  |                  |

**Note:** Score of 1 or 0 on the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Item number from quantitative [QN] and qualitative [QL] studies quality rating checklist)

- Question description [QN 1; QL 1]
- Study design [QN 2; QL 2]
- Study context description [QL 3]
- Theoretical/empirical connection [QL 4]
- Sampling strategy [QN 3; QL 5]
- Subject characteristics reported [QL 4]
- Data collection methods [QN 5, 6, 7, ; QL 6]
- Means of assessment reported [QN 8]
- Sample size [QN 9]
- Data analysis [QN 10; QL 7]
- Estimate of variance reported [QN 11]
- Controlled for confounding [QN 12]
- Results reported in sufficient detail [QN 13]
- Verification procedure to establish credibility [QL 8]
- Conclusions supported by the results [QN 14; QL 9]
- Reflexivity of the account [QL 10]
# Table 4. Attitudes Towards, and Patterns of, Triadic Decision-Making (Studies ordered by Quality Rating)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Country</th>
<th>Year</th>
<th>Quality Rating</th>
<th>Approach, Design &amp; Method</th>
<th>Sample &amp; Setting</th>
<th>Measures specific to results Key: (+)/(-)= validated/unvalidated measure</th>
<th>Results</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nolan MT, Hughes M, et al</td>
<td>USA</td>
<td>2005</td>
<td>100%</td>
<td>Quantitative Design: Cross-sectional Design: Interviews and questionnaires (Answered according to 2 scenarios when able to participate and when unable to participate)</td>
<td>Sample: n=130 patients [52 Congestive Heart Failure (CHF), 47 advanced cancer, and 31 Amyotrophic Lateral Sclerosis (ALS) patients]</td>
<td>(+) Modified version of the Decision Control Preferences Scale- 5 point scale of decision making (+) McGill Quality of Life Questionnaire (+) General Health Questionnaire (+) Short Portable Mental Status Questionnaire (+) Confusion Assessment Method</td>
<td>Present health state: When able to participate When asked about the involvement of loved ones: – 44% would make shared medical decisions with loved ones – 50% would make medical decisions independent of loved ones – 6% would rely on loved ones When asked who’s opinion should weigh more: – 51% of patients would weigh physician’s and loved one’s opinions equally – 42% of patients would weigh physician’s opinion higher than loved ones – 7% of patients would weigh family’s opinion more than physician’s opinion – Patients with cancer were more likely to choose a decision-making style that was independent of their loved ones compared with patients who had ALS or CHF (64% in cancer vs 45% in ALS vs 40% in CHF, p&lt;0.01) Hypothetical scenario: When unable to participate If unconscious, the number of patients who would rely on their physicians increased (15% vs 39%, p&lt;0.001). Patients reported an increased reliance on family members (6% vs 21%, p=0.39). 33% would weigh loved ones’ input more heavily and 19% would weigh the physicians input more heavily (p=0.05) than when able to participate. Of those who changed choices, 88% moved in a direction of increasing involvement of loved ones. Physicians caring for terminally ill patients should not assume that patient decision making preferences remain the same across the illness trajectory.</td>
<td>Most patients with terminal diagnoses preferred to share decision-making with their physicians and loved ones. Given the scenario of being unable to decide for themselves, they shift toward greater reliance on physician input relative to their own wishes but would weigh loved one’s input more heavily than physicians. Physicians caring for terminally ill patients should not assume that patient decision making preferences remain the same across the illness trajectory.</td>
</tr>
<tr>
<td>Pardon K, Descheppe R, et al</td>
<td>Belgium</td>
<td>2010</td>
<td>95%</td>
<td>Quantitative Design: Longitudinal Design: Interviewed every 2 months until fourth interview and every 4 months until the sixth interview</td>
<td>Sample: n=128 advanced lung cancer patients NB: high loss to follow-up, only 13 participants were interviewed 6 consecutive times</td>
<td>(+) Decision-making preferences scale including items for competent and loss of competence scenarios</td>
<td>Present health state: Involvement of others when patient is competent – At first interview, 69% of patients wanted family to be involved in medical decision-making – These percentages did not change significantly over time, but there were changes at the individual level – Predictors of wanting family involvement were: having a partner (p=0.024) and having a lower level of physical functioning (p=0.008) – Of the patients wanting family involvement, 68% reported that they had achieved this preference. Of patients who wanted no one involved, 87% achieved their preference Hypothetical scenario: Involvement of others when the patient becomes incompetent – 94% of patients wanted family involvement in decision-making if they were to become incompetent – Of the patients who wanted family involvement, 23% wanted primary physician control, 41% wanted shared physician-family control, and 37% wanted primary family control – Female patients, those with better emotional functioning, and those with pain were more likely to want shared physician-family control or family control</td>
<td>Whilst competent, two thirds of patients wanted family involvement in decision-making. However, one third of these patients reported that they had not achieved this involvement preference. If they were to become incompetent, almost all patients wanted family involvement. Physicians should periodically re-discuss a patient’s preferred degree of family involvement.</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Country</td>
<td>Method</td>
<td>Setting</td>
<td>Medical Discipline</td>
<td>Sample Size</td>
<td>Sample Description</td>
<td>Response Rate</td>
</tr>
<tr>
<td>-------</td>
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</tr>
<tr>
<td>Sekimoto M, Asai A, et al.</td>
<td>2003</td>
<td>Japan</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Random allocation of patients to one of three case study vignettes (pneumonia, gangrene and cancer); face-to-face interview</td>
<td>n = 134 patients with type 2 diabetes mellitus</td>
<td>( ) Family involvement in decision-making</td>
<td>90%</td>
</tr>
<tr>
<td>Stiggelbout AM, Jansen SF, et al.</td>
<td>2007</td>
<td>The Netherlands</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Self-report questionnaire and face-to-face interview</td>
<td>n = 123 early-stage breast and colorectal cancer patients</td>
<td>( ) Patients rated importance of 6 significant others’ opinions, regarding whether they should be treated with chemotherapy</td>
<td>62%</td>
</tr>
<tr>
<td>Philip J, Gold M, et al.</td>
<td>2009</td>
<td>Australia</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Survey</td>
<td>n = 52 advanced cancer patients</td>
<td>( ) Importance assigned to factors considered in medical decision making</td>
<td>81%</td>
</tr>
<tr>
<td>Goncalves F, Marques A, et al.</td>
<td>2005</td>
<td>Portugal</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Questionnaire before first visit</td>
<td>n = 47 adult advanced cancer patients</td>
<td>( ) Patient preference for disclosure of information and participation in treatment decision-making process</td>
<td>Not stated</td>
</tr>
<tr>
<td>Srinangam SJ, Pearson E, et al.</td>
<td>2003</td>
<td>UK</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Self-administered questionnaire</td>
<td>n = 82 partners of early prostate cancer patients</td>
<td>( ) Partner’s experience of the patient’s diagnosis, subsequent medical consultations, and their involvement in medical decision-making (33 items)</td>
<td>78%</td>
</tr>
<tr>
<td>Petronio S, Sargent J, et al.</td>
<td>2004</td>
<td>USA</td>
<td>Qualitative</td>
<td>Cross-sectional</td>
<td>Semi-structured survey</td>
<td>n = 96 family members</td>
<td>( ) Participants perception of their experience as an advocate, and managed boundaries of privacy and disclosure</td>
<td>Not stated</td>
</tr>
<tr>
<td>Shepherd HL, Tattersall HN, et al.</td>
<td>100%</td>
<td></td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Self-administered questionnaires</td>
<td>n = 604 cancer physicians (83% male)</td>
<td>( ) 4 decision-making scenarios (paternalistic, information sharing only, informed, and shared); 4-point Likert scale about barriers or facilitators to 92% of physicians perceived that the patient being accompanied in the consultation facilitated the treatment decision-making</td>
<td>59%</td>
</tr>
</tbody>
</table>
### Table 4. Attitudes Towards, and Patterns of, Triadic Decision-Making (Studies ordered by Quality Rating)

<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>Medical Discipline</th>
<th>Approach</th>
<th>Design</th>
<th>Sample</th>
<th>Response Rate</th>
<th>Setting</th>
<th>Medical Discipline</th>
<th>Decision making</th>
<th>Information exchange</th>
<th>Studies examining the decision-making preferences/perspectives of 2+ members of the triad</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>Australia</td>
<td>Oncology</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Self-administered questionnaire</td>
<td>Sample: n = 100 medical residents (USA) n = 244 general medical practice residents (Japan)</td>
<td>Response Rate: USA= 71% Japanese= 74% Setting: 2 US sites and 5 Japanese sites</td>
<td>Medical Discipline: Internal and general medicine</td>
<td>(-) Attitudes and experiences regarding end of life care, prognosis disclosure and autonomy (10 items)</td>
<td>Both Japanese and US physicians rated the importance of patient’s involvement in decision-making highly, however, US physicians rated it slightly higher than Japanese physicians (4.67 for Japanese physicians and 4.95 for US physicians). Both Japanese and U.S. physicians rated the importance of family involvement only slightly lower than patient’s involvement (4.12 and 4.14)</td>
<td>Residents in both countries thought involvement of family in medical encounters was of high importance. The study highlights differences between Eastern and Western cultures in patient involvement in decision making. There is a need for better understanding of the way in which a physician’s own cultural perspective influences their practice.</td>
</tr>
<tr>
<td>2005</td>
<td>Canada</td>
<td>Oncology</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Computerised survey</td>
<td>Sample: n = 440 patients with advanced stage diseases (aged &gt;55 years) n = 160 family members</td>
<td>Response Rate: Patients= 79% Family members= 91% Setting: 5 tertiary acute care teaching hospitals</td>
<td>Medical Discipline: Acute care</td>
<td>Part 1: Quality of care at the end-of-life (Heyland et al. 2005) Part 2: CPR communication and decision making</td>
<td>More patients reported to have spoken with family members than physicians about resuscitation treatments (46% vs 34%, respectively) More family members than patients rated receiving information about CPR as being “extremely important” (p &lt; 0.001) Deliberation: 23% of patients wished to engage in deliberation process on own 34% of patients wished for triadic (patient/family/physician) deliberation If the patient was too ill to participate, 52% of family members thought that the deliberation process should include other family members and the doctor Decision making: In their current health state; 23% of patients wished to make the decisions themselves. For those patients with a matched family member, there was poor agreement regarding family member’s preferred decisional role when the patient is unable to participate in decision making (kappa 0.11; p=0.016) Compared to the patient’s preference, family members were more likely to prefer joint decision making with physicians and were less likely to prefer that they or the physician solely decide on the CPR decision-making when the patient is unable to participate (p&lt;0.001)</td>
<td>When able to participate, most patients engage family members throughout the decision making process. Involvement of family member in the decision making increases when patients become unable to participate.</td>
</tr>
<tr>
<td>2006</td>
<td>Canada</td>
<td>Oncology</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Computerised survey</td>
<td>Sample: n = 40 prostate cancer patients n = 40 partners</td>
<td>Response Rate: NB: recruited in pairs Setting: Hospital-based Prostate Centre Medical Discipline: Oncology</td>
<td>(+) Control Preferences Scale - to elicit patients’ preferences for control over treatment decision making (+) Prognosis, stage of disease, side effects, treatment options, social activities, and impact on family</td>
<td>In terms of making medical decisions with their partners, 49% of patients preferred to play an active role while 51% of patients preferred to play a collaborative role 55% of partners reported a preference to play a collaborative role, 41% preferred a passive role, only 4% wanted to be active in making the decision for their husband</td>
<td>Most prostate cancer patients preferred to play either an active or a collaborative role in treatment decision-making; whilst their partners preferred a collaborative or passive role.</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>Canada</td>
<td>Oncology</td>
<td>Quantitative</td>
<td>Cross-sectional</td>
<td>Survey</td>
<td>Sample: n = 128 patients n = 41 family members</td>
<td>Response Rate: Patients=55% Family members= 37%</td>
<td>Medical Discipline: Oncology</td>
<td>(+) Patient and Family Health Care Decision-Making Preferences Questionnaire Three part questionnaire; Part C: Participant’s perceptions</td>
<td>– 53% of patients and 34% of family members did not think that family could make decisions about important medical treatments for competent patients – 62% of patients and 52% of family members felt patients</td>
<td>Even though most patients thought that family could not make decision about important medical treatments for competent patients, most patients and family members desired some level of</td>
</tr>
</tbody>
</table>
Table 4. Attitudes Towards, and Patterns of, Triadic Decision-Making (Studies ordered by Quality Rating)

<table>
<thead>
<tr>
<th>Setting</th>
<th>Medical Discipline</th>
<th>Patient</th>
<th>Triadic decision-making patterns and processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Japan</td>
<td>University hospital and medical centre.</td>
<td>Various</td>
<td>should discuss their condition with family, even when it was a personal matter of life or death</td>
</tr>
<tr>
<td></td>
<td>Medical Discipline: Various</td>
<td>and coding of videotaped consultation</td>
<td>- 32% of patients and 46% of family members thought that patients should make a final decision after consulting with the physician and family.</td>
</tr>
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<td></td>
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<td></td>
<td>- 20% of patients thought that patient, family and physician should share responsibility equally for making the final decision.</td>
</tr>
<tr>
<td>Gilbar R., Gilbar O. 2008 Israel</td>
<td>85%4 6, k</td>
<td>Approach: Quantitative Design: Cross-sectional Method: Interviews and self-report questionnaires</td>
<td>84% of patients thought that their husbands should participate in the medical decision-making process.</td>
</tr>
<tr>
<td></td>
<td>Sample: n= 57 female patients with breast cancer</td>
<td>Medical Discipline: Oncology</td>
<td>89% of patients reported that it was important that their decision was in accord with that of their husband’s.</td>
</tr>
<tr>
<td></td>
<td>n= 57 partners</td>
<td></td>
<td>- 84% of patients thought that the doctor was important in the decision-making process.</td>
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<td></td>
<td>NB: recruited in pairs</td>
<td></td>
<td>18% of patients thought that a friend’s participation was important.</td>
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<tr>
<td></td>
<td>Setting: Oncology Clinic</td>
<td></td>
<td>Patients’ and husbands’ perceptions of the meetings with the doctor.</td>
</tr>
<tr>
<td></td>
<td>Response Rate: 80%</td>
<td>(-) Doctor-patient relationships (16 items, 5-point Likert scale): Attitudes towards paternalism, patient autonomy and deliberation in the doctor-patient relationship.</td>
<td>- No statistical differences found between patients and husbands regarding discussing meetings or disagreement over the treatment proposed by doctor.</td>
</tr>
<tr>
<td></td>
<td>Medical Discipline: Oncology</td>
<td>(+) Treatment decision-making. Based on a scale developed by Supportive Cancer-Care Research Unit and McMaster University (1997)</td>
<td>- A significant moderate correlation was found between patients and husbands regarding their perspective on the participants in the decision-making process: the patient making the decision by herself ($r = .57$, $p&lt;.001$); with husband ($r = .71$, $p&lt;.001$) with a family member ($r = .96$, $p&lt;.001$) and with friends ($r = .99$, $p&lt;.001$).</td>
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<td>(-) How medical decisions should be made (7 items); how they arrived at a decision (6 items); construct a hierarchy of values (2 items); 19 different values on 5 point scale)</td>
<td>Majority of patients wanted to have a triadic shared decision-making process. They rejected the paternalistic model. Most patients wanted family to be informed and involved.</td>
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<tr>
<td>Schafer C, Putnik K, et al 2006 Germany</td>
<td>64%6, f, h, k, l</td>
<td>Approach: Quantitative Design: Cross-sectional Method: Self-administered questionnaire</td>
<td>70% of patients and 54% of family members said that family members should have a say in the medical decision making.</td>
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<td></td>
<td>Sample: n= 50 cancer patients n= 50 relatives (38 were partners)</td>
<td>Medical Discipline: Oncology</td>
<td>67% of patients and 60% of family members said that family members helped to make the decisions.</td>
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<td>NB: recruited in pairs</td>
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<td>60% of patients said that their family members shared in the decision-making.</td>
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<td>Response Rate: 75%</td>
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<td>42% of patients wanted help of family if there was disagreement with doctor.</td>
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<tr>
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<td>Setting: Academic oncology centre</td>
<td></td>
<td>78% of all participants believed that disagreement concerning medical decision-making should be solved jointly by the patient, family and doctor.</td>
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<tr>
<td></td>
<td>Medical Discipline: Oncology</td>
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<td>- Decisions were made in 90% of the visits.</td>
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<td>- In 52% of visits, patients were classified as active decision makers, whereas family members were active decision-makers in only 26% of visits.</td>
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<td>- Active patients made more decisions per visit than non-active patients ($p&lt;.01$), however, family member activity in decision-making was not related to the number of decisions made per visit.</td>
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<td>- The spouse and children of the patient were more likely to be active in the decision-making process than friends or other relatives ($p&lt;.05$).</td>
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<tr>
<th>Triadic decision-making patterns and processes</th>
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<tr>
<td>Patient</td>
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<tr>
<td>(+) Medical Outcomes Study Short Form SF-36 - health status</td>
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<tr>
<td>- Patients were more active decision makers than their family members. Family member activity did not diminish patient’s decision-making activity.</td>
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<tr>
<td>- Spouses and children were more likely to help make a decision than other family members.</td>
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<td>Study</td>
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<td>Shields</td>
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<td>Hubbard</td>
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<td>Hilton A</td>
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<td>Boehmer</td>
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<td>U, Clark JA&lt;sup&gt;a&lt;/sup&gt;</td>
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<td>2001 USA</td>
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**Note:** Score of 1 or 0 on the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Item number from quantitative [QN] and qualitative [QL] studies quality rating checklist)

