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**INVOLVING PATIENTS IN TREATMENT
DECISION-MAKING: THE VIEWS AND
ATTITUDES OF AUSTRALIAN CANCER
DOCTORS TO SHARED DECISION-MAKING**

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*This thesis is submitted in satisfaction of the requirements for
the Degree of Philosophy, University of Sydney*

STATEMENT OF AUTHENTICATION

This thesis is submitted to the University of Sydney in fulfilment of the requirements for the Degree of Doctor of Philosophy.

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or part, for a degree at this or any other institution.

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2005 HL Shepherd, MHN Tattersall, PN Butow.. Shared Treatment Decision Making (STDm): A survey of cancer doctors' views and attitudes across Australia. Presentation of final results. Clinical Oncological Society of Australia (COSA) 32nd Annual Scientific Meeting, Brisbane, QLD.

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2005 HL Shepherd Shared Decision Making – meanings, problems and solutions - Sydney Health Decision Making Group and MPRU, University of Sydney.

SUMMARY

Involving cancer patients in treatment decision-making is considered to be gold standard practice, yet there are limited data on the views of cancer doctors.

The first stage of this thesis identified Australian cancer doctors' usual approach to decision-making and comfort with different decision-making styles when discussing treatment with patients. Barriers and facilitators to patient involvement were investigated.

A response rate of 59% resulted in 624 complete surveys. Most cancer doctors reported using shared decision-making (SDM) and being most comfortable with this approach. Differences were apparent between high comfort with SDM and less frequent usual practice. Specialisation in breast or urological cancer compared to other cancers, high new patient caseload and female gender were independently associated with increased likelihood of use of SDM. Insufficient information and time at first consultation were the most frequent barriers. Less experienced physicians more commonly reported system barriers, while trust and being accompanied at the consultation were most helpful.

Stage two used qualitative methodology to explore influences on doctors' decision-making styles with patients and consequences of involvement with a subset of the sample.

Three main themes emerged. Critical features of involving patients in treatment decisions included the doctor/patient relationship, eliciting preferences and information exchange. Factors which motivate doctors to involve patients were influenced by disease, patient, doctor and society characteristics. Consequences of involvement include improved doctor/patient relationship, increased consultation time and acquiring new skills in eliciting preferences and communicating complex information. Decision responsibility, meaning accountability for the decision, may also be shifted by involving patients in treatment decisions.

Australian cancer doctors report discrepancies between their comfort with and use of SDM. Cancer doctors suggest that the context, impact and effects of involvement influence their support of this, with doctors experiencing difficulties involving patients in treatment decisions. Yet support for interventions and strategies to enhance patient involvement is limited.

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SECTION ONE
INTRODUCTION AND REVIEW OF
THE LITERATURE

CHAPTER ONE

INTRODUCTION

1.1 History of approaches to decision-making

Decision-making in medicine has traditionally been seen as the arena of the doctor. As the expert, the doctor has been seen as the one with the knowledge and responsibility to make treatment decisions. This Hippocratic tradition of medicine is founded on a paternalistic model, with a guiding moral principle of beneficence, the duty of the doctor where possible to do good where possible (Robison 1979; Plueckhahn 1994).

The late twentieth century has seen the emergence of patient autonomy and patient rights as competing ethical principles in patient care (Rosner 2004). The traditional paternalistic model has been challenged by the increased importance placed on the ethos of autonomy in the medical setting, with the anti-paternalistic argument asserting that paternalism contravenes the rights of the individual and inhibits choice (Beauchamp and Childress 2001). Childress writes that one of the true criticisms of paternalism is the increased power that this model of care gives to healthcare professionals and the state. In the domain of healthcare decision-making, the paternalistic model allows the doctor to override the patient's right of self-determination by asserting that he/she can make the best decision for the patient (Robison 1979; Beauchamp and Childress 2001). Häyry (1991) suggests that a fundamental problem with medical paternalism is that while the doctor has factual

medical knowledge, he or she is not necessarily knowledgeable about their patients' personal values and expectations and therefore may not make the 'best' decision for the individual patient. Subsequently, the principle of patient autonomy may better protect patient rights and facilitate optimal outcomes.

Autonomy is one of the four moral principles particularly relevant to medicine and is defined as the right of individuals to make decisions on their own behalf (Häyry 1991; Plueckhahn 1994; Beauchamp and Childress 2001). Autonomy in the healthcare context is described by Garfield in (Shotton 1997) as the right to determine one's own life and medical treatment, having been informed as much as is feasible, and to be respected as a person (Quill and Brody 1996). This description encompasses the right of competent patients to commence, continue or terminate treatment, even when their choice challenges health professionals' beneficence (such as in situations where patients refuse life-sustaining therapy). The World Medical Association outlined the rights of patients in 1981 in the Declaration of Lisbon, defining informed consent as the patient's right to accept or refuse treatment after receiving adequate information (Plueckhahn 1994). The principles of informed consent are now widely accepted in the medical world, encompassing the revelation of pertinent information, the subsequent understanding of that information by the patient, followed by a voluntary decision and granting of permission to proceed with the treatment or therapy being discussed (Beauchamp and Childress 2001). The principle of informed consent, closely aligned with the principle of autonomy, has

now been embodied in charters and rulings, such as the Declaration of Helsinki in 1964, and again in 1996 and 2000.

The principle of autonomy has come to the fore in healthcare due to the progress of medicine. Increased specialisation, the increased availability of treatment options and diagnostic tests, the reduced role of the family doctor and the high profile of health issues in the media have each contributed to this change, in line with the move to a progressively more consumerist society, (Skene and Millwood 1997). Expectations of the public to be informed have also increased over recent years, while there is a decrease in acceptance of medical paternalism, reflected in the reference to patients as consumers in literature concerning medical ethics and healthcare (Shotton 1997). The patients' rights movement supports autonomy, control and patient challenge to medical authority (Quill and Brody 1996; Strum 1997). Also contributing to this changing environment is the increased availability of the internet, the increased access to tertiary education and the activity of the media over the last 50 years, which has made a plethora of information readily accessible to the general public (Strum 1997). With this knowledge, some patients now enter consultations very differently to patients who previously had no way of accessing such medical knowledge, diagnostic information or awareness of treatment availability.