- a Question description [QN 1; QL 1]
- b Study design [QN 2; QL 2]
- c Study context description [QL 3]
- d Theoretical/empirical connection [QL 4]
- e Sampling strategy [QN 3; QL 5]
- f Subject characteristics reported [QN 4]
- g Data collection methods [QN 5, 6, 7; QL 6]
- h Means of assessment reported [QN 8]
- i Sample size [QN 9]
- j Data analysis [QN 10; QL 7]
- k Estimate of variance reported [QN 11]
- l Controlled for confounding [QN 12]
- m Results reported in sufficient detail [QN 13]
- n Verification procedure to establish credibility [QL 8]
- o Conclusions supported by the results [QN 14; QL 9]
- p Reflexivity of the account [QL 10]
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<tr>
<td>Ishikawa H, Hashimoto H, et al</td>
<td>2005a</td>
<td>Japan</td>
<td>100%</td>
<td>Design: Cross-sectional Method: Pre- &amp; post-visit questionnaires; analysis of audio-taped consultation</td>
<td>Sample: 145 patients (age &gt; 65 years)</td>
<td>(+) Pre-visit: Demographics and health status (SF-8, unvalidated translation) (-) Post-visit: Modified version of Patient-Centeredness Scale (+) Roter Interaction Analysis System (-) Modified version of Stewart et al.’s patient-centeredness scale (12 items, scale range 1-4)</td>
<td>- Both accompanied and unaccompanied patients perceived longer consultations (&gt;10 minutes) to be more patient-centred than shorter consultations (&lt;10 minutes). A significant interaction was found between consultation length and patient contribution to the medical dialogue in the presence of a family member (p&lt;0.05). Patients judged longer consultations to be more patient-centred, regardless of their contribution to the medical dialogue but when patients were accompanied short consultations were judged to be more patient centred by patients when they were more verbally active.</td>
<td>In briefer consultations, the presence of a family member may take up a portion of the medical dialogue away from the patient which may result in the patient rating the consultation to be less patient-centred.</td>
</tr>
<tr>
<td>Rosland AM, Piette JD, et al</td>
<td>2011</td>
<td>USA</td>
<td>100%</td>
<td>Design: Cross-sectional Method: Self-administered questionnaire</td>
<td>Sample: 439 diabetic and heart failure patients n= 88 physicians</td>
<td>Patient (-) Family member participation in primary care visits (-) Patient satisfaction: Adapted version of the Endorsement of Physician Scale Physician (-) Physician experiences with family members scale (-) Physician practice attitudes: Adapted from the Physician Satisfaction Scale</td>
<td>Patients whose regular family member actively participated in visits had higher satisfaction with their physician (OR: 1.7, CI: 1.1-2.7) Patients reported that their family members were helpful, and when family members were present, patients: - were more motivated to follow the doctor’s advice (78%) - better understood the doctor’s advice (77%) - found discussing difficult topics easier (44%) Patients also reported that the family members presence was at times negative: - Involvement created disagreements between patient + family (12%) - Family member shared too much information (9%) - Doctor shared too much information (4%) Physicians Overall, physicians acknowledged the helpfulness of family members and that when family members were present they: - Understood the patients concerns better (95%) - Received information that the patient did not give (91%) Physicians raised some concerns about family member involvement, including: - Family participation made them feel more overburdened (39%) - Family member participation took time away from important patient issues (19%) - Family member participation can worsen family conflicts (9%) Patients with active family members were more satisfied with their physician’s care. Patients believed that the presence of the family member was helpful and they enjoyed positive outcomes such as increased motivation, better understanding, and ease of discussion. Patients also noted negative changes as a result of family member participation including conflict and the over-sharing of information. Physicians noted changes as a result of family member participation including an increased understanding and increase in information received about the patient. Physicians also acknowledged concerns such as feeling overburdened and taking time away from patient issues.</td>
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</tr>
<tr>
<td>Probska T &amp; Glasser M</td>
<td>1996</td>
<td>USA</td>
<td>95%</td>
<td>Design: Longitudinal (3 time points; before medical visit, within one week of visit, 10 – 12 weeks after initial visit) Method: Face-to-face interview, telephone interview and/or written survey</td>
<td>Sample: 136 (aged &gt; 60 years) NB: 129 completed all three stages of data collection</td>
<td>(+) General outcomes for the patient, including health status and satisfaction with the physician</td>
<td>The presence of a family member was unrelated to the older patient’s report of feeling better or of satisfaction with care received. 10-12 weeks after the initial visit: -Those who attended the consultation accompanied were less worried about their health (p&lt;.05) - A general trend that accompanied patients were receiving more assistance from family and friends than unaccompanied (only significant difference was the item “help with filling prescriptions” p&lt;.001)</td>
<td>The outcome of those accompanied being less worried may not be due to accompaniment status per se but those who are accompanied generally receive more assistance outside of the consultation</td>
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</table>

Table 5. Impact of family involvement on patient and provider ratings (Studies ordered by Quality Rating)
<table>
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<tr>
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<tbody>
<tr>
<td>Labrecque MS, 1991 USA</td>
<td>91% k</td>
<td>Design: Cross-sectional Method: Post-visit interview</td>
<td>Sample: n = 473 patients</td>
<td>(+) Patient Satisfaction Questionnaire: Satisfaction and Quality of Life measured using 100mm visual analogue scales</td>
<td>When controlling for performance status, there was no significant main effect of satisfaction when patients were unaccompanied or accompanied</td>
<td>There was no significant difference between accompanied and unaccompanied patients on satisfaction.</td>
<td></td>
</tr>
<tr>
<td>Street RL, &amp; Gordon HS, 2008 USA</td>
<td>90% k</td>
<td>Design: Cross-sectional Method: Quantitative analysis of audiotaped consultations, self administered surveys</td>
<td>Sample: n = 48 unaccompanied newly diagnosed lung cancer patients n= 84 accompanied newly diagnosed lung cancer patients with n= 84 family members</td>
<td>(-) Verbal analysis of doctor-patient-family member consultation communication (+) SF-12 to measure Health Status (-) Patient satisfaction measure</td>
<td>Patients’ visit satisfaction was not correlated with degree of family member active participation</td>
<td>Patients whose family members assumed active or passive roles had greater satisfaction with care than did patients whose participation was similar to that of their family members.</td>
<td>It is important to assess how the pattern of patient–family member participation matches patient expectations and whether this affects outcomes</td>
</tr>
<tr>
<td>Shields CG, Epstein RM, et al. 2005 USA</td>
<td>88% k</td>
<td>Design: Randomised study design Method: Random assignment of patients to ‘accompanied’ or ‘unaccompanied’ condition.</td>
<td>Sample: n = 30 patients (aged&gt; 65)</td>
<td>(-) Measure of visit satisfaction not reported</td>
<td>There were no statistical differences in visit satisfaction between accompanied and unaccompanied patients.</td>
<td>Visit satisfaction did not differ between accompanied and unaccompanied patients.</td>
<td></td>
</tr>
<tr>
<td>Glasser M, Prohaska T, et al. 2001 USA</td>
<td>86% k</td>
<td>Design: Cross-sectional Method: Pre- and post-visit self-administered questionnaires</td>
<td>Sample: n = 185 patients (aged &gt; 60 years)</td>
<td>(-) Patient and family member view on patient’s satisfaction with their medical encounters</td>
<td>Patients positively evaluated the extent and kind of support provided by family members and generally felt that neither they nor their family member were excluded during the encounter</td>
<td>Overall, patients and family members were satisfied with family member involvement in the medical encounter.</td>
<td></td>
</tr>
<tr>
<td>Repetto L, Piselli P, et al. 2009 Italy</td>
<td>86% k</td>
<td>Design: Cross-sectional Method: Structured interviews</td>
<td>Sample: n= 598 cancer patients with a newly diagnosed neoplasm or disease progression. (aged&gt; 65 years)</td>
<td>(-) Patients communication preferences and satisfaction</td>
<td>~79% of patients reported that having a family member participate in the oncology consultation made the relationship with the physician easier</td>
<td>Many patients considered the presence of a family member in the medical consultation as supportive and beneficial to facilitating a good relationship with the physician.</td>
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</table>

Table 5. Impact of family involvement on patient and provider ratings (Studies ordered by Quality Rating)
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<tr>
<td>Wolff JL, &amp; Roter DL</td>
<td>2008</td>
<td>USA</td>
<td>86%</td>
<td>Cross-sectional Method: Face-to-face interviews unrelated to any particular consultation</td>
<td>Sample: n = 11,487 community-dwelling Medicare beneficiaries aged &gt; 65 years Note: 4.4% (956/11487) of patients were unable to fully participate in the consultation, therefore a proxy was required</td>
<td>(-) Accompaniment status, demographics, health and disability status (-) Satisfaction (12 items, 4-point Likert scale)</td>
<td>After adjusting for sociodemographic and health differences, accompanied patients were more satisfied with their usual physician’s technical skills, information provision and interpersonal skills compared to unaccompanied patients</td>
<td>Accompanied patients were more satisfied with their usual physician’s care.</td>
</tr>
<tr>
<td>Greene MG, Majerovitz SD, et al</td>
<td>1994</td>
<td>USA</td>
<td>82%</td>
<td>Cross-sectional Method: Audiotaped consultation and post-visit questionnaire</td>
<td>Sample: n = 15 dyadic first visits n = 15 triadic first visits n = 19 physicians Note: Dyadic visits were matched on gender and race of patient and physician</td>
<td>Post visit questionnaire: (-) Adapted version of a satisfaction scale (14 items-patients, 2 items-physicians; scale ranged from 1 to 5)</td>
<td>No significant differences in patient or physician visit satisfaction were found between triadic and dyadic visits</td>
<td>Patients’ and physicians’ visit satisfaction was the same between accompanied and unaccompanied visits.</td>
</tr>
<tr>
<td>Beisecker AE, &amp; Moore WP</td>
<td>1994</td>
<td>USA</td>
<td>90%</td>
<td>Cross-sectional Method: Semi-structured face-to-face interviews</td>
<td>Sample: n = 12 oncologists (6 medical, 4 surgical and 2 radiation)</td>
<td>(-) Perceptions of cancer patients/ family members within medical encounters; description of coalition formation; benefits/ problems with family members</td>
<td>All physicians viewed the family member as helpful to the consultation Physicians noted that changes can occur when the family member attends the consultation, including: - Encounter becomes more complex - Patient asks more questions - Family members ask questions, which takes time to answer - Physician obtains more information - Coalitions or alliances emerge All physicians had observed coalitions/alliances form, and some suggested that the term ‘coalition’ denotes conflict, which can be an inaccurate representation They described four types of coalitions: - Patient + Physician (e.g. needed if family member needs to be controlled or persuaded due to unrealistic expectations) - Family member + Physician (e.g. persuading patient to follow treatment regimen) - Patient + Family member (an expected and often beneficial alliance) - Family coalition (e.g. intrafamily coalitions to persuade patient to pursue a course of action)</td>
<td>Physicians expressed positive consequences as a result of the presence of a family member, and believed that family members are an asset in the consultation. Potential problems associated with family member involvement, were also identified, including detracting from time with the patient and increased consultation complexity.</td>
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<tr>
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<td>Speice J, Harkness J, et al</td>
<td>2000</td>
<td>USA</td>
<td>80%</td>
<td>Design: Cross-sectional</td>
<td>Sample: n= 96 patients (various stages of cancer treatment, mostly breast cancer, n= 40) n= 58 providers (mostly medical oncologists followed by nurses, surgical oncologist)</td>
<td>(-) Family member involvement in cancer consultations</td>
<td>Healthcare providers stated that sometimes family involvement in cancer consultations can lead to issues, such as disruptive family dynamics that may take time away from discussing treatment plans Healthcare providers stated that some family members may repeatedly ask for second opinions, push for definitive answers from health care providers, or conceal information from one another Patients noted that providers’ poor communication skills can contribute to problems in managing disruptive family dynamics affecting the treatment process</td>
<td>Healthcare providers reported that family involvement in medical consultations can place them in difficult situations. Healthcare providers may benefit from communication skills training and assessing their own comfort and skill level for working with families. Enlisting the help of allied health professionals such as psychologists with specific skills for working with families may help to reduce provider frustration.</td>
</tr>
<tr>
<td>Barone AD, Yoels WC, &amp; Clair JM</td>
<td>1999</td>
<td>USA</td>
<td>75%</td>
<td>Design: Cross-sectional</td>
<td>Sample: n= 18 geriatricians (only data from geriatricians is included) Response Rate: 75%</td>
<td>(-) Physicians’ views concerning family members and their effects on medical interviews</td>
<td>61% of geriatricians agreed that the presence of a family member may prevent patients and physicians from discussing sensitive issues. Sensitive issues include sexuality, depression, or problems with the family member. Geriatricians reported that - Diagnosing depression becomes more difficult with the family member present - Family members and physicians can form an alliance that ignores the patient - Family member’s presence can be seen as an indication that the patient is incapable of answering questions</td>
<td>In the presence of a family member, geriatricians tend not to discuss sensitive issues with the patient. Geriatricians may form alliances with the family member that may exclude the patient in the medical encounter. There is a need for communication skills training involving triadic medical encounters. Allocation of time alone with patients in the consultation to allow patients and physicians to discuss sensitive issues is crucial.</td>
</tr>
<tr>
<td>Hubbard G, Illingworth N, et al</td>
<td>2010</td>
<td>Scotland</td>
<td>70%</td>
<td>Design: Longitudinal</td>
<td>Sample: n=66 patients (first year following cancer diagnosis) n= 43 carers (matched pairs)</td>
<td>(+) Experiences pre-diagnosis and through diagnosis, during treatment including involvement in treatment decision-making and follow-up experiences</td>
<td>- Involving the family member can improve the quantity and quality of the information exchanged about treatments - Patients who do not directly ask questions during consultation discuss information about treatment through interactions with family members, often outside of the consultation</td>
<td>The presence of the family member in the consultation can improve information exchange and help facilitate discussion about treatment decision-making with the patient outside of the consultation.</td>
</tr>
<tr>
<td>Kimberlin C, Brushwood D, et al</td>
<td>2004</td>
<td>USA</td>
<td>75%</td>
<td>Design: Cross-sectional</td>
<td>Sample: n= 22 cancer patients n= 16 family members</td>
<td>(+) Barriers to communication; positive and negative communication behaviours</td>
<td>Patients reported that family member involvement assisted them in asking more questions and obtaining more information Family members acknowledged potential problems related to their involvement in consultations, including dominating the consultation and inhibiting the patient from expressing their desires Family members acknowledged that conflict can arise between family members and patients</td>
<td>Family members were aware of the possible problems that can arise with their involvement including dominating discussions or inhibiting patients during consultations and potential intra-family conflict. A need for clearer role recognition and open communication between all involved to ascertain preferred roles.</td>
</tr>
<tr>
<td>Coe RM, Prendergast CG</td>
<td>1985</td>
<td>CG7</td>
<td>60%</td>
<td>Design: Cross-sectional; one triadic visit and one patient-physician dyad visit audiotaped</td>
<td>Sample: n= 7 elderly patients (aged &gt; 65 years) n= 7 relatives of the patients NB: 14 audiotaped sessions analysed (2 audiotaped consultations per patient) Transcripts analysed using: (+) Interaction Process Analysis (+) Interpersonal Skills Assessment Technique</td>
<td>Several different coalitions can form within one medical consultation. For example: - patient and family member vs. doctor - doctor and family member vs. patient Objectives varied for different members, common themes</td>
<td>Coalition formation can vary within a single consultation and these coalitions differ in duration, topic and objectives of the involved parties.</td>
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<td>included seeking information, obtaining permission, obtaining</td>
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<td>compliance and ending the encounter</td>
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<tr>
<td>Beisecsker AE,</td>
<td>1997</td>
<td>90% p</td>
<td>Mixed Methods Study</td>
<td>18 heterogeneous cancer patients accompanied to an oncology consultation</td>
<td>Overall, patients perceived little difference in medical encounters regardless of whether a family member was present or not</td>
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<td>Brecheisen MA, et al</td>
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<td>n= 17 family members</td>
<td>Patients noted minor changes when a family member was present, including:</td>
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<td>N.B. 7 patient-family member pairs</td>
<td>- an increase in the total number of questions asked</td>
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<td>- increase in patient participation</td>
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<td>- increase in the comfort level during encounters</td>
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<td>The coalitions observed were formed because of disagreements about treatment and protocols, differences in interpretation or hindrances caused by the family member. The most common coalition was between a patient and oncologist concerning a particular treatment option that the family member did not agree on</td>
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<td>Patients believed there was little difference in the consultation when the family member was present, but mentioned small changes such as: an increased the number of questions asked, increased their participation and helped them feel more at ease in the consultation. The most common coalition was between patient and oncologist concerning a treatment option that the family member did not agree on.</td>
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**Note:** Score of 1 or 0 on the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Item number from quantitative [QN] and qualitative [QL] studies quality rating checklist)

- a Question description [QN 1; QL 1]
- b Study design [QN 2; QL 2]
- c Study context description [QL 3]
- d Theoretical/empirical connection [QL 4]
- e Sampling strategy [QN 3; QL 5]
- f Subject characteristics reported [QN 4]
- g Data collection methods [QN 5, 6, 7; QL 6]
- h Means of assessment reported [QN 8]
- i Sample size [QN 9]
- j Data analysis [QN 10; QL 7]
- k Estimate of variance reported [QN 11]
- l Controlled for confounding [QN 12]
- m Results reported in sufficient detail [QN 13]
- n Verification procedure to establish credibility [QL 8]
- o Conclusions supported by the results [QN 14; QL 9]
- p Reflexivity of the account [QL 10]
Appendix B

Systematic review article published in Patient Education and Counselling
Copy of published systematic review article removed due to copyright reasons.

Please see:

Appendix C

Health Professional Invitation Email/Letter
Understanding the role of family members: Communication and decision-making within cancer consultations

Dear [Insert Participants Name Here],

You are invited to take part in a study we are conducting at the Centre for Medical Psychology and Evidence-based Decision-making at The University of Sydney, to better understand the nature and role of family members who attend cancer consultations with a cancer patient. This project could potentially lead to strategies which improve communication and support in cancer care.

Participating in the study involves attending either a focus group discussion with other people who have similar experiences to you, or taking part in a one-on-one interview either in person or over the telephone. You will also be asked to complete a short questionnaire about yourself. Overall, we think that the focus groups will take about one and a half hours, or if you participate in an interview, it will take about one hour. We expect that the questionnaire will take you no more than 30 minutes to complete.

If you think that you might be interested in taking part in this study, please complete the contact details form and return it in the reply paid envelope provided. We will then send you an information sheet which includes more information about the study and a consent form if you wish to participate in the study. Alternatively you can contact the study coordinator, Rebekah Powell, on 02 9036 5289 or rpow2608@uni.sydney.edu.au with your name and contact details. We will then mail you a study package.

We think this is an important study and we thank you very much for considering taking part. If you decide not to participate, it will not affect your relationship with any health professionals, hospitals, researchers, advocacy groups or professional associations related to cancer.

Kind Regards,

Dr Ilona Juraskova
Appendix D

Health Professional Information Sheets
PARTICIPANT INFORMATION SHEET

ONCOLOGY PHYSICIANS

Understanding the role of family members:

Communication and decision-making within cancer consultations

Invitation

You are invited to take part in a research study investigating:
1) The nature and impact of family members who attend cancer consultations with a cancer patient.
2) The role family members play in helping patients make decisions about their cancer treatments.

This information will lead to a better understanding of family members in medical encounters, and will lead to interventions and strategies which improve communication and support in cancer consultations.

The study is being conducted by researchers from the Centre for Medical Psychology and Evidence-based Decision-making at The University of Sydney.

It is also being conducted as part of a graduate study program within the School of Psychology, at The University of Sydney.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

If you agree to participate in this study, you will be asked to sign the attached Participant Consent Form.

1. ‘What is the purpose of this study?’

The purpose is to:

a) Explore the doctor-patient-family relationship within cancer consultations

b) Investigate the role family members play in assisting cancer patients make decisions about treatments

c) Identify factors that help or hinder family member participation in the cancer consultation
This study will explore the role of family within cancer consultations. To date, research into this area has been minimal, with very limited research investigating the family’s role in medical decision-making. Family members can have a considerable impact on the dynamics and outcomes of medical encounters, therefore it is important to explore the nature of the doctor-patient-family relationship.

2. ‘Why have I been invited to participate in this study?’
You are eligible to participate in this study because you have participated in at least one cancer consultation which involved a doctor, cancer patient, and family member.

A total of 30 current/previous cancer patients, 30 family members, 10 nurses, and 10 oncologists will participate in this study.

3. ‘What if I don’t want to take part in this study or if I want to withdraw later?’
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect your relationship with the professional association with which you are affiliated, or any other relationships with any treatment staff or the research team.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. Withdrawing from this study will not affect your relationship with any professional associations, other doctors, or the research team.

4. ‘What does this study involve?’
This study will be conducted over 2 years. If you agree to participate, you will be contacted by a member of the research team to arrange a time to participate in a semi-structured interview via the telephone. A questionnaire will be posted to you, which you will be asked to complete. The questionnaire should take less than 10 minutes to complete. You will be asked to return the questionnaire in a reply paid envelope. Once a suitable time has been arranged, a member of the research team will call you to conduct the interview. The interview will take approximately 1 hour.

5. ‘How is this study being paid for?’
The study is being conducted as part of a graduate study program with the School of Psychology at The University of Sydney. Funding has been sought by the Foundation for Informed Medical Decision Making. There are no commercial interests or conflicts of interest in this study. No money is paid directly to individual researchers or the professional association with which you are affiliated.
6. ‘Are there risks to me in taking part in this study?’
There is a chance you may find some of the material in the questionnaire or interview confronting or upsetting, or that it raises new issues. If you decide that you need help in dealing with these issues, please contact the study coordinator, Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au.

7. ‘Will I benefit from the study?’
This study aims to improve the experience of future cancer patients and their family members within cancer consultations, however, it will not directly benefit you.

8. ‘Will taking part in this study cost me anything, and will I be paid?’
Participation in this study will not cost you anything, nor will you receive any payment for taking part.

9. ‘How will my confidentiality be protected?’
Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, except as required by law. Only the researchers immediately involved with the study will have access to your details. Results will be held securely at the University of Sydney.

10. ‘What happens with the results?’
If you give us your permission by signing the consent form, the information you give will be part of summary results that are reported to ethics committees for monitoring purposes and in a PhD thesis, peer-reviewed journals, at conferences and at other professional forums.

In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish. If you want a copy of the study results you should contact the advocacy group from which you were recruited, or Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au

11. ‘What should I do if I want to discuss this study further before I decide?’
If you would like to know more at any stage, please do not hesitate to contact Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au

12. ‘Who should I contact if I have concerns about the conduct of this study?’
This study has been approved by the NSW Population and Health Services Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Ethics Coordinator who is the person nominated to receive complaints from research participants. You should contact them on 02 8374 5600 and quote HREC reference number:
You can also contact the lead researcher on the project, Doctor Ilona Juraskova, who you can telephone on 02 9036 5275 or email at ilona.juraskova@sydney.edu.au.

Finally, feel free to discuss any concerns about this study, not only with the professional association, with which you are affiliated, but also your family, friends, other health care professionals, advocacy groups, or legal advisors.

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.
PARTICIPANT INFORMATION SHEET

ONCOLOGY NURSES

Understanding the role of family members:
Communication and decision-making within cancer consultations

Invitation

You are invited to take part in a research study investigating:
1) The nature and impact of family members who attend cancer consultations with a cancer patient.
2) The role family members play in helping patients make decisions about their cancer treatments.

This information will lead to a better understanding of family members in medical encounters, and will lead to interventions and strategies which improve communication and support in cancer consultations. The study is being conducted by researchers from the Centre for Medical Psychology and Evidence-based Decision-making at The University of Sydney. It is also being conducted as part of a graduate study program within the School of Psychology, at The University of Sydney.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

If you agree to participate in this study, you will be asked to sign the attached Participant Consent Form.

1. ‘What is the purpose of this study?’
The purpose is to:

a) Explore the doctor-patient-family relationship within cancer consultations

b) Investigate the role family members play in assisting cancer patients make decisions about treatments

c) Identify factors that help or hinder family member participation in the cancer consultation

This study will explore the role of family within cancer consultations. To date, research into this area has been minimal, with very limited research investigating the family’s role in medical decision-making. Family members can have a considerable impact on the dynamics and outcomes of medical encounters, therefore it is important to explore the nature of the doctor-patient-family relationship.
2. **‘Why have I been invited to participate in this study?’**
You are eligible to participate in this study because you have been present in at least one cancer consultation which involved a doctor, cancer patient, and family member.

A total of **30 current/previous cancer patients, 30 family members, 10 nurses, and 10 oncologists** will participate in this study.

3. **‘What if I don’t want to take part in this study or if I want to withdraw later?’**
**Participation in this study is voluntary.** It is completely up to you whether or not you participate. If you decide not to participate, it will not affect your relationship with the professional association with which you are affiliated, or any other relationships with any treatment staff or the research team.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. Withdrawing from this study will not affect your relationship with any professional associations, other doctors or nurses, or the research team.

4. **‘What does this study involve?’**
This study will be conducted over 2 years. If you agree to participate, you will be contacted by a member of the research team to arrange a time to participate in a focus group discussion. If you are unable to attend a focus group, or would feel more comfortable participating in a one-on-one interview, you will be provided with the option to arrange a time to complete an interview via the telephone. If you attend the focus group, you will be asked to complete a questionnaire. The questionnaire should take less than 10 minutes to complete. Once this has been completed, you will be asked to participate in a focus group discussion. The focus group discussion will take approximately 1.5 hours.

If you choose to complete an interview via the telephone, the questionnaire will be posted to you with a reply paid envelope included. Once a suitable time has been arranged, a member of the research team will call you to conduct the interview. The interview will take approximately 1 hour.

5. **‘How is this study being paid for?’**
The study is being conducted as part of a graduate study program with the School of Psychology at The University of Sydney. Funding has been sought by the Foundation for Informed Medical Decision Making. There are no commercial interests or conflicts of interest in this study. No money is paid directly to individual researchers or the professional association with which you are affiliated.
6. ‘Are there risks to me in taking part in this study?’
There is a chance you may find some of the material in the questionnaire or interview confronting or upsetting, or that it raises new issues. If you decide that you need help in dealing with these issues, please contact the study coordinator, Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au.

7. Will I benefit from the study?’
This study aims to improve the experience of future cancer patients and their family members within cancer consultations, however, it will not directly benefit you.

8. ‘Will taking part in this study cost me anything, and will I be paid?
Participation in this study will not cost you anything, nor will you receive any payment for taking part.

9. ‘How will my confidentiality be protected?’
Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, except as required by law. Only the researchers immediately involved with the study will have access to your details. Results will be held securely at the University of Sydney.

10. ‘What happens with the results?’
If you give us your permission by signing the consent form, the information you give will be part of summary results that are reported to ethics committees for monitoring purposes and in a PhD thesis, peer-reviewed journals, at conferences and at other professional forums.

In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish. If you want a copy of the study results you should contact the advocacy group from which you were recruited, or Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au

11. ‘What should I do if I want to discuss this study further before I decide?’
If you would like to know more at any stage, please do not hesitate to contact Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au

12. ‘Who should I contact if I have concerns about the conduct of this study?’
This study has been approved by the NSW Population and Health Services Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Ethics Coordinator who is the person nominated to receive complaints from
research participants. You should contact them on 02 8374 5600 and quote HREC reference number:

You can also contact the lead researcher on the project, Doctor Ilona Juraskova, who you can telephone on 02 9036 5275 or email at ilona.juraskova@sydney.edu.au

Finally, feel free to discuss any concerns about this study, not only with the professional association, with which you are affiliated, but also your family, friends, other health care professionals, advocacy groups, or legal advisors.

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.
Appendix E
Health Professional Consent Form
PARTICIPANT CONSENT FORM

Understanding the role of family members: Communication and decision-making within cancer consultations

1. I, .................................................................................., agree to participate in the study described in the participant information sheet attached to this form.

2. I acknowledge that I have read the participant information sheet, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

3. Before signing this Consent Form, I have been given the opportunity to ask any questions relating to any possible physical and mental harm I might suffer as a result of my participation. I have received satisfactory answers to any questions that I have asked.

4. My decision whether or not to participate will not prejudice my present or future relationships with staff at any organisation cooperating in this study. If I decide to participate, I am free to withdraw my consent and to discontinue my participation at any time without prejudice.

5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I may contact the lead investigator, Dr Ilona Juraskova, on 02 9036 5275, or the study coordinator Rebekah Powell on 02 9036 5289, who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Sheet.

Complaints may be directed to the NSW Population and Health Services Research Ethics Committee (phone 02 8374 5600).

Signature of participant________________ Signature of witness________________

Please PRINT name____________________ Please PRINT name____________________

Date_________________________ Date____________________
Appendix F
Health Professional Questionnaires
Understanding the role of family members:
Communication and decision-making within cancer consultations

ONCOLOGY PHYSICIANS

Please fill out this questionnaire

WHAT IS THIS QUESTIONNAIRE ABOUT?

This is the questionnaire for a study exploring the role of family within cancer consultations. Please fill out this questionnaire regardless of whether you are participating in a focus group discussion or an interview.

INSTRUCTIONS:

Please fill out the questionnaire as soon as possible. Please make an effort to answer all the questions in the questionnaire.

If you are completing the questionnaire before a focus group discussion, please return it to a member of the research team when you have completed.

If you are completing the questionnaire before a telephone interview, please return it in the reply paid envelope provided.

If you have any questions or concerns please phone the researchers on (02) 9036 5289.

CONFIDENTIALITY:

All information will be treated as strictly confidential and your identity will not be revealed in any reports. The completed questionnaires will be kept securely under lock and key. To assist us in ensuring anonymity, please do not write your name on this questionnaire.

Thank you for your help with this study
SECTION ONE
DEMOGRAPHICS

This section of the questionnaire asks some general questions about you. Please tick (✓) the statement that best describes you. You may also be required to fill in additional information.

1. What is your age? __________

2. What is your gender?
   - Male
   - Female

3. What aspect of oncology are you specialised in?
   - Medical Oncology
   - Surgical Oncology
   - Radiation Oncology

4. What types of cancer do you specialise in? ___________________________

5. What position do you currently hold?
   - Intern
   - Resident Medical Officer
   - Registrar
   - Advanced Trainee
   - Consultant/ Staff Specialist
   - Other → _______________________
     (Please specify)

6. How many years have you practiced in medicine? ________________years
7. How many years have you practiced in oncology? ____________ years

8. On average, how many hours each week do you spend in direct patient contact? ____________ hours

9. On average, what percentage of your patient consultations involve a family member? ____________ %

10. On average, what percentage of your patient consultations involve two or more family members? ____________ %

11. Since medical school, have you had any formal communication skills training?

☐ No
☐ Yes→ Please provide details

_____________________________________________________________
_____________________________________________________________
_____________________________________________________________
SECTION TWO
FAMILY MEMBER CHARACTERISTICS

This section of the questionnaire asks a question about the family’s role in cancer consultations.

1. *Based on your experience, please rank the top five most frequent family members which accompany a patient to cancer consultations*

- Husband/Wife
- Male/Female Partner
- Mother
- Father
- Daughter
- Son
- Sister
- Brother
- Other → ___________________
- Other → ___________________
- Other → ___________________
Understanding the role of family members:
Communication and decision-making within cancer consultations

ONCOLOGY NURSES

Please fill out this questionnaire

WHAT IS THIS QUESTIONNAIRE ABOUT?

This is the questionnaire for a study exploring the role of family within cancer consultations. Please fill out this questionnaire regardless of whether you are participating in a focus group discussion or an interview.

INSTRUCTIONS:

Please fill out the questionnaire as soon as possible. Please make an effort to answer all the questions in the questionnaire.

If you are completing the questionnaire before a focus group discussion, please return it to a member of the research team when you have completed.

If you are completing the questionnaire before a telephone interview, please return it in the reply paid envelope provided.

If you have any questions or concerns please phone the researchers on (02) 9036 5289.

CONFIDENTIALITY:

All information will be treated as strictly confidential and your identity will not be revealed in any reports. The completed questionnaires will be kept securely under lock and key. To assist us in ensuring anonymity, please do not write your name on this questionnaire.