1.2 Legal issues

The changing role of the patient in healthcare has been reflected through a number of legal proceedings, namely where lack of information provision to patients concerning possible outcomes prior to medical intervention, and a resulting poor outcome has

brought about successful challenges to the definition of informed consent prior to the 1970s (Laine and Davidoff 1996). In law, consent was defined through the often-cited 1957 Bolam case in the United Kingdom (UK). This case determined that doctors were required to provide information to patients which a “responsible body of doctors would regard as appropriate”. A case in the High Court of Australia, Rogers versus Whittaker (1992), challenged the Bolam process of consent and asserted the importance of communication of material risk and the significance this may have to individual patients (Campbell-Tiech 2003). In Australia, the High Court outlined two requirements of medical practitioners in gaining the consent of their patients to procedures. Firstly, the doctor must inform the patient of the procedure or therapy to be performed and secondly, the doctor is required to provide the patient with material information concerning the planned therapy. Failure to meet the first requirement could result in liability in terms of trespass or assault; failure to meet the second requirement would leave the doctor liable for negligence in failing to meet his or her duty of care (Häyry 1991; Skene and Millwood 1997; Protection 2003). The same High Court went further in the Chappel versus Hart case (1998) in supporting a patient’s comprehensive right to know. Through these high profile cases, informed consent has become embodied in law as a patient right (Campbell-Tiech 2003).

In the United States, law suits that sought to determine whether informed consent had been achieved appeared to support paternalistic behaviour of the medical community by summoning doctors as expert witnesses in such cases. The expert witnesses were required to assist in determining whether sufficient information had been given to the

patients. By using just doctors in this instance, doctors themselves were able to govern how much information a patient should receive. However in recent years ‘expert’ witnesses have included laypeople, illustrating the shift toward respecting the autonomy and rights of patients (Frosch and Kaplan 1999).

A number of high profile scandals concerning healthcare have reduced the confidence of the general public in the medical profession, thus producing enquiring, question-asking patients (Charles, Gafni et al. 1999; Coulter and Dunn 2002). In 2004 the UK Prime Minister used the phrase “end of medical paternalism” to define a new approach to medical practice. This new approach aims to encourage patients to participate in treatment decisions (Dean 2004). These recent developments reinforce the notion that it is ethically sound that people should be informed and should be able to participate in and influence decisions about their own healthcare (Entwistle 2000).

1.3 Models of decision-making

Treatment decision-making models in healthcare are generally described in terms of the roles taken by the participants, the doctor and the patient, in the interaction and the resulting treatment decision (Emanuel and Emanuel 1992; Wirtz, Cribb et al. 2006). The first model discussed below portrays the doctor/clinician as the controller of the situation.

1.3.1 *Paternalistic model*

The paternalistic model is characterised by the patient playing a passive role in any communication with the clinician (Charles, Gafni et al. 1997), stemming from the sick role first alluded to in the literature by Parsons in 1951, as cited by Charles et al (1997). The patient, in this ‘sick role’, was obligated to recover from their illness by adhering to the treatments prescribed by their doctor/clinician and was relieved of any responsibility in their family during their sickness, clearly assuming a passive stance in relation to the expert doctor. Some advantages of the paternalistic model highlighted in the literature are its protective nature in relieving the family and patient of consideration of treatments which had only a minimal possibility of success (Quill and Brody 1996). Disadvantages now acknowledged are the difficulty doctors/clinicians may have in eliciting patients’ preferences and subsequent identification of their best interests. For example the effect of bias based on gender, ethnicity and socio-economic status, and the possibility of patients not being able to make decisions due to ignorance of their medical status can each impact a patient’s best interest (Quill and Brody 1996). Interestingly, as early as 1956, Szasz and Hollander suggested that the physician-patient relationship was changing.

1.3.2 *Informed model*

The next model to enter the medical decision-making literature has been described under a variety of different titles, including the informative model, the consumer model and the model of independent choice (Marzuk 1985; Emanuel and Emanuel 1992; Quill and Brody 1996). The *informed model* of decision-making in healthcare

was a response to the imbalance of information exchanged between doctor and patient in the paternalistic model and was formulated to embrace the legal requirements of informed consent which surfaced in the 1970s (Emanuel and Emanuel 1992; Charles, Gafni et al. 1997; Sheridan, Harris et al. 2004). This model focuses on the premise of information sharing, in the main part from the doctor to the patient, but giving the patient the two main ingredients necessary for decision-making: information and preferences (Levine, Gafni et al. 1992). Information gathering by the patient is stated by Charles et al (1997) to be the catalyst for empowerment as a decision maker. In the informed model the patient is in control of the decision-making, a complete role reversal for the doctor who can be excluded from any discussion of decisions once he or she has provided the relevant information. This information, as hypothesised by Charles et al (1997), could even be in a multi-media format, which means the doctor does not even need to be present when a decision regarding treatment is made. The *independent choice* and *consumer* models are described similarly in the literature to the informed model with the doctor's role being mainly as information providers in terms of treatment options and evidence-based information on outcomes (Marzuk 1985; Emanuel and Emanuel 1992; Quill and Brody 1996). The model promotes a truly patient-centred approach in that the patient is not exposed to any bias on the part of the clinician; the doctor's recommendations do not feature in the consultation. The human face of the clinician is considered to be superfluous, with their experience and values unnecessary and even a hindrance to the patient's decision-making (Quill and Brody 1996), implying

that any recommendation or expression of past experience in similar situations by the clinician is unwelcome.

One major stumbling block for this model in modern healthcare is the potential for patients sanctioning an indefinite continuation of treatment considered futile by the medical establishment (Quill and Brody 1996). Other criticisms of the informed model focus on the reduction of the clinician to information giver only, with the dangers of this approach being the de-skilling of health professionals, as well as the abandonment of the patient who may feel insufficiently knowledgeable, skilled or emotionally capable of making a decision (Emanuel and Emanuel 1992; Quill and Cassel 1995).