Thank you for your help with this study
SECTION ONE
DEMOGRAPHICS

This section of the questionnaire asks some general questions about you. Please tick ( ✓ ) the statement that best describes you. You may also be required to fill in additional information.

1. What is your age? __________

2. What is your gender?
   □ Male
   □ Female

3. What aspect of oncology nursing are you involved in?
   □ Medical Oncology
   □ Surgical Oncology
   □ Radiation Oncology
   □ Other→ ____________________________
                  (Please specify)

4. What types of cancer do you specialise in? ____________________________

5. What position do you currently hold?
   □ Enrolled Nurse
   □ Registered Nurse
   □ Clinical Nurse Specialist
   □ Clinical Nurse Educator
   □ Clinical Trials Nurse
   □ Clinical Nurse Consultant
   □ Nurse Practitioner
   □ Other→ ____________________________
                  (Please specify)

6. Have you completed a postgraduate specialisation in oncology nursing?
   □ No
   □ Yes→ ____________________________
                  (Please specify)
7. Have you been involved in a cancer consultation, which included the doctor, patient, and family member?

☐ No
☐ Yes→ ________________________________

(Please estimate how many consultations you have been present in)

8. How many years have you practiced in nursing? ____________ years

9. How many years have you practiced in oncology nursing? ____________ years

10. On average, how many hours each week do you spend in direct patient contact?

______________ hours
SECTION TWO
FAMILY MEMBER CHARACTERISTICS

This section of the questionnaire asks a question about the family’s role in cancer consultations.

1. Based on your experience, please rank the top five most frequent family members which accompany a patient to cancer consultations

- [ ] Husband/Wife
- [ ] Male/Female Partner
- [ ] Mother
- [ ] Father
- [ ] Daughter
- [ ] Son
- [ ] Sister
- [ ] Brother
- [ ] Other → __________________
- [ ] Other → __________________
- [ ] Other → __________________
Appendix G
Qualitative Study Ethics Approvals
Dr Ilona Juraskova  
University of Sydney  
Centre for Medical Psychology and Evidence Based Decision-making  
Brennan McCallum A18, Room 341  
NSW 2006  

19 January 2011  

Dear Dr Juraskova,  

NSW Population & Health Services Research Ethics Committee  

AU RED Reference: HREC/10/CIPHS/50  

Cancer Institute NSW reference number: 2010/07/251  

Project Title: Understanding the role of family members: Communication and decision-making within cancer consultations  

Thank you for your correspondence received 30 Nov 2010 responding to a request for further information/ modification of the above referenced study, submitted for single ethical review to the NSW Population & Health Services Research Ethics Committee. The Committee reviewed your documents at its meeting held on 26 Nov 2010, and I am pleased to advise that full ethical approval of this research proposal has been granted, with the following condition:  

- Indigenous status must not be collected.  

The following documents were reviewed during the Committee’s deliberation of the study:  

- Letter of reply, dated 22 Nov 2010  
- National Ethics Application Form version 2, submission code AU/2/96B6016, dated 25 Jun 2010  
- Protocol version 3, dated 22 Nov 2010  
- Participant Information Sheet – Current/ previous cancer patients, undated  
- Participant Information Sheet – Family members, undated  
- Participant Information Sheet – oncology nurses, undated  
- Participant Information Sheet – oncology physicians, undated  
- Participant consent form, undated  
- Invitation letter, undated  
- Questionnaire - Current/ previous cancer patients, undated  
- Questionnaire – family members, undated  
- Questionnaire – oncology nurses, undated  
- Questionnaire – oncology physicians, undated  
- Focus group & semi-structured interview items - current/ previous cancer patients, undated  
- Focus group & semi-structured interview items - Family members, undated  
- Focus group & semi-structured interview items - oncology nurses, undated
• Semi-structured interview items - oncology physicians, undated

The NSW Population & Health Services Research Ethics Committee has been accredited by the NSW Department of Health to provide single ethical and scientific review of research proposals conducted within the NSW public health system.

The Committee is a joint initiative of the Cancer Institute NSW and NSW Department of Health. The Committee has been constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) and relevant legislation and guidelines.

Please note that ethical approval is valid for 5 years, conditional on the following:

• Principal investigators will immediately report anything which might warrant a review of ethical approval of the research, including unforeseen events that might affect continued ethical acceptability.
• Proposed amendments to the research proposal or conduct of the research which may affect the ethical acceptability of the research are to be provided to the NSW Population & Health Services Research Ethics Committee for review.
• The NSW Population & Health Services Research Ethics Committee will be notified giving reasons, if the research is discontinued before the expected date of completion.
• The Principal Investigator will provide an annual progress report to the NSW Population & Health Services Research Ethics Committee and at the completion of the study.

For further information about the NSW Population & Health Services Research Ethics Committee please refer to our website www.cancerinstitute.org.au/research.

Should you have any queries about the ethical review of your research proposal please contact Marion Marson, Admin Support Officer - Ethics on 02 8374 3562 or email ethics@cancerinstitute.org.au.

The NSW Population & Health Services Research Ethics Committee wishes you well in your research endeavours.

Yours sincerely,

Sharon Falleiro
Ethics Coordinator
Cancer Institute NSW
NSW Population & Health Services Research Ethics Committee
Dr Ilona Juraskova  
University of Sydney  
Centre for Medical Psychology and Evidence Based Decision-making  
Brennan McCallum A18, Room 341  
NSW 2006

11 May 2011

Dear Dr Juraskova,

NSW Population & Health Services Research Ethics Committee

AU RED Reference: HREC/10/CIPHS/50

Cancer Institute NSW reference number: 2010/07/251

Project Title: Understanding the role of family members: Communication and decision-making within cancer consultations

Thank you for your recent correspondence requesting an amendment to the above referenced study, submitted for single ethical review to the NSW Population & Health Services Research Ethics Committee. The Committee reviewed your documents at its meeting held on 9 May 2011, and I am pleased to advise that ongoing ethical approval of this study has been granted.

The following documents were reviewed and approved:
- Request for amendment form, dated 20 Apr 2011
- Amendment explanation of interview items
- Protocol version 5, dated 20 Apr 2011
- Participant Information Sheet – Current/previous cancer patients, version 5, dated 20 Apr 2011
- Participant Information Sheet – Family members, version 5, dated 20 Apr 2011
- Participant Information Sheet – oncology nurses, version 5, dated 20 Apr 2011
- Participant Information Sheet – oncology physicians, version 5, dated 20 Apr 2011
- Invitation letter, version 5, dated 20 Apr 2011
- Focus group & semi-structured interview items - current/previous cancer patients, version 5, dated 20 Apr 2011
- Focus group & semi-structured interview items - Family members, version 5, dated 20 Apr 2011
- Focus group & semi-structured interview items - oncology nurses, version 5, dated 20 Apr 2011
- Semi-structured interview items - oncology physicians, version 5, dated 20 Apr 2011

The NSW Population & Health Services Research Ethics Committee has been accredited by the NSW Department of Health to provide single ethical and scientific review of research proposals conducted within the NSW public health system.
The Committee is a joint initiative of the Cancer Institute NSW and NSW Department of Health. The Committee has been constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) and relevant legislation and guidelines.

For further information about the NSW Population & Health Services Research Ethics Committee please refer to our website www.cancerinstitute.org.au/research.

Should you have any queries about the ethical review of your research proposal please contact Marion Marson, Admin Support Officer - Ethics on 02 8374 3562 or email ethics@cancerinstitute.org.au.

The NSW Population & Health Services Research Ethics Committee wishes you well in your research endeavours.

Yours sincerely,

Kimberly Strong PhD
Ethics Coordinator
Cancer Institute NSW
NSW Population & Health Services Research Ethics Committee
7 June 2011

Dr I Juraskova
Room 160
Transient Building F12
UNIVERSITY OF SYDNEY NSW 2006

Dear Dr Juraskova,

Re: Protocol No X11-0171 - “Understanding the role of family members in cancer consultations”

HREC/10/CIPHS/50 SSA/11/RPAH/244

Thank you for submitting a Site Specific Assessment Form for this study. I am pleased to inform you that authorisation has been granted for it to be undertaken at the Royal Prince Alfred Hospital.

The approved information and consent documents for use at this site are:

- Information for Participants – Current/Previous Cancer Patients (RPAH Version 1, 13 May 2011)
- Participant Consent Form – Current/Previous Cancer Patients (RPAH Version 1, 13 May 2011)
- Current/Previous Cancer Patients Patient Questionnaire (Version 1, 11 May 2011)
- Current/Previous Cancer Patients Focus Group and Semi-Structured Interviews (Version 5, 20 April 2011)
- Information for Participants – Family Members (RPAH Version 1, 13 May 2011)
- Participant Consent Form – Family Members (RPAH Version 1, 13 May 2011)
- Family Member Questionnaire (Version 1, 11 May 2011)
- Family Member Focus Group and Semi-Structured Interviews (Version 5, 20 April 2011)
The following conditions apply to this research study. These are additional to those conditions imposed by the human research ethics committee (HREC) that granted ethical approval:

1. A copy of the annual report and any other reports to the approving HREC, accompanied by a copy of the HREC’s acknowledgement letter, should be provided to me for review.

2. Provision of the signature of Professor Butow on her return from leave.

4. Proposed amendments to the research protocol or conduct of the research, which may affect the ethical acceptability of the study and which are submitted to the lead HREC for review, must be copied to me.

5. Proposed amendments to the research protocol or conduct of the research, which may affect the ongoing site acceptability of the study, must be submitted to me.

I wish you every success in your research.

Yours sincerely,

Lesley Townsend
Research Governance Officer
SLHN (RPAH Zone)

RGO - Lesley\CORRES\X11-0171
Appendix H

Health Professional Interview Schedule
ONCOLOGY PHYSICIAN INTERVIEW ITEMS

Introduction

• Thank you for your time and for sharing your opinions
• Study is focusing on the involvement of families in cancer consultations, particularly their involvement in the treatment decision-making process. Our main focus is the doctor-patient-family relationship.
• The interview will take about 40 minutes. If you need to take a break, let me know.
• Interview is recorded, and answers are strictly confidential.
• We will firstly talk more generally about the involvement of families in the overall consultation and general communication. Later in the interview we will talk more specifically about their involvement in treatment decision-making.
• We realise that the involvement of family can range from situation to situation, so we would appreciate you thinking about your range of experiences.
• Finally, although we will use the term family member, we are referring to any non-professional companion that might accompany a patient (e.g. adult child, sibling, friend).

Do you have any questions before we begin?

1) OPENING QUESTION
   a. Firstly, what do you think about having family members participate in consultations?
      • [Instruction: You can describe positive and negative experiences]
      • How helpful do you think family members are in the consultation?
      • Are there certain patients where family involvement is more/less helpful?
      • Are some family members more/less helpful? What is it about these people that makes them more/less helpful?

2) FAMILY MEMBER INVOLVEMENT IN COMMUNICATION
   a. Do things change when a family member is present compared to if the patient comes alone?
      • Do you think you or your patients communicate differently when family members are present?

3) FAMILY MEMBER ROLES IN THE CONSULTATION
   a. What roles have you observed family members play in a consultation
      • [Rephrase: In a couple of words, describe the main function of the family member within the consultation]
      • Do the roles family members adopt differ according to patient characteristics (such as age, gender, cancer stage)?

   b. We have talked about what roles you have observed family members play, in your opinion, what roles do you think they should play?
      • [Rephrase: Do you have a preference for what the main function of the family member should be during the consultation?]
      • Does your preference vary according to the situation or patient?

Since we have discussed the wider aspects of communication and overall family involvement, I would now like to focus in on family involvement in decision-making within consultations.
4) **IMPORTANCE OF FAMILY IN DECISION-MAKING**

a. Firstly, what do you think about family members being involved in the decision-making process?
   - What are the benefits of including family members in decision-making?
   - What are the costs/challenges of including family members in decision-making?

b. What do you think about consultations which involve 2+ family members
   - Is a conversation about a decision different if more than one family member is present

c. Are there particular patients whose family are more (or less) involved in the decision-making
   - [Rephrase: Are there particular types of people or individual characteristics whose family are more involved]
   - Are there certain family members who are more (or less) involved in the decision-making? What is it about these family members?

d. Are there any specific decisions in the cancer experience that you think family members should have greater (or lesser) involvement?

e. Do you ever see conflict between patients and family members when a decision is being made?
   - What do you do in this situation? How do you handle the conflict?

5) **DECISION-MAKING STAGES**

a. Can you describe the range of ways that family members are involved in decision-making about cancer treatment

b. Can you give me a description of what usually happens when making decisions in a consultation/s which includes a family member. What do the consultations look like when there is a decision to be made?

**Information exchange**
We are now going to try to break down the steps of decision-making

a. Can you tell me about how information about different options is discussed in consultations (which include a family member)?
   - [Rephrase: How do you go about giving and receiving information from patients/family members when a decision needs to be made]
   - [Rephrase: How does the information flow in a consultation which includes a family member when a decision needs to be made]

**Deliberation**

b. Once the information had been discussed, what happens when the different options are being weighed up within consultations?
   - [Rephrase: What happens when you are deliberating about which option to decide upon?]
   - [Rephrase: Do you, the patient, or family discuss your preferences for the decision?]

**Decision**

c. When it comes down to making the decision, what is the influence of the family?
   - Does this differ depending on different patients/family characteristics?

6) **BARRIERS AND FACILITATORS**

a. What do you think prevents family members from participating in treatment decision-making?

b. What do you think helps family members participate in treatment decision-making
c. If the patient wants their family member to be involved, can you think of any strategies to better involve the family members in decision-making?

7) DECISION-MAKING OUTSIDE OF THE CONSULTATION
a. Thinking about when a decision needs to be made, what do you think happens when the patient and family member leave the consultation and go home?
   • [Rephrase: What do you think happens at home with the patient/family when a decision needs to be made]
   • Do the patient/family ever return with a different perspective or decision

Finally, is there anything else about family involvement in consultations or decision-making that we haven’t touched on?
ONCOLOGY NURSE INTERVIEW ITEMS

**Introduction**
- Thank you for your time and for sharing your opinions.
- Study is focussing on the involvement of families in cancer consultations. Main focus is the oncologist-patient-family relationship. It can be the medical/surgical/radiation oncologist.
- The interview will take about one hour. If you need to take a break, let me know.
- Interview is recorded, and answers are strictly confidential.
- We will firstly talk more generally about the involvement of families in the overall consultation and communication. Later in the interview we will talk more specifically about their involvement in treatment decision-making.
- We realise that the involvement of family can range from situation to situation, so we would appreciate you thinking about your range of experiences.
- Finally, although we will use the term family member, we are referring to any non-professional companion that might accompany a patient (e.g. adult child, sibling, friend).

1) **OPENING QUESTION**
   a. Firstly, what do you think about having family members participate in cancer consultations?
      - *Instruction: You can describe positive and negative experiences*
      - How helpful do you think family members are in the consultation?
      - Are there certain patients where family involvement is more/less helpful?
      - Are some family members more/less helpful? What is it about these people that makes them more/less helpful?

2) **FAMILY MEMBER INVOLVEMENT IN COMMUNICATION**
   a. Do you think things change when a family member is present compared to if the patient attends a consultation alone?

3) **FAMILY MEMBER ROLES IN THE CONSULTATION**
   a. What roles have you observed family members play in a consultation?
      - *Rephrase: In a couple of words, describe the main function of the family member within the consultation*
      - Do the roles family members adopt differ according to patient characteristics (such as age, gender, cancer stage)?
   b. We have talked about what roles you have observed family members play, in your opinion, what roles do you think they should play?
      - *Rephrase: Do you have a preference about what the main function of the family member should be during the consultation?*
      - Does your preference vary according to the situation or patient?

Since we have discussed the wider aspects of communication and overall family involvement, I would now like to focus in on family involvement in decision-making within consultations.

4) **IMPORTANCE OF FAMILY IN DECISION-MAKING**
   a. Firstly, what do you think about family members being involved in the decision-making process?
      - What are the benefits of including family members in decision-making?
      - What are the costs/challenges of including family members in decision-making?
b. What do you think about consultations which involve 2+ family members

c. Are there particular patients whose family are more (or less) involved in the decision-making
   - [Rephrase: Are there particular types of people or individual characteristics whose family are more involved]
   - Are there certain family members who are more (or less) involved in the decision-making? What is it about these family members?

d. Are there any specific decisions in the cancer experience that you think family members should have greater (or lesser) involvement?

e. Do you ever see conflict between doctors, patients, or family members when a decision is being made?
   - What happens in this situation? How does the doctor handle the conflict?