A variant of the informed model is that of **enhanced autonomy**. This model can be viewed as a reaction to the concern that the informed or independent choice model blurred the concepts of autonomy and independence (Quill and Brody 1996). Key components of this model are free discussion and exchange of information concerning treatment options, their risks, benefits and chances of success according to the evidence, the preferences and values of both parties, and recommendations based on this information (Quill and Brody 1996). This model places high value on the importance of the relationship between the doctor and patient and significant others, in contrast to the purely patient-centred nature of the independent choice model. The importance placed on the doctor-patient dialogue is illustrated by the emphasis given to the doctor's skills of active listening, acknowledging and

considering the patient's perspective and considering this perspective when making any treatment recommendations (Quill and Brody 1996). Quill and Brody (1996) state that treatment decisions are improved when made by the patient assisted by an experienced and knowledgeable doctor. This model lies at the autonomous end of the spectrum of the informed model of decision-making. The model permits the clinician to discuss treatment options and allows the patient to make a decision based on the expertise and advice of the clinician in terms of his or her medical knowledge (Quill and Brody 1996).

1.3.3 Interpretive model

In the interpretive model, the doctor takes the lead in informing the patient and guiding them towards a treatment choice by gathering information from the patient and deciphering his or her values (Emanuel and Emanuel 1992). The defining characteristic of this model, versus the paternalistic and informed models, is the emphasis on the discussion of what is important to the patient and the necessary skills required by the doctor to do this. An extreme example of this model is the 'physician as agent' model.

The agency or '*physician as agent*' model as described by Charles et al (1997) lies at the paternalistic end of the spectrum of the informed models of decision-making, with the aim being to correct the informational imbalance of the paternalistic model, but with the clinician controlling the decision-making once the patient has divulged

personal values and preferences. Information and preferences are in the power of one of the participants in the decision-making process. However though the doctor makes the decision, the process is not regarded as paternalistic, as the decision is likely to be the same decision as the one the patient would have made (Gafni, Charles et al. 1998). Shared decision-making has some similarities with interpretive decision-making, as both models acknowledge the importance of discovering the patient's values (Wirtz, Cribb et al. 2006)

1.3.4 *Shared decision-making*

One of the earliest descriptions of what we now might recognise as a shared decision-making model was a **deliberative** model (Emanuel and Emanuel 1992). Shared decision-making is seen as the middle ground between paternalism and informed decision-making (Edwards, Evans et al. 2003), and is considered an important component of patient-centred care. Patient-centred care supports the notion of sharing and the clinician must have the ability to empower patients, to share power within their relationship with patients, emphasising that this entails a change to the traditional view of a doctor-patient relationship (Stewart, Brown et al. 2003).

1.4 Concepts of shared decision-making

1.4.1 *Partnership*

In Eddy's analysis of shared decision-making, he describes a two step process, facts and preferences, where the patient's values determine the final decision (Eddy 1990).

The challenges for the clinician are to prevent their patients from misunderstanding the facts, leading to misinterpretation of risk or value, and for the clinician to avoid imposing his or her own preferences onto the patient. One central idea in shared decision-making is that of equal contribution, where both doctor and patient are equal partners in the decision process (Gattellari, Butow et al. 2001). This notion of partnership and of power being interchangeable in the doctor-patient relationship is also used to describe shared decision-making (Trevena and Barratt 2003).

1.4.2 *Information exchange*

Emanuel and Emanuel (1992) allude to the need for clinicians to provide information concerning the clinical status of the patient alongside clarification of what each or any treatment option would mean for the patient. Feldman-Stewart et al (2000) define shared decision-making as the means of assisting patients in treatment decision-making, by providing comprehensible information and in aiding the patient through the cognitive processes that result in a treatment decision. A number of researchers have defined information sharing as key to the process of shared decision-making (Gattellari, Butow et al. 2001). In the context of treatment decision-making, the most important information is often referred to as risk communication, which permits any management decisions to be based on knowledge by both parties of the choices and possible outcomes of those choices (Elwyn, Edwards et al. 1999). Coulter (2003) asserts that shared decision-making requires clinicians to present patients with information concerning diagnosis, prognosis, treatment options and their outcome probabilities. In order to practise shared decision-making, the

information needs to be entirely comprehensible by patients (Edwards, Elwyn et al. 2001).

1.4.3 Eliciting preferences

Coulter (1997; 2003) states that as well as providing information, the clinician should allow patients to express their preferences for involvement in any decision-making and treatment choice. Having elicited the patient's preferences, the doctor should then modify their consultation style in response to the patient's chosen decision-making role. This definition and interpretation is essential to avoid forcing some patients to participate in a process when they prefer not to.

1.4.4 Negotiation and agreement

Agreement between clinician and patient is highlighted as a marker of a shared decision process by Stewart (1995). She suggests that empowerment to be involved and support of the patient throughout the decision-making process to reach agreement, gives rise to positive outcomes. Shared decision-making is defined by Frosch as a discussion of treatment options by the doctor and patient, followed by an agreed selection of one which fits the preferences of the patient (Frosch and Kaplan 1999). In their critical analysis of treatment decision-making models, Wirtz, Cribb and Barber (2006) posit that negotiation has been a neglected component of shared decision-making, with minimal explanation about how clinicians can facilitate this crucial aspect of their communication with patients.

1.4.5 Implementation

Consistent with the characteristics of shared decision-making outlined above, three important goals have been identified for doctors to achieve during their interactions with patients; establish a good interpersonal relationship; facilitate information exchange; and facilitate patient involvement in decision-making (Ong, de Haes et al. 1995). Towle and Godolphin (1999) developed an informed shared decision-making competency list to assist doctors in their discussions with patients which consists of the following; establishing a partnership; eliciting preferences for information and involvement; acknowledging and responding to patient's views; outlining choices and providing the research evidence to support or refute these; discussion of possible outcomes, good and bad; decision negotiation and further planning. In their research to produce this framework, competencies for patients were also suggested by patient educators and patients themselves, namely: defining the preferred relationship and location of the clinician to establish and develop that relationship; ability to enunciate and communicate health issues, expectation and preferences to the clinician; and accessing information and skills to comprehend and evaluate this; capability to discuss, negotiate and manage differences of opinion; and capacity to form an agreed plan for treatment.