5) DECISION-MAKING STAGES
a. Could you describe what generally happens in a consultation where a decision needs to be discussed
   - [Instructions: You can describe a couple of ‘typical’ scenarios if you like]
   - [Instructions: Try to describe the whole decision-making process from the start to when the decision is made]

Information exchange
We are now going to try to break down the steps of decision-making
a. Can you tell me about how information about different options is discussed in consultations (which include a family member)?
   - [Rephrase: How does the doctor go about giving and receiving information from patients/family members when a decision needs to be made]
   - [Rephrase: How does the information flow in a consultation which includes a family member when a decision needs to be made]

Deliberation
b. Once the information had been discussed, what happens when the different options are being weighed up within consultations?
   - [Rephrase: What happens when the doctor, patient, and family are deliberating about which option to decide upon?]}
   - [Rephrase: Do you, the patient, or family discuss your preferences for the decision?]

Decision
c. When it comes down to making the decision, what is the influence of the family?
   - Does this differ depending on different patients/family characteristics?

6) BARRIERS AND FACILITATORS
a. What do you think prevents family members from participating in treatment decision-making?

b. What do you think helps family members to participate in treatment decision-making?

c. If the patient wants their family member to be involved, can you think of any strategies to better involve the family members in decision-making
7) DECISION-MAKING OUTSIDE OF THE CONSULTATION

a. Thinking about when a decision needs to be made, what have you heard happens when the patient and family member leave the consultation and go home?
   • [Rephrase: What do you think happens at home with the patient/family when a decision needs to be made]
   • Do patients/family members ever return with a different perspective or decision

8) NURSE SPECIFIC ITEMS

a. Have patients ever discussed their family’s involvement in the consultation/decision-making process with you?

b. Have family members ever discussed their involvement in the consultation/decision-making process with you?

c. Do you have any other observations of triadic consultations
   Finally, is there anything else about family involvement in consultations or decision-making that we haven’t touched on?
Appendix I

Breast Cancer Patient Advocacy Group Recruitment Email
An invitation to share your experiences to help improve
FAMILY INVOLVEMENT CANCER CONSULTATIONS

Cancer Survivors, Patients, and Family Members are invited to take part in a study to better understand how family members are involved in cancer consultations. Your experiences will help us develop strategies to improve communication and support in consultations.

Participating in the study involves taking part in EITHER:

- a focus group discussion
- OR
- a one-on-one interview (in person or via the telephone)

If you or a family member have had a primary or secondary diagnosis of cancer within the past 2 years and are interested in taking part in this study, please contact the study coordinator, Rebekah Powell, on 02 9036 5289 or rpow2608@uni.sydney.edu.au

The study is being conducted by researchers at The University of Sydney
Appendix J
Patient Participant Information Sheet
PARTICIPANT INFORMATION SHEET
CURRENT/PREVIOUS CANCER PATIENTS

Understanding the role of family members:
Communication and decision-making within cancer consultations

Invitation

You are invited to take part in a research study investigating:
1) The nature and impact of family members who attend cancer consultations with a cancer patient.
2) The role family members play in helping patients make decisions about their cancer treatments.

This information will lead to a better understanding of family members in medical encounters, and will lead to interventions and strategies which improve communication and support in cancer consultations. The study is being conducted by researchers from the Centre for Medical Psychology and Evidence-based Decision-making at The University of Sydney. It is also being conducted as part of a graduate study program within the School of Psychology, at The University of Sydney.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

If you agree to participate in this study, you will be asked to sign the attached Participant Consent Form.

1. ‘What is the purpose of this study?’
The purpose is to:

a) Explore the doctor-patient-family relationship within cancer consultations

b) Investigate the role family members play in assisting cancer patients make decisions about treatments

c) Identify factors that help or hinder family member participation in the cancer consultation

This study will explore the role of family within cancer consultations. To date, research into this area has been minimal, with very limited research investigating the family’s role in medical decision-making. Family members can have a considerable impact on the dynamics and outcomes of medical encounters, therefore it is important to explore the nature of the doctor-patient-family relationship.
2. ‘Why have I been invited to participate in this study?’
You are eligible to participate in this study because you have participated in at least one cancer consultation which involved a doctor, cancer patient, and family member.

A total of 30 current/previous cancer patients, 30 family members, 10 nurses, and 10 oncologists will participate in this study.

3. ‘What if I don’t want to take part in this study or if I want to withdraw later?’
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect your relationship with the advocacy group you are affiliated with, or any other relationships you have with any treatment staff or the research team.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. Withdrawing from this study will not affect your relationship with your doctors, any treatment you may be receiving, or any relationship with an advocacy group.

4. ‘What does this study involve?’
This study will be conducted over 2 years. If you agree to participate, you will be contacted by a member of the research team to arrange a time to participate in a focus group discussion. If you are unable to attend a focus group, or would feel more comfortable participating in a one-on-one interview, you will be provided with the option to arrange a time to complete an interview via the telephone. You will also be given a participant information sheet and a consent form to give to a family member who attended at least one of your cancer consultations with you. The research team will arrange a time with your family member for them to participate in a focus group or interview. If you attend the focus group, you will be asked to complete a questionnaire. The questionnaire should take about 30 minutes to complete. Once this has been completed, you will be asked to participate in a focus group discussion. The focus group discussion will take approximately 1.5 hours.

If you choose to complete an interview via the telephone, the questionnaire will be posted to you with a reply paid envelope included. Once a suitable time has been arranged, a member of the research team will call you to conduct the interview. The interview will take approximately 1 hour.

5. ‘How is this study being paid for?’
The study is being conducted as part of a graduate study program with the School of Psychology at The University of Sydney. Funding has been sought by the Foundation for Informed Medical Decision Making. There are no commercial interests or conflicts of interest in this study. No money is paid directly to individual researchers or the advocacy groups with which you are affiliated.
6. ‘Are there risks to me in taking part in this study?’
There is a chance you may find some of the material in the questionnaire, focus group, or interview confronting or upsetting, or that it raises new issues. If you decide that you need help in dealing with these issues, please contact the study coordinator, Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au. Alternatively, you can call the Cancer Council Helpline on 13 11 20, which is a free confidential telephone information and support service available to anybody affected by cancer.

7. Will I benefit from the study?’
This study aims to improve the experience of future cancer patients and their family members within cancer consultations, however, it will not directly benefit you.

8. ‘Will taking part in this study cost me anything, and will I be paid?’
Participation in this study will not cost you anything, nor will you receive any payment for taking part.

9. ‘How will my confidentiality be protected?’
Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, except as required by law. Only the researchers immediately involved with the study will have access to your details. Results will be held securely at the University of Sydney.

10. ‘What happens with the results?’
If you give us your permission by signing the consent form, the information you give will be part of summary results that are reported to ethics committees for monitoring purposes and in a PhD thesis, peer-reviewed journals, at conferences and at other professional forums.

In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish. If you want a copy of the study results you should contact the advocacy group from which you were recruited, or Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au

11. ‘What should I do if I want to discuss this study further before I decide?’
If you would like to know more at any stage, please do not hesitate to contact Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au

12. ‘Who should I contact if I have concerns about the conduct of this study?’
This study has been approved by the NSW Population and Health Services Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Ethics Coordinator who is the person nominated to receive complaints from research participants. You should contact them on 02 8374 5600 and quote HREC reference number:

You can also contact the lead researcher on the project, Doctor Ilona Juraskova, who you can telephone on 02 9036 5275 or email at ilona.juraskova@sydney.edu.au
Finally, feel free to discuss any concerns about this study, not only with your medical team, but also your family, friends, other health care professionals, advocacy groups, or legal advisors.

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.
Appendix K
Patient Consent Form
Understanding the role of family members:
Communication and decision-making within cancer consultations

PARTICIPANT CONSENT FORM

CURRENT/PREVIOUS CANCER PATIENTS

I, ........................................................................................................................................... [name]
of ........................................................................................................................................... [address]

have read and understood the Information for Participants on the abovenamed research study
and have discussed the study with ........................................................................................................

I have been made aware of the procedures involved in the study, including any known or expected
inconvenience, risk, discomfort or potential side effect and of their implications as far as they are
currently known by the researchers.

I understand that the interview / focus group discussion will be audiotaped, and I agree to this.

I freely choose to participate in this study and understand that I can withdraw at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

NAME: .................................................................................................................................

SIGNATURE: .........................................................................................................................

DATE: .................................................................................................................................

NAME OF WITNESS: ............................................................................................................

SIGNATURE OF WITNESS: .................................................................................................
Appendix L
Patient Questionnaire
Understanding the role of family members:
Communication and decision-making within cancer consultations

CURRENT/PREVIOUS CANCER PATIENTS

Please fill out this questionnaire

WHAT IS THIS QUESTIONNAIRE ABOUT?
This is the questionnaire for a study exploring the role of family within cancer consultations. Please fill out this questionnaire regardless of whether you are participating in a focus group discussion or an interview.

INSTRUCTIONS:
Please fill out the questionnaire as soon as possible. Please make an effort to answer all the questions in the questionnaire.

If you are completing the questionnaire before a focus group discussion, please return it to a member of the research team when you have completed.

If you are completing the questionnaire before a telephone interview, please return it in the reply paid envelope provided.

If you have any questions or concerns please phone the researchers on (02) 9036 5289.

CONFIDENTIALITY:
All information will be treated as strictly confidential and your identity will not be revealed in any reports. The completed questionnaires will be kept securely under lock and key. To assist us in ensuring anonymity, please do not write your name on this questionnaire.

Thank you for your help with this study
SECTION ONE
DEMOGRAPHICS

This section of the questionnaire asks some general questions about you. Please tick (√) the statement that best describes you. You may also be required to fill in additional information.

1. What is your age? __________

2. What is your gender?
   □ Male
   □ Female

3. What is the highest education qualification you obtained?
   □ Year 10 or below (intermediate)
   □ Year 12 / HSC or leaving certificate
   □ TAFE certificate / diploma
   □ University degree
   □ Postgraduate degree (e.g. PhD, Masters)

4. Are you currently employed?
   □ Yes
   □ No
   □ Other→ ________________________
      (Please specify)

5. What is your occupation (or previous occupation if retired)?

   _____________________________________________________________________
6. **What country were you born?**

_______________________________________________
(Please specify)

7. **What language do you speak most at home?**

_______________________________________________
(Please specify)

8. **What is your present marital status?**
   - [ ] Not married or living with partner
   - [ ] Married or living with partner
   - [ ]Separated or divorced
   - [ ] Widowed

9. **Has your marital status changed since you were first diagnosed?**
   - [ ] No
   - [ ] Yes → ______________________________
     (please specify your marital status at diagnosis)

10. **Do you have any children?**
    - [ ] No
    - [ ] Yes → ______________________________
     (Please specify ages of children)
SECTION TWO
CLINICAL CHARACTERISTICS

This section of the questionnaire asks about the diagnosis and treatment of your cancer. Please tick (✔) the statement that best describes you. You may also be required to fill in additional information.

1. At what age were you first diagnosed with cancer? ______________

2. What type of cancer were you first diagnosed with (e.g. lung, breast, testicular)?
   _______________________________________________________

3. Was cancer detected in your lymph glands?
   □ No
   □ Yes
   □ Don’t know

4. Did the cancer spread to other parts of your body (e.g. bones, lungs)?
   □ No
   □ Yes → ______________________________________________________
           (Please specify)
   □ Don’t know

5. What type of treatment did you have? (please tick all relevant answers)
   □ Surgery to remove the cancer
   □ Chemotherapy
   □ Radiotherapy
   □ Hormone therapy
   □ Complementary and alternative medications
   □ Other → ______________________________________________________
           (Please specify)
6. **What stage of the cancer experience are you currently at?**

- Discussing diagnosis
- Discussing treatment options (no treatment chosen yet)
- Awaiting treatment (treatment option chosen)
- Receiving active treatment (chemotherapy, radiotherapy)
- Completed active treatment, no evidence of recurrence
- Discussing cancer recurrence
- Discussing treatment options after recurrence (no treatment chosen yet)
- Awaiting treatment of recurrence (treatment option chosen)
- Receiving treatment after recurrence (chemotherapy, radiotherapy)
- Receiving palliative care
- Other → ____________________________________________  
  (Please specify)

7. **Have you finished active treatment?**

- No
- Yes → ____________________________ months  
  (Please specify months since completion of treatment)

8. **Are you suffering from any chronic medical conditions (other than cancer)?**

- No
- Yes → ____________________________  
  (Please specify)
SECTION THREE
FAMILY MEMBER CHARACTERISTICS

This section of the questionnaire asks some questions about your family’s role in your cancer experience. Please tick (✓) the statement that best describes you. You may also be required to fill in additional information.

1. Which family member/s have attended at least one of your cancer consultations? (please tick all relevant answers)

   - [ ] Wife
   - [ ] Husband
   - [ ] Female Partner
   - [ ] Male Partner
   - [ ] Mother
   - [ ] Father
   - [ ] Daughter
   - [ ] Son
   - [ ] Sister
   - [ ] Brother
   - [ ] Other → __________________________________________

   (Please specify)

2. Which family member has attended the most number of cancer consultations? (please tick only one answer)

   - [ ] Wife
   - [ ] Husband
   - [ ] Female Partner
   - [ ] Male Partner
   - [ ] Mother
   - [ ] Father
   - [ ] Daughter
   - [ ] Son
   - [ ] Sister
   - [ ] Brother
   - [ ] Other → __________________________________________

   (Please specify)
Appendix M

Family Member Participant Information Sheet
PARTICIPANT INFORMATION SHEET
FAMILY MEMBERS
Understanding the role of family members:
Communication and decision-making within cancer consultations

Invitation
You are invited to take part in a research study investigating:
1) The nature and impact of family members who attend cancer consultations with a cancer patient.
2) The role family members play in helping patients make decisions about their cancer treatments.

This information will lead to a better understanding of family members in medical encounters, and will lead to interventions and strategies which improve communication and support in cancer consultations. The study is being conducted by researchers from the Centre for Medical Psychology and Evidence-based Decision-making at The University of Sydney. It is also being conducted as part of a graduate study program within the School of Psychology, at The University of Sydney.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

If you agree to participate in this study, you will be asked to sign the attached Participant Consent Form.

1. ‘What is the purpose of this study?’
The purpose is to:
   a) Explore the doctor-patient-family relationship within cancer consultations
   b) Investigate the role family members play in assisting cancer patients make decisions about treatments
   c) Identify factors that help or hinder family member participation in the cancer consultation

This study will explore the role of family within cancer consultations. To date, research into this area has been minimal, with very limited research investigating the family’s role in medical decision-making. Family members can have a considerable impact on the dynamics and outcomes of medical encounters, therefore it is important to explore the nature of the doctor-patient-family relationship.

2. ‘Why have I been invited to participate in this study?’
You are eligible to participate in this study because you have participated in at least one cancer consultation which involved a doctor, cancer patient, and family member.
A total of 30 current/previous cancer patients, 30 family members, 10 nurses, and 10 oncologists will participate in this study.

3. ‘What if I don’t want to take part in this study or if I want to withdraw later?’
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect your (or your family members) relationship with the advocacy group, or any other relationships with any treatment staff or the research team.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. Withdrawing from this study will not affect your relationship with any doctors, advocacy groups, or the research team.

4. ‘What does this study involve?’
This study will be conducted over 2 years. It is likely that a family member of yours (that has been affected by cancer at some point) has recruited you to take part in the study. If you agree to participate, you will be contacted by a member of the research team to arrange a time to participate in a focus group discussion. If you are unable to attend a focus group, or would feel more comfortable participating in a one-on-one interview, you will be provided with the option to arrange a time to complete an interview via the telephone. If you attend the focus group, you will be asked to complete a questionnaire. The questionnaire should take about 30 minutes to complete. Once this has been completed, you will be asked to participate in a focus group discussion. The focus group discussion will take approximately 1.5 hours.

If you choose to complete an interview via the telephone, the questionnaire will be posted to you with a reply paid envelope included. Once a suitable time has been arranged, a member of the research team will call you to conduct the interview. The interview will take approximately 1 hour.

5. ‘How is this study being paid for?’
The study is being conducted as part of a graduate study program with the School of Psychology at The University of Sydney. Funding has been sought by the Foundation for Informed Medical Decision Making. There are no commercial interests or conflicts of interest in this study. No money is paid directly to individual researchers or the advocacy groups with which you are affiliated.

6. ‘Are there risks to me in taking part in this study?’
There is a chance you may find some of the material in the questionnaire, focus group, or interview confronting or upsetting, or that it raises new issues. If you decide that you need help in dealing with these issues, please contact the study coordinator, Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au. Alternatively, you can call the Cancer Council Helpline on 13 11 20, which is a free confidential telephone information and support service available to anybody affected by cancer.
7. **Will I benefit from the study?**
This study aims to improve the experience of future cancer patients and their family members within cancer consultations, however, it will not directly benefit you.