1.5 Models of shared decision-making

Several authors have attempted to explicate models of shared decision-making. Ratzan (1996) discusses a model of effective healthcare decision-making based on the principles of workable integrative negotiation and illustrates the process to

achieve this through the acronym COAST, **C**ommunication, **O**ptions, **A**lternatives, **S**tandards and **T**rust. The model he presents is illustrated as a circular process, beginning with communication which incorporates the identification of standpoints and an agenda, and listening to the other parties involved. Options are put on the table through continued dialogue, and alternatives are explored by identifying those that are available and realistic. The Standards stage concerns coming to an agreed goal and the sharing of information of what can be expected according to pertinent evidence. Trust is included as a two-way arrow feeding into communication, illustrating that unless trust between parties is established through honesty and openness, decisions may often be short-lived. This model emphasises the substantial role of communication in shared decision-making.

A model of shared decision-making in the context of patients with life-threatening disease and different treatment options has been described by Charles, Gafni et al (1997) This outlines four essential characteristics:

- ❑ Two people at least are involved in the decision-making process
- ❑ Both patient and doctor take part in the treatment decision-making
- ❑ There is a two-way flow of information between the clinician and the patient
- ❑ A treatment decision is made when both the clinician and the patient agree on the most appropriate treatment.

These four characteristics demonstrate collaboration between doctor and patient through information, personal value and preference exchange about potential treatment options. However these essential characteristics do not imply that they are all that is required. For example, as Charles, Gafni and Whelan state, there are many situations in which more than two parties are involved. Examples of these situations include a newly diagnosed breast cancer patient who consults a medical oncologist, radiation oncologist and a surgeon in addition to her general practitioner. Likewise, in situations of serious illness, significant others of the patient are often involved in making treatment decisions every step of the way.

One of the major challenges in implementing shared decision-making is the second step outlined above, namely ensuring that both parties participate in the process. As Charles, Gafni et al (1997) assert, shared decision-making is extremely difficult for the patient to instigate and requires the doctor to be supportive of this approach. Doctors are therefore faced with the task of creating a consultation environment in which the patient senses that his or her role is valued, and that his or her views and concerns about potential treatment options and outcomes are welcome. The doctor also needs to acquire skills to elicit preferences from the patient as well as communicate complex information concerning risks and benefits, probabilities of treatment success or failure. Similarly, the patient needs to embrace this approach too. The substantial literature devoted to patient information and involvement preferences is described in more detail below. A key but somewhat hidden point raised by this model is the assertion that shared decision-making has occurred if both

the patient and the doctor are satisfied with the level of involvement they have achieved.

Information sharing is fundamental to shared decision-making and it would be surprising to find any doctor who did not endorse this aspect of their role. However, the model requires that the patient also contributes information, including details of their illness or information they may have obtained from other sources such as from internet sites, friends or disease-related pamphlets and consumer groups. The gleaning of information from the patient serves to assist the patient and clinician to communicate and comprehend each others' values and preferences and thereby developing mutual trust and respect. The final component described by Charles, Gafni and Whelan is that of agreement by both (or more) parties to the decision reached. This consensus is a defining feature of shared decision-making. The model accepts that the treatment decided upon may not necessarily be the option that either participant considers to be the optimum, but it is the one which both support and acknowledge responsibility for.

Following further research with breast cancer patients and doctors. Charles, Gafni and Whelan (1999) added to their model. The resulting new framework illustrated three stages of the decision-making process: information exchange; deliberation; and deciding on which treatment to implement. This updated model was reported to be more user-friendly, both as a teaching tool for doctors and also to assist them in identifying their own and their patients' preferences for involvement in the process.

Further, the authors acknowledged the dynamism of decision-making and the likelihood that preferences of either party change along the process, either within a consultation or at subsequent meetings. In 2003, the model was refined yet further, emphasising the importance of doctor facilitation of shared decision-making, by encouraging patients to take sufficient time to make decisions, tailoring information to patients' needs and reinforcing the importance of patients' values in determining the optimal treatment (Charles, Whelan et al. 2003).

In response to existing models of shared decision-making, Siminoff and Step (2005) present a Communication Model of Shared decision-making (CMSDM). This interpretation of shared decision-making seeks to hone in on the vital role that communication and the doctor-patient relationship play in the process and particularly relates the process to treatment decision making with cancer patients. Criticism of prior models targets the lack of emphasis on the different behaviours and roles that participants engage in. The model comprises three factors based on four underlying assumptions. The factors are: patient and doctor communication antecedents; the communication climate; and the treatment decision. The first underlying assumption is that both parties bring their own experience, skills and characteristics to the encounter and are receptive to verbal and non-verbal cues in order to achieve goals such as information exchange, relationship establishment and knowledge gain. Second, the communication includes not only the verbalised topics but also non-verbal transfer of information about roles and values. Third, Siminoff and Step (2005) endorse the physician's role in setting the climate for this patient

interaction. They assert that even though a patient may be assertive, the nature of the interaction in a new environment and the doctor's greater familiarity with the language of illness means that the patient is unlikely to feel sufficiently confident to direct the encounter. Thus the responsibility lies with the doctor to engage with the patient and allow them to function as they would like to. The final assumption is that the patient is capable of identifying and informing the clinician of the active, collaborative or passive role he or she prefers to play in the decision. It is important to re-emphasise here that shared decision-making is a process and is not solely concerned with the decision.

1.6 Why use shared decision-making?

Shared decision-making is a process which in many respects is a response to and acknowledgement of the right of patients to be informed of potential healthcare interventions and to choose between them. Reflecting on the philosophy of patient-centred care, the patient clearly has a role to play in this process, but the value which clinicians bring to the process above and beyond information giving should not be ignored. Shared decision-making is often seen as the optimal model due to both health professionals and patients not wanting to relinquish or accept sole responsibility for a treatment decision (Sculpher, Gafni et al. 2002). From the clinician's perspective, shared decision-making is a useful way of presenting to patients the reality that outcomes medicine is not certain. Thus shared decision-making is particularly promoted in instances where there is more than one clinically reasonable treatment option, or where there is a reasonable degree of uncertainty

about the benefit of a particular intervention (Kaplan 2004; Whitney, McGuire et al. 2004). It also allows clinicians the possibility of abrogating responsibility for decisions which they do not consider wise or where the outcome is not the success hoped for. In addition, there has been increasing acknowledgement of the differing attitudes of patients to the amount of risk they consider acceptable (Sculpher, Gafni et al. 2002; Thewes, Meiser et al. 2005). Shared decision-making is seen as a method of allowing both the perspective of the patient and of the doctor to be discussed and given equal value (Whitney 2003). However, not all stakeholders see shared decisions as appropriate in all settings all the time, although much of the debate revolves around the use of the word “shared” and definitions that overlap with other decision-making model descriptions, rather than the model itself (Elwyn, Edwards et al. 1999).

1.7 When is shared decision-making appropriate?

Some authors consider shared decision-making unrealistic in healthcare (McNutt 2004). Others suggest that shared decision-making is only possible when real options are available and the doctor is happy to allow the patient to be involved in the process (Whitney, McGuire et al. 2004). According to Whitney, shared decision-making is only feasible in medical decisions of low certainty, with either high or low risk, where there are two or more alternatives. Thus the appropriateness of shared decision-making may vary according to the diagnosis, the type of decision being made, and the context (for example, General Practice versus specialist care). Patients may prefer to be the decision maker in family planning or for treatment decisions

about chronic but not life threatening disease situations, while in instances that are considered urgent or life threatening, or in diseases where the outcome of choices will be more significant such as in cancer, patients may prefer the clinician to take the lead (Edwards, Evans et al. 2003). Edwards asserts that a shared decision is more likely in contexts where decisions may affect risk of diseases such as hypertension or ischaemic heart disease at a later stage, or when deciding about screening where the risk and benefit of the intervention need to be considered by the doctor and the patient (Edwards, Evans et al. 2003).

Murray, Charles and Gafni (2006) discuss adaptation of their original model to the General Practice setting. The differences identified between General Practice and doctors specialising in life-threatening illness are listed as: patient characteristics; multi-faceted symptoms; the doctor-patient relationship; the role of the doctor; and the responsibility for the wider population.

As a consequence of these different characteristics, General Practitioners face patients with a multitude of problems. Therefore the first stage of any shared decision-making process needs to be the identification of the problem to be discussed and an agenda to reach the agreed starting point at which the shared decision-making framework commences. This stage may or may not be complex and can be tackled using the principles of information sharing, negotiation and decision-making.

The types of decisions made in general practice can be very different from those for which the original framework was developed. Often decisions in primary care are in a chronic environment where decisions are not binding as compared to, for example, surgical decisions faced by breast cancer patients. Typically treatment decisions can be postponed, and/or revisited with minimal consequences. A further model variation for general practice is the recognition of the information and sources which a patient might bring. In the acute setting, physicians were labelled by Charles et al (1999) as the information givers, whereas in general practice the authors acknowledge that the role of the GP includes direction of the patient to seek information from other sources. Additionally, in primary care the participant in the process who carries out the decision is usually the patient, not the General Practitioner (GP). For example, it is the patient who takes the prescribed antibiotics at home rather than being admitted to hospital for surgery or chemotherapy performed by a health professional. As Murray, Charles and Gafni (2006) emphasise this additional responsibility for the patient is perhaps further endorsement of the need for the patient to fully understand the treatment program decided upon, precisely one of the benefits of using a shared decision-making approach.

The shared treatment decision-making model has also been discussed for the chronic disease context, specifically diabetes (Montori, Gafni et al. 2006). This setting differs in that patients are not faced with one decision but rather a series of decisions, each with costs and benefits within or outside medical parameters (Watt 2000). The goals revolve around management of the condition instead of the possibility of cure or

restoration to wellness as in the cancer or general practice setting. Often decisions are multi-faceted, such as taking medications appropriately and adjusting lifestyle, and are implemented as in general practice outside of a healthcare facility. The success of decision implementation depends on the behaviour of the patient. Montori, Gafni and Charles (2006) suggest that patients experienced in their disease can determine success by communicating foreseeable problems with a treatment plan in discussion with their clinician; the idea is that with this shared knowledge and understanding, the treatment plans chosen have a greater chance of success.

Having presented the conceptual understanding of shared decision-making and the context in which it has been developed, it is important to examine the existing evidence to support such an approach. As has been described above, shared decision-making is an approach which requires at least two participants, a patient and a doctor. It is therefore important to consider the evidence that either party endorses or demands this approach.

1.8 Patient preferences for involvement and styles of decision-making

1.8.1 What do patients want?

As the concept of shared decision-making has gathered support from health professionals, it has become important to ascertain what the patient wants. Is there support from patients for this model of decision-making? A number of studies have explored patient preferences for involvement and produced variable results.

Involvement in decision-making has been described by three phases: acquiring knowledge; discussion of options; making the decision. Preferences for involvement acknowledge that patients may vary their preferences according to the three stages of the process (Levinson, Kao et al. 2005). Similarly, what patients want must distinguish between their preferences for information and preferences for decision-making responsibility (Fallowfield 2001).

1.8.2 Information preferences

Most studies reveal a strong desire for maximum information amongst patients. In an Australian study of 65 female cancer patients, over 80% wanted to receive as many details as possible and more than 85% wanted as much information as possible, both before and after their initial consultations with their oncologists (Brown, Butow et al. 2004). Similarly, in a survey of over 2000 cancer patients in the UK, Jenkins, et al, (2001) found that the vast majority wanted maximum information (Schofield, Elwyn et al. 2003). Beisecker and Beisecker also reported that participants wanted to receive full information about their medical situation, but they felt that the doctor was the correct person to make a final decision (Beisecker and Beisecker 1990). Despite their desire for information, participants in this study did not display any information-seeking behaviours when consulting with their clinician. Ogden's study of components of patient-centredness with general practice patients showed that patients rated all information items as more important than the doctors (Ogden, Ambrose et al. 2002).

Other studies have also shown that information needs are greater than the need or wish to be involved in decision-making (Strull, Lo et al. 1984; Ende, Kazis et al. 1989; Degner, Kristjanson et al. 1997; Vick and Scott 1998). In one study, 41% of participants wanted more information than they received from their doctors, yet the doctors in this study overestimated, 78% compared to 53%, the wish of their patients to participate in decisions (Strull, Lo et al. 1984). Ende's study also showed a high patient desire for information, 79.5 out of 100 compared to a score of 33.2 out of 100 for participation in decision-making (Ende, Kazis et al. 1989). Vick's study of General Practice consultations in Scotland showed that the desire for a lot of information was much higher than the wish to be the actual decision maker (Vick and Scott 1998).