8. **‘Will taking part in this study cost me anything, and will I be paid?**
Participation in this study will not cost you anything, nor will you receive any payment for taking part.

9. **‘How will my confidentiality be protected?’**
Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, except as required by law. Only the researchers immediately involved with the study will have access to your details. Results will be held securely at the University of Sydney.

10. **‘What happens with the results?’**
If you give us your permission by signing the consent form, the information you give will be part of summary results that are reported to ethics committees for monitoring purposes and in a PhD thesis, peer-reviewed journals, at conferences and at other professional forums.

In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish. If you want a copy of the study results you should contact the advocacy group from which you were recruited, or Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au

11. **‘What should I do if I want to discuss this study further before I decide?’**
If you would like to know more at any stage, please do not hesitate to contact Rebekah Powell on 02 9036 5289 or at rpow2608@uni.sydney.edu.au

12. **‘Who should I contact if I have concerns about the conduct of this study?’**
This study has been approved by the NSW Population and Health Services Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Ethics Coordinator who is the person nominated to receive complaints from research participants. You should contact them on 02 8374 5600 and quote HREC reference number:

You can also contact the lead researcher on the project, Doctor Ilona Juraskova, who you can telephone on 02 9036 5275 or email at ilona.juraskova@sydney.edu.au

Finally, feel free to discuss any concerns about this study, not only with your family member’s medical team, but also your family, friends, other health care professionals, advocacy groups, or legal advisors.

**Thank you for taking the time to consider this study.**

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.
Appendix N
Family Member Consent Form
Understanding the role of family members:

Communication and decision-making within cancer consultations

PARTICIPANT CONSENT FORM

FAMILY MEMBERS

I, ...................................................................................................................................... [name] of .............................................................................................................................. [address] have read and understood the Information for Participants on the abovenamed research study and have discussed the study with ......................................................................................................................

I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

I understand that the interview / focus group discussion will be audiotaped, and I agree to this.

I freely choose to participate in this study and understand that I can withdraw at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

NAME: .........................................................................................................................

SIGNATURE: ............................................................................................................... 

DATE: ............................................................................................................................

NAME OF WITNESS: ..............................................................................................

SIGNATURE OF WITNESS: .....................................................................................
Appendix O

Family Member Questionnaire
Understanding the role of family members:
Communication and decision-making within cancer consultations

FAMILY MEMBERS

Please fill out this questionnaire

WHAT IS THIS QUESTIONNAIRE ABOUT?

This is the questionnaire for a study exploring the role of family within cancer consultations. Please fill out this questionnaire regardless of whether you are participating in a focus group discussion or an interview.

INSTRUCTIONS:

Please fill out the questionnaire as soon as possible. Please make an effort to answer all the questions in the questionnaire.

If you are completing the questionnaire before a focus group discussion, please return it to a member of the research team when you have completed.

If you are completing the questionnaire before a telephone interview, please return it in the reply paid envelope provided.

If you have any questions or concerns please phone the researchers on (02) 9036 5289.

CONFIDENTIALITY:

All information will be treated as strictly confidential and your identity will not be revealed in any reports. The completed questionnaires will be kept securely under lock and key. To assist us in ensuring anonymity, please do not write your name on this questionnaire.

Thank you for your help with this study
SECTION ONE
DEMOGRAPHICS

This section of the questionnaire asks some general questions about you. Please tick (✔) the statement that best describes you. You may also be required to fill in additional information.

1. **What is your age?** __________

2. **What is your gender?**
   - □ Male
   - □ Female

3. **What is the highest education qualification you obtained?**
   - □ Year 10 or below (intermediate)
   - □ Year 12 / HSC or leaving certificate
   - □ TAFE certificate / diploma
   - □ University degree
   - □ Postgraduate degree (e.g. PhD, Masters)

4. **Are you currently employed?**
   - □ Yes
   - □ No
   - □ Other → __________________________
     (Please specify)

5. **What is your occupation (or previous occupation if retired)?**

___________________________________________________________________
6. **What country were you born?**

_______________________________________________

(Please specify)

7. **What language do you speak most at home?**

________________________________________________

(Please specify)

8. **What is your present marital status?**

- [ ] Not married or living with partner
- [ ] Married or living with partner
- [ ] Separated or divorced
- [ ] Widowed
SECTION TWO
CLINICAL CHARACTERISTICS

This section of the questionnaire asks about the diagnosis and treatment of your family member’s cancer. Please tick (✓) the statement that best describes the situation. You may also be required to fill in additional information.

1. At what age was your family member first diagnosed with cancer?

_______________

2. What type of cancer was your family member first diagnosed with (e.g. lung, breast, testicular)?

___________________________________________________

3. Was cancer detected in your family member’s lymph glands?

☐ No
☐ Yes
☐ Don’t know

4. Did the cancer spread to other parts of your family member’s body (e.g. bones, lungs)?

☐ No
☐ Yes → ____________________________________________________________
   (Please specify)
☐ Don’t know

5. What type of treatment did your family member have? (please tick all relevant answers)

☐ Don’t know
☐ Surgery to remove the cancer
☐ Chemotherapy
☐ Radiotherapy
☐ Hormone therapy
☐ Complementary and alternative medications
☐ Other → ____________________________________________________________
   (Please specify)
6. *What stage of the cancer experience is your family member currently at?*

- Don’t know
- Discussing diagnosis
- Discussing treatment options (no treatment chosen yet)
- Awaiting treatment (treatment option chosen)
- Receiving active treatment (chemotherapy, radiotherapy)
- Completed active treatment, no evidence of recurrence
- Discussing cancer recurrence
- Discussing treatment options after recurrence (no treatment chosen yet)
- Awaiting treatment of recurrence (treatment option chosen)
- Receiving treatment after recurrence (chemotherapy, radiotherapy)
- Receiving palliative care
- Other → __________________________________________
  (Please specify)

7. *Has your family member finished active treatment?*

- No
- Yes → __________________________________________ months
  (Please specify months since completion of treatment)
- Don’t know

8. *Is your family member suffering from any chronic medical conditions (other than cancer)?*

- No
- Yes → ______________________________________
  (Please specify)
- Don’t know
This section of the questionnaire asks some questions about your family’s role in your cancer experience. Please tick (✓) the statement that best describes you. You may also be required to fill in additional information.

1. What relationship is your family member (who has previously been diagnosed with cancer) to you?

The current/previous cancer patient is my:

- [ ] Wife
- [ ] Husband
- [ ] Female Partner
- [ ] Male Partner
- [ ] Mother
- [ ] Father
- [ ] Daughter
- [ ] Son
- [ ] Sister
- [ ] Brother
- [ ] Other → ________________________________

(Please specify)
Appendix P
Patient and Family Interview Schedule
PATIENT INTERVIEW ITEMS

Introduction
• Thank you for your time and for sharing your opinions
• Study is focusing on the involvement of families in cancer consultations the benefits, the challenges, and the ways that family are involved and particularly their involvement in the treatment decision-making process.
• We hope that our research will lead to better understanding of how family members are involved in consultations, and will lead to practical strategies to improve consultations
• The interview will take about 30-40 mins. If you need to take a break, let me know.
• Interview is recorded so that I can concentrate on your responses. Is that ok?
• We will firstly talk more generally about the involvement of families in the overall consultation. We will then talk more specifically about their involvement when important decisions needed to be made.
• Be assured that your responses are completely confidential. It is ok to talk about positive or negative experiences that you had with your family and doctors.
• If you feel distressed, or just don't want to answer any of the questions, just let me know and that is fine.

Do you have any questions before we begin?

1) OPENING QUESTIONS:
a. Can you give me a brief overview of your cancer process up until now?

b. Who has come to the consultations with you?

c. Can you tell me about why your family member came along to cancer consultations with you
   • What are the reasons behind them attending the consultation
   • Who made the decision for them to attend the consultation

d. Can you tell me about what it is like having a family member attend cancer consultations?
   • [Instructions: You can describe both positive and negative experiences]
   • [Instructions: You can describe a range of consultations, with a range of cancer specialists]
   • Did your experience change when you attended different appointments with cancer specialists?

e. What were some of you family member’s roles in cancer consultations?
   • [Rephrase: Can you describe some of the specific things that your family member did in the consultation(s)]

f. Was there anything that was hard about having a family member in a consultation?

g. Can you tell me about how the doctor behaved towards your family member in the consultation?

2) HELPFUL FAMILY MEMBER
a. People have different ideas about how family members are helpful in consultations, How would you describe a helpful family member in a consultation
**Decision-making**

- We are now going to talk about your family member’s involvement in the different decisions that were made surrounding the treatment of cancer. Some of the decisions that might have been made include:
  - Whether or not to have chemotherapy
  - Whether or not to have surgery
  - What type of surgery to have
  - Whether or not to have radiotherapy
  - Whether to change the type of chemotherapy to use
  - Whether to enter a clinical trial
  - Whether to stop treatment
  - Whether to have any Complimentary or Alternative Therapies

- We are interested in how your family member or family members were involved in the decisions related to your care. This might include discussions in the consultation, or discussions at home.

3) **IMPORTANCE OF FAMILY IN DECISION-MAKING**

a. Firstly, could you tell me about the different decisions you needed to consider with your cancer specialist(s)?

b. Could you tell me about how your family member was involved when you were making the decisions?

c. What would you say was your family member's level of involvement in the decision?

4) **DECISION-MAKING STAGES**

Thinking about a specific decision- we are now going to try to break down the steps of when decisions are made. Can you give me one example of a decision that needed to be made when you were present in the consultation. Using that example......

**Information exchange**

a. Can you tell me about how the information about different options was discussed in the consultation (which included a family member)?

- [Rephrase: What information did the doctor, yourself, or your family member provide when discussing the different options?]

**Deliberation (process of expressing/discussing treatment preferences)**

a. Once the information had been discussed, how did you weigh up the pros and cons before coming to a decision?

- [Rephrase: Did yourself, your family member, or your doctor express their preferences for the treatment decision?]

b. Did you and your family member think or talk more about options once you left the consultation? What happened?

**Decision**

a. When it came down to making the decision, how involved was your family member? What did they do?

b. When it came down to actually making the decision, who do you think had the most influence?

c. On the questionnaire that you completed, you answered that the patient should make decisions......... Can you tell me about why you selected that option
5) SPECIFICS OF FAMILY INVOLVEMENT IN DECISION-MAKING
a. What are the benefits of including family members in the decision?

b. What are the challenges of including family members in the decision?

c. Were there any particular times or decisions over the course of the cancer experience where you needed family member to be involved in the decisions more?

d. Was there ever any conflict about a decision within a consultation that included you, your doctor, and your family member?

e. Thinking about the way you and your family member make decisions about other things in life, how was it the same or different to decisions about cancer treatment?
   • [Instructions: You can think about big decisions such as buying a house, buying a car, planning a trip, deciding on moving house, making arrangements for elderly parents etc]

4) BARRIERS AND FACILITATORS
a. Did anything help your family member to participate when you were making decisions about your treatment? If so, what was it?

b. Was there anything that prevented or stopped your family member from participating when you were making decisions about your treatment? If so, what was it?

5) STRATEGIES
a. Can you think of anything that could improve a consultation that involves a family member?

6) DECISION-MAKING OUTSIDE OF THE CONSULTATION
a. How much did you discuss the decisions with your family member outside of the consultation?

b. Did you discuss the decision with anyone else who was not involved in the consultation?

Finally, is there anything else about family involvement in decision-making that we haven’t touched on?
FAMILY MEMBER INTERVIEW ITEMS

Introduction

• Thank you for your time and for sharing your opinions
• Study is focussing on the involvement of families in cancer consultations the benefits, the challenges, and the ways that family are involved and particularly your involvement when important decisions need to be made.
• We hope that our research will lead to better understanding of how family members are involved in consultations, and will lead to practical strategies to improve consultations
• The interview will take about 30-40 mins. If you need to take a break, let me know.
• Interview is recorded so that I can concentrate on your responses. Is that ok?
• We will firstly talk more generally about the involvement of families in the overall consultation. We will then talk more specifically about their involvement when important decisions needed to be made.
• Be assured that your responses are completely confidential. It is ok to talk about positive or negative experiences that you had with your family and doctors. Your family member and doctor will not find out anything that has been said in this interview.
• If you find any questions distressing/upsetting, please let me know and we can skip them

Do you have any questions before we begin?

1) OPENING QUESTIONS

h. Can you give me a brief overview of the cancer process up until now?

i. Who has come to the consultations with your family member?

j. Can you tell me about why you come along to cancer consultations with your family member
   • What are the reasons behind you attending the consultation
   • Who made the decision for you to attend the consultation

k. Can you tell me about what it is like being a family member in cancer consultations?
   • Could you tell me about your experience of attending cancer consultations with your family member?
   [Instructions: You can describe both positive and negative experiences]
   [Instructions: You can describe a range of consultations, with a range of cancer specialists]
   • Did your experience change when you attended different appointments with cancer specialists?

l. What were some of your roles in cancer consultations?

m. Was there anything that was hard about being a family member in a consultation?

n. Can you tell me about how the doctor behaved towards you in the consultation
Decision-making

o. We are now going to talk about your involvement in the different decisions that were made surrounding the treatment of cancer. You may have been presented with different options and choices or you may have considered different treatments. Some of the things that you might have considered, are things like:
   a. Whether or not to have chemotherapy
   b. What type or strength chemotherapy to have
   c. Whether or not to have surgery
   d. Whether or not to have radiotherapy
   e. Whether to change the type of chemotherapy to use
   f. Whether to enter a clinical trial
   g. Whether to stop chemotherapy
   h. Whether to change your lifestyle, eating, etc
   i. Whether to have any Complimentary or Alternative Therapies

p. We are interested in how you or other family members were involved in the decisions related to you family member’s care. This might include discussions in the consultation, or discussions at home.

2) IMPORTANCE OF FAMILY IN DECISION-MAKING

   a. Firstly, could you tell me about the different decisions that needed to be made when you were present in a consultation with a cancer specialist?
      • A decision might be related to which treatment you receive, whether you receive treatment, or the timing of your treatment

   b. Could you tell me about how you were involved in the decisions?

   c. What would you say was your level of involvement in the decision

3) DECISION-MAKING STAGES

We are now going to try to break down the steps of when decisions are made. Can you give me one example of a decision that needed to be made when you were present in the consultation. Using that example......

   Information exchange
   b. Can you tell me about how the information about different options was discussed in the consultation?

   c. What information did the doctor provide when discussing the different treatment options?

   d. What information did you provide when discussing the different treatment options?

   e. What information did you provide when discussing different treatment options
      • Did you/your family member talk more or do anything else about the information or options when you left the consultation?

   Deliberation (process of expressing/discussing treatment preferences)
   c. Once the information had been discussed, how did you weigh up the pros and cons before coming to a decision?
d. Did anyone talk about their preferences/wishes or what was important to them when thinking about the decision

e. Did you and your family member think or talk more about options once you left the consultation? What happened?

**Decision**
a. When it came down to making the decision, how involved were you? What did you do?

b. When it came down to actually making the decision, who do you think had the most influence?

c. Was the decision made in the doctor's office or somewhere else? What happened with you and your family outside of the doctor's office?

d. On the questionnaire that you completed, you answered that the patient should make decisions. Can you tell me about why you selected that option?

4) **SPECIFICS OF FAMILY INVOLVEMENT IN DECISION-MAKING**

a. What do you see as the benefits of including family members in the decision?

b. What are the challenges of including family members in the decision?

c. Were there any particular times or decisions over the course of the cancer experience where you were more involved in the decisions?

d. Was there ever any conflict about a decision within a consultation that included you, your doctor, and your family member?

e. Thinking about the way you and your family member make decisions about other things in life, how was it the same or different to decisions about cancer treatment?
   
   • [Instructions: You can think about big decisions such as buying a house, buying a car, planning a trip, deciding on moving house, making arrangements for elderly parents etc]

5) **BARRIERS AND FACILITATORS**

a. Did anything stop from participating in any of the decisions? Or anything make it hard for you to participate in the decisions? If so, what was it?

b. Did anything help you to participate in making any of the decisions? Or made it easier to participate in making decisions. If so, what was it?

5) **STRATEGIES**

b. Can you think of anything that the doctor can do to improve consultations with a patient, family member, and doctor?

c. Can you think of anything that anyone else can do to improve the consultation?
6) DECISION-MAKING OUTSIDE OF THE CONSULTATION

c. How much did you discuss the decisions with your family member outside of the consultation?