In cancer patients, information needs have been found to be similar, regardless of the cancer site. Breast and colorectal cancer patients, in a study by Beaver, all reported chances of cure and spread of disease and treatment choices as the most important information items they wanted to receive (Beaver, Bogg et al. 1999). Similar information priorities have also been reported in prostate cancer (Davison, Degner et al. 1995).

1.8.3 *Discussion preferences*

A population-based survey in 2002 in the United States showed that 96% of participants wanted to be offered choices and be able to express their opinion to their

doctors (Levinson, Kao et al. 2005). Strull (1984) highlighted a discrepancy in clinicians' perception of their patients' wish to discuss treatments, with 29% of the doctors underestimating this preference. Being able to talk to the doctor, defined by the doctor listening to what the patient has to say, was rated as the most important feature of the doctor-patient relationship in another Scottish study which surveyed consecutive General Practice patients (Vick and Scott 1998). This study used hypothetical scenarios with different consultation and communication attributes for the participants to choose from.

1.8.4 Decision-making preferences

Involvement preferences of patients with cancer have varied, perhaps because of different disease types and stages in the samples involved. However, in most studies, a majority of patients prefer shared decision-making to passivity or complete autonomy. In Brown's study, decisional preferences were lower than preferences for information, with 52% wishing to share the decision equally with their doctor, 16% wishing to make the decision themselves but strongly considering the doctor's opinion, and 27% wishing the doctor to make the decision but with consideration of their needs and priorities (Brown, Butow et al. 2004). Studies of breast cancer patients report that from 48% (Beaver, Luker et al. 1996) to 66% (Degner, Kristjanson et al. 1997); to 89% (Bruera, Willey et al. 2002) want to play an active or a shared role in decision-making. A study in lung cancer patients revealed that 57% wished to play an active or collaborative role in decision-making about treatments (Davidson, Brundage et al. 1999). Gwede et al (2005) reported in a study of prostate

cancer patients that 63% preferred an active role in decision-making, 29% preferred a collaborative role and just 9% preferred a passive role. Beaver, Bogg and Luker (1999) reported that there were differences in involvement preferences of patients with different cancer types; 78% of colorectal cancer patients preferred a passive role compared to 52% of breast cancer patients. Studies of heterogeneous samples of cancer patients have reported 41% (Degner and Sloan 1992), 69% (Blanchard, Labrecque et al. 1988) and 88% (Keating, Guadagnoli et al. 2002) preferred a collaborative or active role. In another study, participation in decision-making was broken down into knowledge, options and decision, with 52% preferring to leave final decisions to the doctor (Levinson, Kao et al. 2005). In a United States study of 2,197 patients with chronic disease, 69% of participants preferred that their doctors make any medical decisions (Arora and McHorney 2000), however this preference was dependent on patient characteristics, with older age predicting more passivity and higher education and female gender predictive of a desire for a more active role. Survey results of patient preferences for involvement outlined above do point to changes over time, with a shift from 40-70% of samples preferring collaboration or an active role reported up to 1999, to 68-89% of samples in survey reported after 2002.

1.8.5 *Predictors of involvement preferences*

1.8.5.1 *Knowledge*

Fallowfield asserts that participation in decision-making by patients is not possible unless they receive quality information and comprehend what they are given

(Fallowfield 2001). Fallowfield et al (2003) also suggested that the low percentage (20%) in their breast cancer cohort who preferred an active role in decision-making may have been related to poor knowledge due to the assessment being completed prior to participants being informed about definitive diagnosis, prognosis or possible treatment. Indeed, Elwyn and colleagues suggest it is unreasonable for patients to express preferences for decision-making without having sufficient information about the pros and cons about the choices which they may have (Elwyn, Edwards et al. 1999). One conclusion drawn by Guadagnoli and Ward's review supports the notion that patients' wish for involvement is increased when their knowledge of available options is increased (Guadagnoli and Ward 1998).

While patients' interpretation of decision-making participation can be constrained by their own lack of knowledge of the options available, these options may not be known to them due to system limitations, such as clinical practice guidelines within which their doctor may practice or time pressures in a busy clinic setting (Entwistle, Watt et al. 2004). If patients are to be supported and encouraged to participate in decision-making, health authorities need to embrace and fund strategies which encourage this (Entwistle 2000). However there is potential for conflict particularly in public-funded health systems where the need for adequate resources is constantly high on the political agenda and where the promotion of patient choice may raise public expectations.

1.8.5.2 *Demographics*

Age and education level have been found to correlate with desire for patient participation (Cassileth, Zupkis et al. 1980; Ende, Kazis et al. 1989; Degner and Sloan 1992; Thompson, Pitts et al. 1993; Arora and McHorney 2000; Orsino, Cameron et al. 2003). Younger people, those with more education and women show more inclination towards a collaborative or active role in decision-making than older people, those with less education, and men (Degner and Sloan 1992; Arora and McHorney 2000; Levinson, Kao et al. 2005). The gender effect may be influenced by the type of cancer and the role of the consumer and women's movement in advocating choice in surgical treatment of breast cancer (Degner and Sloan 1992).

1.8.5.3 *Disease severity*

Clearly, the severity of the disease and the potential benefits and costs of treatment may influence patient and doctor attitudes to shared decision-making. The severity of illness has been shown to have varying effects on patient and doctor involvement preferences. Studies have reported that the more serious the illness, the less patients' preference for participation in decision-making (Ende, Kazis et al. 1989). In one study, 25% of participants with 'serious' illness wanted full information about their illness but did not want to be involved in treatment decisions (Blanchard et al, 1988). These patients were generally male, older and sicker. Participants with 'benign' disease showed more enthusiasm for participation in treatment decisions, with 69% preferring an active or shared role (Degner and Sloan 1992; Beaver, Luker et al. 1996). Similarly, in a prospective study, patients whose disease worsened altered

their involvement preference towards greater passivity (Butow, Maclean et al. 1997). In contrast, a more recent study found that the desire to participate in decision-making increased along the disease trajectory, with 76% of end stage renal patients preferring to have an active or shared role in decisions (Orsino, Cameron et al. 2003).

Additional predictors of patient involvement include the psychological factors such as anxiety, self-efficacy and locus of control. Data reporting the link between these factors and patients preferences for involvement in decision making is limited, although these factors are alluded to in studies identifying improved psychological outcomes as a result of greater involvement.

1.9 Impact of decisional involvement and style on patient outcomes

1.9.1 Enhanced patient satisfaction

Many studies report that patient decisional involvement improves patient outcomes including higher satisfaction, greater compliance and improved psychological wellbeing. Several studies have explored the match between patient and doctor preferences. Jahng et al (2005) reported agreement on involvement preferences between doctor and patient showed strong correlation with patients' satisfaction. This study also found that matched patient and clinician preferences for the highest patient involvement produced the highest mean patient satisfaction levels. Satisfaction was not reduced when the doctor desired active involvement but the patient did not, nor when both patient and doctor preferred a passive patient role.

Similarly, when patients' preferred involvement and actual role in decision-making matched, patients were significantly more satisfied with treatment choice and with the amount of information they received (Keating, Guadagnoli et al. 2002).

Other studies have shown that satisfaction is highest when doctors actively encourage patients to participate regardless of the patients' participation preferences (Golin, DiMatteo et al. 2002). Actually taking an active role in decision-making was found in another study to correlate with perceived receipt of sufficient information and satisfaction with the consultation (Lam, Fielding et al. 2003). Similarly, cancer patients who reported sharing decisions were significantly more satisfied with the consultation, regardless of their initial preference for involvement (Gattellari, Butow et al. 2001). Greater patient satisfaction has also been noted in encounters with doctors who displayed an increased participatory style (Kaplan, Greenfield et al. 1996). Doctors who have had specific interviewing technique training, or who were primary care trained, were reported as displaying a consultation style which embraced patient involvement and which subsequently left patients more satisfied (Kaplan, Greenfield et al. 1996). These studies suggest that given appropriate support, patients may find value in a shared decision-making approach, even if they initially feel unable to be actively involved in their treatment decisions.

1.9.2 *Improved physiological outcomes*

Improved patient physical health outcomes have been reported in studies where patients played an active role in decisions about their treatment (Morris and Ingham 1988; Morris and Royle 1988). Greater adherence to treatment plans was demonstrated in patients who were more involved in the decision about their treatment (Kaplan, Greenfield et al. 1996). Similarly, Jahng et al (2005) reported agreement on involvement preferences between doctor and patient showed strong correlation with adherence and health perception. Involving diabetic patients in decisions led to increased adherence to treatment regimes resulting in improved diabetic health (Anderson, Funnell et al. 1995). Patients with diabetic ulcer disease, randomised to receive an intervention which encouraged and coached them to increase their involvement in decisions about their care, showed fewer physical and role limitations two months on (Greenfield, Kaplan et al. 1985). Communication style was found to effect clinical outcome in a group of Austrian cardiac patients, with an empowering style taught in a communication skills program reducing the length of hospitalisation and increasing the patient rated quality of care (Trummer, Mueller et al. 2006)

1.9.3 *Enhanced psychological wellbeing*

Some studies suggest that shared decision-making leads to enhanced psychological outcomes. For women with breast cancer being offered a treatment choice or seeing a surgeon who encouraged choice correlated with better patient psychological outcomes, including lower levels of depression, (Morris and Ingham 1988; Morris

and Royle 1988; Fallowfield, Hall et al. 1990; Fallowfield, Hall et al. 1994). However, this significant difference was not documented three years post operatively (Fallowfield, Hall et al. 1994). Anxiety levels were found to be lower in educated patients who believed they had participated in decision-making, and in those patients who reported a passive coping style but had received information or had been involved in decision-making (Margalith and Shapiro 1997). However, a study of initial consultations of 96 cancer patients in the Netherlands showed no significant relationship between the clinicians' communication behaviour and patients' quality of life (Ong, Visser et al. 2000). Communication behaviours here allude to the instrumental (information giving, question asking) and socio-economic (social behaviour, concern, verbal attentiveness and negative talk) clusters identified in the Roter Interaction Analysis System (RIAS) (Ong, Visser et al. 1998), which do not exactly correspond with behaviours designed to encourage shared decision-making.

1.10 Match between current practice and models

As has been outlined above, there have been a number of conceptual models of shared decision-making outlined in the literature along with evidence of benefit from use of these models. However the implementation of these ideas into current practice is not well documented (Sculpher, Gafni et al. 2002). A number of studies in recent years have sought to document patient involvement in decision-making in practice and explore whether patients benefit from achieving their desired preference. Shared decision-making in practice is still uncommon (Elwyn, Edwards et al. 1999; Holmes-Rovner, Valade et al. 2000).

1.10.1 Practice evidence

1.10.1.1 Coding studies

A number of studies have reported evidence of shared decision-making based on analysis of audio recordings of real consultations in outpatient clinics or general practice surgeries. Coding schemes aim to identify presence of shared decision-making or presence of elements identified as shared decision-making behaviours. Therefore the scores aimed for are the highest, implying that all elements which signify shared or collaborative decision-making were present in the consultation. Analysis was completed in most cases using verbatim transcriptions of the consultations. Most studies reveal a low level of adherence to shared decision-making.

Brown et al (2004) reported analysis of 59 consultations between cancer patients and ten Australian oncologists. The main aim of the study was to identify the quality of informed consent by patients considering entering clinical trials. As part of the study, the consultation content was coded. Fourteen elements were selected which epitomised a shared decision-making framework; the presence or absence and quality of these elements in the consultation audio recordings were coded. Shared decision-making was introduced in only 24% of oncology consultations, but this component was rated as poor in 75%; preferences for involvement were checked in 10%, and information preferences were checked in 40% (Brown, Butow et al. 2004). Choice between standard treatment and no treatment was explicitly offered in only 19% of consultations and an explicit choice was presented between standard treatment and

clinical trial participation in 32%. Decisional delay was offered in 78% of consultations. Understanding was verified on one occasion in 46% of consultations, but was rated poorly in 76% of cases. Understanding was verified more than once in 15% of consultations. Questions were invited in 60% of consultations; however this invitation was rated as poor on 70% of occasions. Thus some but not all elements of shared decision-making models were present in most of these consultations, but a high level of skill was rarely displayed.