Finally, is there anything else about family involvement in decision-making that we haven't touched on?
Appendix Q
TRIO Coding Manual
<table>
<thead>
<tr>
<th>Roles</th>
<th>Role</th>
<th>Explanation</th>
<th>Stages</th>
<th>Item Origin</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Passive</td>
<td>- Speaks rarely&lt;br&gt;- Asks limited questions&lt;br&gt;- Patient more active than family member</td>
<td>History Taking&lt;br&gt;Information exchange&lt;br&gt;Deliberation/DM&lt;br&gt;Logistics</td>
<td>1, 3, 4</td>
</tr>
<tr>
<td>B</td>
<td>Supportive</td>
<td>- Enhances patient’s autonomy&lt;br&gt;- Prompts/reminds patient&lt;br&gt;- Uses supportive language or indicates agreement&lt;br&gt;- Encourages patient to speak up&lt;br&gt;- Does not tend to highlight own opinions, feelings, agenda</td>
<td>History Taking&lt;br&gt;Information exchange&lt;br&gt;Deliberation/DM&lt;br&gt;Logistics</td>
<td>1, 3, 4</td>
</tr>
<tr>
<td>C</td>
<td>Active</td>
<td>- Ensures patient answers questions correctly&lt;br&gt;- Ensures patient understands information&lt;br&gt;- Corrects patient/physician&lt;br&gt;- Asks own questions&lt;br&gt;- Provides information to physician&lt;br&gt;- Elaborates patient information&lt;br&gt;- Clarifies and obtains information from the physician&lt;br&gt;- Discusses treatment options&lt;br&gt;- Offers opinions/suggestions</td>
<td>History Taking&lt;br&gt;Information exchange&lt;br&gt;Deliberation/DM&lt;br&gt;Logistics</td>
<td>1, 3, 4</td>
</tr>
<tr>
<td>D</td>
<td>Dominant</td>
<td>- Speaks more than the patient&lt;br&gt;- Detracts from patient’s autonomy&lt;br&gt;- Speaks for the patient&lt;br&gt;- Interrupts patient&lt;br&gt;- May form coalition with physician</td>
<td>History Taking&lt;br&gt;Information exchange&lt;br&gt;Deliberation/DM&lt;br&gt;Logistics</td>
<td>1, 3, 4</td>
</tr>
<tr>
<td>Category</td>
<td>Item</td>
<td>Explanation</td>
<td>Scoring</td>
<td>Item Origin</td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Physician</td>
<td>Overall communication</td>
<td>Physician and family member discuss a topic unrelated to treatment or engage in a humorous exchange. E.g. What book are you reading there? Is it a good one?</td>
<td>Yes/No</td>
<td>2, 3, 5</td>
</tr>
<tr>
<td>1.1</td>
<td>Actively engages in social interaction/laughter with family member</td>
<td>Physician and family member discuss a topic unrelated to treatment or engage in a humorous exchange. E.g. What book are you reading there? Is it a good one?</td>
<td>Yes/No</td>
<td>2, 3, 5</td>
</tr>
<tr>
<td></td>
<td>1.2</td>
<td>Physician acknowledges and answers a question or comment raised by family member E.g. I think that going on a short holiday would be no problem at all</td>
<td>N/A</td>
<td>3, 4</td>
</tr>
<tr>
<td></td>
<td>1.3</td>
<td>Physician asks family member at least one question e.g. And how have you been coping with the diagnosis?</td>
<td>Yes/No</td>
<td>3, 4</td>
</tr>
<tr>
<td></td>
<td>1.4</td>
<td>Physician asks family member for information to confirm or corroborate what the patient has said E.g. Is he telling the truth?</td>
<td>Yes/No/NA</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>1.5</td>
<td>Physician interrupts/speaks over family member. Family member is unable to finish sentence, or topic of conversation is changed abruptly. Family member has clearly not finished speaking. Not an interruption if individual before stutters e.g. the, the.... Not an interruption if the individual before says ummm or ah</td>
<td>0: Never 1: Once 2: More than once</td>
<td>2, 3, 4</td>
</tr>
<tr>
<td></td>
<td>1.6</td>
<td>Physician engages in an exclusive exchange with family member. Speech turns back and forth &gt;3 times (however verbal encourages such as mmmmm, yes, right do not constitute a speech turn). May be a sign of coalition formation.</td>
<td>0: Never 1: Once 2: More than once</td>
<td>1, 4</td>
</tr>
<tr>
<td></td>
<td>1.7</td>
<td>Physician does not attempt to speak directly to family member throughout consultation</td>
<td>Yes/No</td>
<td>2, 3</td>
</tr>
<tr>
<td></td>
<td>1.8</td>
<td>Physician discusses potentially sensitive information (e.g. sexuality, depression, prognosis, fertility) in the presence of the family member, without checking patient preferences</td>
<td>Yes/No</td>
<td>2, 3</td>
</tr>
<tr>
<td></td>
<td>Preference Negotiation</td>
<td></td>
<td>Decision-making</td>
<td>Information Exchange</td>
</tr>
<tr>
<td>---</td>
<td>------------------------</td>
<td>---</td>
<td>-----------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>1.9</td>
<td>Shows appreciation or respect of family member</td>
<td>Physician shows that they appreciate or respect the involvement or care that the family member provides. <em>E.g. It seems like you are being a great support to your husband</em></td>
<td>Yes/No</td>
<td>2, 3</td>
</tr>
<tr>
<td>1.10</td>
<td>Establishes why family member has attended consultation</td>
<td>Physician establishes (by asking patient or family member) why the family member is present in the consultation. <em>E.g. And why have you come along today?</em></td>
<td>Yes/No</td>
<td></td>
</tr>
<tr>
<td>1.11</td>
<td>Clarifies family member role in consultation</td>
<td>Physician establishes (by asking patient or family member) what the role of the family member will be throughout the consultation <em>E.g. How would you like your wife to be involved in this consultation today?</em></td>
<td>Yes/No</td>
<td>2, 5</td>
</tr>
<tr>
<td>1.12</td>
<td>Establishes patient’s preference for family involvement in decisions</td>
<td>Physician explicitly attempts to establish the patient’s preferences for how involved the family should be in decisions</td>
<td>Yes/No</td>
<td>2, 5</td>
</tr>
<tr>
<td>1.13</td>
<td>Establishes family members preference for involvement in decisions</td>
<td>Physician explicitly attempts to establish the family members preferences for how involved they would like to be in the decision-making process</td>
<td>Yes/No</td>
<td>2, 5</td>
</tr>
<tr>
<td>1.14</td>
<td>Confirms family members role in decision-making</td>
<td>Physician confirms the role of the family member in the decision-making process <em>E.g. Ok, so you are here mainly to provide support, but nor influence you son’s decisions</em></td>
<td>Yes/No</td>
<td>2, 5</td>
</tr>
<tr>
<td>1.15</td>
<td>Clarifies that patient is focus of consultation</td>
<td>Physician makes it explicitly clear that the patient is the focus of the consultation (patient centredness) <em>E.g. Well, we are all here today to help Cathy, so she will be the focus of our conversation</em></td>
<td>Yes/No</td>
<td>3, 5</td>
</tr>
<tr>
<td></td>
<td>Decision-making</td>
<td></td>
<td>Decision-making</td>
<td>Information Exchange</td>
</tr>
<tr>
<td>1.16</td>
<td>Invites family member question (related to decision)</td>
<td>Invites family member to ask a question (related to treatment decision) at least once</td>
<td>Yes/No</td>
<td>3, 5</td>
</tr>
<tr>
<td>1.17</td>
<td>Responsive to family member questions/comments (related to decision)</td>
<td>Physician responds to a question family member has asked regarding a treatment decision</td>
<td>N/A 0: Ignores 1: Partially responds 2: Fully responds</td>
<td>3, 4, 5</td>
</tr>
<tr>
<td>1.18</td>
<td>Asks family member question (related to decision)</td>
<td>Physician asks family member at least one question (related to treatment decision) <em>E.g. And Mrs Smith, have you had any experience of chemotherapy in the past?</em></td>
<td>Yes/No</td>
<td>3, 5</td>
</tr>
</tbody>
</table>
| 1.19 | Engages in conversation explicitly with family member (related to decision) | Physician engages in an exclusive exchange with family member (related to treatment decision). Back and forth 3 or more times. May be a sign of coalition formation. 
*E.g.*
*Dr:*
*Fm:*
*Dr:* 
*Fm:* 
*Dr:* 
*Fm:* | 0: Never 
1: Once 
2: More than once | 1, 4 |
| 1.20 | Provides information about how decision will impact on the family member | Physician explains how the potential treatments may impact on the family member's life. 
*E.h. Well, Mrs Smith, your husband will be very unwell for weeks at a time due to the chemotherapy, so you will probably have more responsibility around the house and may need to drive him into the hospital each week.* | Yes/No/NA | 3 |
| Deliberation | 1.21 | Invites family member preference for decision | Physician encourages family member to express their preference for the treatment decision 
*E.g. Do you have a preference for your husband's treatment, Mrs Smith?* | Yes/No/NA | 3, 5 |
| 1.22 | Encourages family member and patient to discuss decision outside consultation | Physician encourages the patient and/or family member to discuss and consider the decision outside of the consultation 
*E.g. Of course, you don’t have to make the decision today. If you like, you can go home and think more about it.* | Yes/No/NA | 3 |
<p>| Decision | 1.23 | Highlights that it is the patient's final decision | Physician explicitly states that the decision is the patient's to make | Yes/No/NA | 3, 5 |
| 1.24 | Confirms family member is happy with final decision | Physician confirms that the family member is happy/content with the decision that has been reached | Yes/No/NA | 3, 5 |</p>
<table>
<thead>
<tr>
<th>Patient Overall Communication</th>
<th>Overall Communication</th>
<th>0: Never</th>
<th>1: Once</th>
<th>2: More than once</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2.1</strong></td>
<td>Corrects or disagrees with family member (not related to decision)</td>
<td>Patient corrects or disagrees with a comment that family member has made. <em>E.g. No, I had the scan in May, not April</em></td>
<td>0: Never</td>
<td>1: Once</td>
<td>2: More than once</td>
</tr>
<tr>
<td><strong>2.2</strong></td>
<td>Interrupts family member</td>
<td>Patient interrupts/speaks over family member. Family member is unable to finish sentence, or topic of conversation is changed abruptly. Family member has clearly not finished speaking. Not an interruption if individual before stutters <em>e.g. the, the...</em> Not an interruption if the individual before says <em>ummm</em></td>
<td>0: Never</td>
<td>1: Once</td>
<td>2: More than once</td>
</tr>
<tr>
<td><strong>2.3</strong></td>
<td>Asks family member a question (not related to decision)</td>
<td>Patient asks family member a question. <em>E.g. Do you remember the name of the blood pressure tablets I am on</em></td>
<td>Yes/No</td>
<td>3, 4</td>
<td></td>
</tr>
<tr>
<td><strong>2.4</strong></td>
<td>Answers for family member</td>
<td>Patient answers a physician question aimed at the family member</td>
<td>0: Never</td>
<td>1: Once</td>
<td>2: More than once</td>
</tr>
<tr>
<td><strong>2.5</strong></td>
<td>Speaks directly to family member (not a question)</td>
<td>Patient speaks directly to the family member. Not a question. <em>E.g. Oh, yeah- that’s a good question I forgot to ask</em></td>
<td>Yes/No</td>
<td>3, 4</td>
<td></td>
</tr>
<tr>
<td>Preference Negotiation</td>
<td>Preference Negotiation</td>
<td>Yes/No</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2.6</strong></td>
<td>Indicates a desire for family member to stop talking/become more passive</td>
<td>Patient indicates that they would like the family member to stop talking or that they would like the family member to take on a more passive role. <em>E.g. Well, just hand on a second, and let me get a word in.</em></td>
<td>Yes/No</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>2.7</strong></td>
<td>Expresses a wish for active family involvement</td>
<td>Patient openly expresses that they would like their family member to be involved in the consultation. <em>E.g. Well, I’d like my wife to be able to be as involved as I am</em></td>
<td>Yes/No</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>2.8</strong></td>
<td>Voices preference for family member involvement in decisions</td>
<td>Patient initiates highlighting their preference for family member involvement themselves.</td>
<td>Yes/No</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Decision-making</td>
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<tr>
<td><strong>Information Exchange</strong></td>
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</tbody>
</table>
| 2.9 | Asks family member if they have any questions (related to decision) | Patient asks family member if they have any questions related to the treatment  
*E.g. Ok, the treatment sounds good. Do you have any questions?* | Yes/No | 3 |
| 2.10 | Provides information about family member (related to decision) | Patient provides some information about the family member relevant to the decision  
*E.g. Joseph likes to play golf on Wednesdays. So I don’t think I can do chemotherapy at this hospital if it is only on Wednesdays.* | Yes/No | 3 |
| **Deliberation** |  |  |
| 2.11 | Asks family member preference/opinion | Patient asks family member if they have a preference for the decision  
*E.g. What do you think about the options?* | Yes/No | 3 |
| 2.12 | Argues with family member about decision | Patient argues/disagrees with family member about decision  
*E.g. No, I know you want me to live as long as possible, but my quality of life is no good and I don’t really want treatment* | Yes/No | 3 |
| **Decision** |  |  |
| 2.13 | Defers decision to family member | Patient defers the decision to their family member  
*E.g. You just tell the doctor what you think is best for me* | Yes/No/NA | 3 |
| 2.14 | Confirms family member is happy with decision | Patient checks with the family member that they are agreeable to the decision that has been made  
*E.g. Is that ok with you?* | Yes/No/NA | 3 |
<table>
<thead>
<tr>
<th>Family Member</th>
<th>Overall Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1</td>
<td>Apologises for speaking/asks for permission to speak</td>
</tr>
<tr>
<td>3.2</td>
<td>Recalls information about patient history</td>
</tr>
<tr>
<td>3.3</td>
<td>Shows partnership with patient</td>
</tr>
<tr>
<td>3.4</td>
<td>Corrects or disagrees with patient</td>
</tr>
<tr>
<td>3.5</td>
<td>Interrupts patient</td>
</tr>
<tr>
<td>3.6</td>
<td>Interrupts doctor</td>
</tr>
<tr>
<td></td>
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</tr>
</tbody>
</table>
| 3.7 | Answers for patient (not related to decision) | Family member answers a physician question aimed at the patient  
*E.g. No, she doesn’t have any allergies* | 0: Never  
1: Once  
2: More than once |
| 3.8 | Prompts patient questions (not related to decision) | Family member prompts or reminds patient about a question  
*E.g. Didn’t you want to ask the doctor about those blood test results* | Yes/No |
| 3.9 | Confirms information that patient provides | Family member confirms/corroborates information that the patient tells the doctor  
*E.g. Yes, the GP only tested the PSA once in 2011* | Yes/No/NA |
| 3.10 | Summarises/repeats information for patient | Family member simplifies or summarises information for the patient to enhance understanding  
*E.g. Ok, so the doctor is saying that we need to get 3 more tests before you can start treatment* | Yes/No |
| 3.11 | Asks questions (not related to decision) | Family member asks questions within the consultation | 0: Never  
1: Once  
2: More than once |
| 3.12 | Asks questions about themselves | Family member asks questions about their own health or coping during consultation  
*E.g. What do you think my chances of cancer are?* | Yes/No |
| 3.13 | Asks patient a question | Family member asks patient a question  
*E.g. Do you think you should cut down on the smoking, if the doctor is saying it is so bad* | Yes/No |
| 3.14 | Patient and family member combined talk | Patient and family member engage in talk which is reciprocal and bounces back and forth- but could not be considered interruptions. | Yes/No |
| 3.15 | Speaks directly to patient | Family member speaks directly to the patient within the consultation  
*E.g. Dad, you probably can’t go on holidays again this year if you’re having treatment* | Yes/No |
| 3.16 | Makes optimistic/positive statement | Family member makes a statement which is considered optimistic or positive about the patient or their health/treatment  
*E.g. well, there is so much research out there that we can’t give up hope* | Yes/No |
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<thead>
<tr>
<th>Preference Negotiation</th>
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</thead>
<tbody>
<tr>
<td>3.17</td>
<td>Expresses desire to be actively involved in consultation</td>
<td>Family member makes it explicitly known that they would like to be actively involved in the consultation. <em>E.g.</em> We have shared this whole journey, so I’d like to be actively involved here today.</td>
</tr>
<tr>
<td>3.18</td>
<td>Voices preference for involvement in decisions</td>
<td>Family member initiates highlighting their preference for involvement themselves.</td>
</tr>
</tbody>
</table>

| Decision-making |  |  |

<table>
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<tr>
<th>Information Exchange</th>
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<tbody>
<tr>
<td>3.19</td>
<td>Provides information/suggestion (related to decision)</td>
<td>Family member provides information relevant to decision, or makes a suggestion regarding the treatment decision. <em>E.g.</em> I read online that there is a new chemotherapy drug which works with Mary’s type of cancer</td>
</tr>
<tr>
<td>3.20</td>
<td>Raises patient’s previous reactions to treatments</td>
<td>Family member highlights/recalls the patient’s reactions to any previous medical treatments (in reference to current treatment decision-making discussion). <em>E.g.</em> Well, you tolerated chemo alright last time, so…</td>
</tr>
<tr>
<td>3.21</td>
<td>Asks question about treatment or decision/seeks supplementary information</td>
<td>Family member indicates that they would like to receive additional information. Includes pain questions. <em>E.g.</em> So, this new chemotherapy drug. Can you tell us more about the side effects.</td>
</tr>
<tr>
<td>3.22</td>
<td>Discusses the risks/benefits of treatment</td>
<td>Family member asks about or engages in a discussion about the possible risks or benefits of potential treatments. <em>E.g.</em> And what are the side effects? <em>E.g.</em> And what is the likelihood of her heart muscles weakening?</td>
</tr>
<tr>
<td>3.23</td>
<td>Asks specific question about pain/treatment of pain</td>
<td>Family member asks a question about pain management or pain patient is experiencing as a result of the cancer or other treatments.</td>
</tr>
<tr>
<td>3.24</td>
<td>Asks about issues relating to themselves (related to decision)</td>
<td>Family member asks physician a question which is relevant to themselves about the treatment options. <em>E.g.</em> Will I still be able to work if John is having chemotherapy?</td>
</tr>
<tr>
<td>Code</td>
<td>Description</td>
<td>Family member example</td>
</tr>
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</tr>
<tr>
<td>3.25</td>
<td>Questions information provided by physician (related to decision)</td>
<td>Family member questions or challenges information provided by physician. <em>E.g. Are you really sure that surgery is the best option for my wife at this stage?</em></td>
</tr>
<tr>
<td>3.26</td>
<td>Answers for the patient (related to decision)</td>
<td>Family member answers a physician question aimed at the patient. <em>E.g. No, she doesn’t know much about chemotherapy</em></td>
</tr>
<tr>
<td>3.27</td>
<td>Prompts patient questions (related to decision)</td>
<td>Family member asks/prompts the patient about questions. <em>E.g. Darling, do you have any questions you want to ask the doctor about those potential treatments?</em></td>
</tr>
<tr>
<td>3.28</td>
<td>Presents information back to patient (related to decision)</td>
<td>Family member summarises or simplifies information back to patient to aid understanding. <em>E.g. So, you have 2 options mum, chemotherapy alone or chemotherapy with hormone tablets.</em></td>
</tr>
<tr>
<td></td>
<td><strong>Deliberation</strong></td>
<td></td>
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<tr>
<td>3.29</td>
<td>Expresses treatment preference</td>
<td>Family member openly expresses their preference for treatment. <em>E.g. Well I think that option sounds good</em></td>
</tr>
<tr>
<td>3.30</td>
<td>Expresses a general wish for treatment outcomes/aims</td>
<td>Family member expresses a more general wish for treatment aim or outcome. <em>E.g. I just want you to hang around for as long as possible</em></td>
</tr>
<tr>
<td>3.31</td>
<td>Indicates preference for further discussion outside consultation</td>
<td>Family member indicates that they would like the opportunity to think about and/or discuss the decision outside the consultation. <em>E.g. We don’t have to make the decision today do we? Can we go home and talk more?</em></td>
</tr>
<tr>
<td>3.32</td>
<td>Helps articulate patient goals</td>
<td>Family member helps to highlight the patient’s goals for treatment or more general goals in life. <em>E.g. Well, mum really wants to see her first grandchild born, so can we keep her cancer under control for another 4 months?</em></td>
</tr>
<tr>
<td>3.33</td>
<td>Helps highlight patient preference</td>
<td>Family member helps to highlight the patients preferences or opinions to the physician. <em>E.g. Mum, you said you wanted to maintain a good quality of life didn’t you?</em></td>
</tr>
</tbody>
</table>
| Decision | Highlights that patient is ultimate decision-maker | Family member shows that the patient has the right to make the final decision  
*E.g. Well dad, it's up to you* | Yes/No/NA | 3, 5 |
| --- | --- | --- | --- | --- |
| 3.35 | Confirms patient is satisfied with decision | Family member confirms/ double checks with patient that they are happy with the decision that is being made  
*E.g. And you're happy with this dad?* | Yes/No/NA | 3, 5 |
| 3.36 | Shows agreement with, or support of, decision | Family member shows their agreement with the decision that has been reached or support of the decision that has been reached  
*E.g. Yep, I think that's the way to go* | Yes/No/NA | 3, 4, 5 |
| 3.37 | Shows disagreement with decision | Family member shows their disagreement or concern about the decision that has been reached  
*E.g. I just don't think that this is going to be the best way of curing you mum* | Yes/No/NA | 3, 5 |
| 3.38 | Informs doctor of decision | Family member is the person who informs the physician of the decision  
*E.g. Well, I think we'll go ahead with the chemotherapy* | Yes/No/NA | 3, 5 |

*Item Origin:*

1. *Previous triadic interaction analysis coding systems;*
2. *Relevant behaviours identified in a systematic review of triadic consultations*
3. *Relevant behaviours identified from interviews with patients, family members, and health professionals*
4. *Relevant behaviours from a qualitative analysis of initial medical consultations*
5. *Previous dyadic communication and decision-making coding systems and theory*
Appendix R
TRIO Coding Marking Sheet
<table>
<thead>
<tr>
<th>Roles</th>
<th>Consultation stage</th>
<th>Role</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>History taking</td>
<td>Passive</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Supportive</td>
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<td>Active</td>
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<td></td>
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<td>Dominant</td>
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<tr>
<td>D</td>
<td>Deliberation and decision-making</td>
<td>Passive</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Supportive</td>
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<tr>
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<td>Active</td>
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<td></td>
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<td>Dominant</td>
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</tbody>
</table>

Audio-tape file type: _____________________  Tape ID: _____________________  Coder: _____________________  Date: __________  Relationship Type: _____________________
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<thead>
<tr>
<th>Category</th>
<th>Item</th>
<th>Scoring</th>
<th>Remarks</th>
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</thead>
<tbody>
<tr>
<td>Physician</td>
<td></td>
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<tr>
<td><strong>Overall communication</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>1.1</td>
<td>Actively engages in social interaction/laughter with family member</td>
<td>□Yes</td>
<td></td>
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<td></td>
<td></td>
<td>□No</td>
<td></td>
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<tr>
<td>1.2</td>
<td>Responsive to family member questions/comments (not related to decision)</td>
<td>□0: Ignores</td>
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<tr>
<td></td>
<td></td>
<td>□1: Occasionally responds</td>
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<td></td>
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<td>□2: Mostly responds</td>
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<td></td>
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<td>□N/A</td>
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</tr>
<tr>
<td>1.3</td>
<td>Asks family member a question (not related to decision)</td>
<td>□Yes</td>
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<td></td>
<td></td>
<td>□No</td>
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<tr>
<td>1.4</td>
<td>Asks family member to confirm/corroborate patient information</td>
<td>□Yes</td>
<td></td>
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<td></td>
<td></td>
<td>□No</td>
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<td>□N/A</td>
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<tr>
<td>1.5</td>
<td>Interrupts family member</td>
<td>□0: Never</td>
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<td></td>
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<td>□1: Once</td>
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<td></td>
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<td>□2: More than once</td>
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<tr>
<td>1.6</td>
<td>Engages in conversation explicitly with family member (not related to decision)</td>
<td>□0: Never</td>
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<tr>
<td></td>
<td></td>
<td>□1: Once</td>
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<td></td>
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<td>□2: More than once</td>
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</tr>
<tr>
<td>1.7</td>
<td>Family member not acknowledged or spoken to</td>
<td>□Yes</td>
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<td></td>
<td></td>
<td>□No</td>
<td></td>
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<td>1.8</td>
<td>Reveals potentially sensitive information</td>
<td>□Yes</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>□No</td>
<td></td>
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<tr>
<td>1.9</td>
<td>Shows appreciation or respect of family member</td>
<td>□Yes</td>
<td></td>
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<td></td>
<td></td>
<td>□No</td>
<td></td>
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<tr>
<td>Preference Negotiation</td>
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<tr>
<td>1.10</td>
<td>Establishes why family member has attended the consultation</td>
<td>□Yes</td>
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<tr>
<td></td>
<td></td>
<td>□No</td>
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<tr>
<td>1.11</td>
<td>Clarifies family member role in consultation</td>
<td>□Yes</td>
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<td></td>
<td></td>
<td>□No</td>
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<tr>
<td>1.12</td>
<td>Establishes patient’s preference for family involvement in decisions</td>
<td>□Yes</td>
<td></td>
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<td></td>
<td></td>
<td>□No</td>
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<td></td>
<td></td>
<td>Establishes family members preference for involvement in decisions</td>
<td>Yes</td>
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<tr>
<td>1.13</td>
<td></td>
<td>Confirms family members role in decision-making</td>
<td>Yes</td>
</tr>
<tr>
<td>1.14</td>
<td></td>
<td>Clarifies that patient is focus of consultation</td>
<td>Yes</td>
</tr>
<tr>
<td>1.15</td>
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<td>Information Exchange</td>
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</tr>
<tr>
<td>1.16</td>
<td></td>
<td>Invites family member question (related to decision)</td>
<td>Yes</td>
</tr>
<tr>
<td>1.17</td>
<td></td>
<td>Responsive to family member questions/comments (related to decision)</td>
<td>0: Ignores</td>
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<td>1.18</td>
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<td>Asks family member question (related to decision)</td>
<td>Yes</td>
</tr>
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<td>1.19</td>
<td></td>
<td>Engages in conversation explicitly with family member (related to decision)</td>
<td>0: Never</td>
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<td>1.20</td>
<td></td>
<td>Provides information about how decision will impact on the family</td>
<td>Yes</td>
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<td></td>
<td></td>
<td>Deliberation</td>
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<tr>
<td>1.21</td>
<td></td>
<td>Invites family member preference for decision</td>
<td>Yes</td>
</tr>
<tr>
<td>1.22</td>
<td></td>
<td>Encourages family member and patient to discuss decision outside consultation</td>
<td>Yes</td>
</tr>
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<td>Decision</td>
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<tr>
<td>1.23</td>
<td></td>
<td>Highlights that it is the patient's final decision</td>
<td>Yes</td>
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<tr>
<td>1.24</td>
<td>Confirms family member is happy with decision</td>
<td>☐ Yes  ☐ No  ☐ N/A</td>
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<thead>
<tr>
<th>Patient</th>
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</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Corrects or disagrees with family member</td>
</tr>
<tr>
<td>2.2</td>
<td>Interrupts family member</td>
</tr>
<tr>
<td>2.3</td>
<td>Asks family member a question (not related to decision)</td>
</tr>
<tr>
<td>2.4</td>
<td>Answers for family member</td>
</tr>
<tr>
<td>2.5</td>
<td>Speaks directly to family member (not a question)</td>
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<td>2.6</td>
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<tbody>
<tr>
<td>Information Exchange</td>
</tr>
<tr>
<td>2.9</td>
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<td>2.10</td>
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<table>
<thead>
<tr>
<th>Deliberation</th>
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<tbody>
<tr>
<td>2.11</td>
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<tr>
<td>2.12</td>
</tr>
<tr>
<td>Decision</td>
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<tr>
<td>----------------------------------</td>
</tr>
<tr>
<td>2.13</td>
</tr>
<tr>
<td>2.14</td>
</tr>
<tr>
<td>Family Member</td>
</tr>
<tr>
<td>---------------</td>
</tr>
</tbody>
</table>
| 3.1           | Apologises for speaking/asks permission to speak | Yes  
No |
| 3.2           | Recalls information about patient history | 0: Never  
1: Once  
2: More than once |
| 3.3           | Shows partnership with patient | Yes  
No |
| 3.4           | Corrects or disagrees with patient | 0: Never  
1: Once  
2: More than once |
| 3.5           | Interrupts patient | 0: Never  
1: Once  
2: More than once |
| 3.6           | Interrupts doctor | 0: Never  
1: Once  
2: More than once |
| 3.7           | Answers for patient (not related to decision) | 0: Never  
1: Once  
2: More than once |
| 3.8           | Prompts patient questions (not related to decision) | Yes  
No |
| 3.9           | Confirms information that patient provides | Yes  
No  
N/A |
| 3.10          | Summarises/repeats information for patient | Yes  
No |
| 3.11          | Asks questions (not related to decision) | 0: Never  
1: Once  
2: More than once |
| 3.12          | Asks questions about themselves | Yes  
No |
<p>| | | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td><strong>3.13</strong></td>
<td>Asks patient a question</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.14</strong></td>
<td>Patient and family member combined talk</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.15</strong></td>
<td>Speaks directly to patient</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.16</strong></td>
<td>Makes optimistic/positive statement</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>Preference Negotiation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3.17</strong></td>
<td>Expresses desire to be actively involved in consultation</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.18</strong></td>
<td>Voices preference for involvement in decisions</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>Decision-making</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Information Exchange</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3.19</strong></td>
<td>Provides information/suggestion (related to decision)</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.20</strong></td>
<td>Raises patient’s previous reactions to treatments</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.21</strong></td>
<td>Asks question about treatment or decision/ seeks supplementary information</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.22</strong></td>
<td>Discusses the risks/benefits of treatment</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.23</strong></td>
<td>Asks specific question about pain or management of pain</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.24</strong></td>
<td>Asks about issues relating to themselves (related to decision)</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.25</strong></td>
<td>Questions information provided by physician (related to decision)</td>
<td>☐ Yes ☐ No</td>
</tr>
<tr>
<td><strong>3.26</strong></td>
<td>Answers for the patient (related to decision)</td>
<td>☐ 0: Never ☐ 1: Once ☐ 2: More than once</td>
</tr>
<tr>
<td>3.27</td>
<td>Prompts patient questions (related to decision)</td>
<td>□ Yes</td>
</tr>
<tr>
<td>3.28</td>
<td>Presents information back to patient (related to decision)</td>
<td>□ Yes</td>
</tr>
</tbody>
</table>

**Deliberation**

| 3.29 | Expresses treatment preference | □ Yes | □ No |
| 3.30 | Expresses a general wish for treatment outcomes/aims | □ Yes | □ No |
| 3.31 | Indicates preference for further discussion outside consultation | □ Yes | □ No |
| 3.32 | Helps articulate patient goals | □ Yes | □ No |
| 3.33 | Helps highlight patient preference | □ Yes | □ No |

**Decision**

| 3.34 | Highlights that patient is ultimate decision-maker | □ Yes | □ No | □ N/A |
| 3.35 | Confirms patient is satisfied with decision | □ Yes | □ No | □ N/A |
| 3.36 | Shows agreement with, or support of, decision | □ Yes | □ No | □ N/A |
| 3.37 | Shows disagreement with decision | □ Yes | □ No | □ N/A |
| 3.38 | Informs doctor of decision | □ Yes | □ No | □ N/A |
Appendix S
Secondary Analyses Ethics Approval
Dear Phyllis,

I am pleased to inform you that the Human Research Ethics Committee (HREC) approved your protocol entitled “Secondary analysis of non-identifiable transcripts and demographic data collected in the Australian Cancer Trials Online Study” at its meeting held on the 3rd of April, 2012.

Details of the approval are as follows:

Protocol No.: 14701
Approval Date: 3 April 2012
First Annual Report Due: 30 April 2013
Authorised Personnel: Prof. Phyllis Butow
Prof. Martin Tattersall
Prof. Alexandra Barratt
Dr Rachel Dear
Dr Kevin McGeechan
Ms Rebekah Powell
Ms Stella Bu
Ms Frances Bellemore

Documents Approved:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version Number</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant information statement</td>
<td>1</td>
<td>Submitted 19/3/2012</td>
</tr>
<tr>
<td>Consent form</td>
<td>1</td>
<td>Submitted 19/3/2012</td>
</tr>
</tbody>
</table>

HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:

**Condition/s of Approval**

- Continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.
• Provision of an annual report on this research to the Human Research Ethics Committee from the approval date and at the completion of the study. Failure to submit reports will result in withdrawal of ethics approval for the project.

• All serious and unexpected adverse events should be reported to the HREC within 72 hours.

• All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

• Any changes to the protocol including changes to research personnel must be approved by the HREC by submitting a Modification Form before the research project can proceed.

Chief Investigator / Supervisor’s responsibilities:

1. You must retain copies of all signed Consent Forms (if applicable) and provide these to the HREC on request.

2. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

[Signature]

Associate Professor Ian Maxwell
Chair
Human Research Ethics Committee

cc:

This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.