An analysis of audio-taped cancer consultations by Ford, Fallowfield and Lewis (1996) in the UK aimed to identify the content of the doctor-patient interaction when bad news was given. Analyses were completed using the RIAS. Twelve clinician and eight patient categories were identified: emotional responsiveness; partnership building; open and closed questions; biomedical and psychosocial information giving; and biomedical and psychosocial counselling. Patient clinician ratios were calculated identifying the direction of the consultation; i.e. patient or clinician-led; patient centeredness; and clinician-patient psycho-social exchange versus biomedical exchange. These ratios, in particular patient centeredness, provide some insight into the collaborative nature of the consultations despite not actually measuring shared decision-making itself. Patient-centeredness was measured by dividing the total utterances of all patient questions, psycho-social and lifestyle content and doctor partnership building statements by total doctor closed questions and total biomedical information giving for doctor and patient. The ratio was 0.33 for the first

consultation and 0.41 at the follow up consultation, demonstrating that patient-centeredness was not the norm.

In an analysis of 118 audio-taped consultations with advanced cancer patients discussing treatment options, just 14% were given information about life expectancy with and without treatment, 57% were not given any prognostic information, and acknowledgement of trade-offs, one of the characteristics of informed treatment decision-making, was presented in 60% of the consultations (Gattellari, Voigt et al. 2002). Patient comprehension was checked in just 10% of the consultations, and even though patients' views were expressed in 75% of cases in only a third were these opinions invited by the doctor.

Similar results have been obtained in studies of general practice consultations. Kinnersley, Stott, Peters and Harvey (1999) audio-taped 143 general practice consultations to identify patient-centeredness using the Measurement of Patient Centered Communication (Brown, Stewart et al. 1986; Levenstein, McCracken et al. 1986; Brown, Stewart et al. 2003). This method provides scores for understanding patients' disease and illness, integrated understanding of the whole person and finding common ground through doctor expressions and the interaction. The mean score for the General Practitioners was 0.51; score range was from 0-1, with a score nearer 1 indicating greater patient centeredness.

A study identifying the existence of informed decision-making in outpatient practice used a bank of 1057 audiotapes of outpatient consultations in the practices of General Practitioners, general internists, orthopaedic and general surgeons (Braddock III, Edwards et al. 1999). Elements of informed decision-making were analysed using content analysis only. Nine percent of consultations achieved the criteria for informed decision-making. Basic decisions, described as decisions to undergo a laboratory test, were more likely to be informed (17%) than complex decisions such as prostate cancer screening (0.5%). For all types of decisions, discussion of alternatives was present in 11% of consultations, discussion of pros and cons in 8% and mention of uncertainties in 4%. Checking patient understanding featured the least, 1%, although this was higher for complex decisions (7%).

Design of an instrument to measure the extent to which doctors involve patients in decision-making incorporated analysis of 186 general practice consultations with 21 different General Practitioners in the UK (Elwyn, Edwards et al. 2003). The OPTION tool which was developed to measure evidence of shared decision-making, uses a five-point Likert scale (strongly agree to strongly disagree) for 12 items identified as required components of a shared decision-making consultation. Existence of clinical equipoise, listing of options and explanation of pros and cons were coded as strongly disagree for 71%, 72% and 71% of consultations respectively. Coders strongly disagreed that doctors explored patient expectations and concerns in 70% and 59% of consultations respectively. The mean score for shared decision-

making was 17 on a scale of 1-100, signifying that in this cohort, patients rarely experienced a shared decision-making consultation.

Ford, Schofield and Hope (2006) analysed 149 videotaped consultations with 13 General Practitioners in the UK to identify types of decisions and the skills displayed by doctors to meet the preferences of their patients. Video analysis was completed using the Oxbridge Rating Scale (ORS), a measure of ten items, four of which represent effectiveness and six of which represent skills, scores given on a five-point Likert scale for each item (0 = not at all, 4 = very effectively). Mean score for the effectiveness elements was reported as 8.6 (maximum score 16) and the mean score of 11.9 (maximum score 24) for the skills elements. This study also measured congruence and grouped the 13 participating doctors into two consultation styles; congruent, defined as doctors who displayed flexible styles and who were able to alter their approach, or rigid, doctors who persisted with either a doctor-led style or a shared style regardless of the preferences of the patient.

With the exception of Elwyn et al (2003), shared decision-making has been identified through elements of the process rather than examination of the whole process. However it is clear in all these studies that shared decision-making or elements described as characteristics or requirements for a shared decision in the models have not been identified as prevalent in current practice. Of course, this is not necessarily a bad thing, since not all patients desire involvement. A Norwegian study demonstrated the complexity of this issue. They focused on palliative care cancer

patients and used semi-structured interviews to identify the role played when discussing continuation or not of 'active' treatment (Friedrichsen, Strang et al. 2000). Participants' perception of their participation was described by three subcategories; verbal passivity, verbal activity and interpretive activity. Participants indicated that their verbally passive stance was intentional in some cases in order to avoid hearing undesired information, verbal activeness was described as communicating a clear wish for information whilst in other circumstances it signified distress or misunderstanding. Consequently, it may be important to look at the match between patient preferences and patient involvement.

1.10.2 Patient reported decision-making styles

Much literature has identified the type of decision-making experienced by patients through their reports post consultation, most commonly using the five-point involvement preferences scale developed by Degner and Sloan (1988; 1992). This scale, whilst originally designed to elicit involvement preferences, is commonly used as a descriptive tool to report what actually happened. Often these two results have been compared to determine whether patient preferences have been met. Many of these studies show that many patients do not achieve their desired level of involvement (Gattellari, Butow et al. 2001; Bruera, Willey et al. 2002; Davison, Gleave et al. 2002).

The study which included videotaping of consultations described above also included patient reports of the style of consultation that they perceived they had experienced (Ford, Schofield et al. 2003). This perception was measured using a validated enablement scale (Howie, Heaney et al. 1999) as well as Degner's involvement preference scale. The results for this study show that 47% of patients considered that the doctor made the decision, 39% that the decision was shared and 14% that they made the decision. The patients experienced their preferred level of involvement in 64% of consultations for doctor-led, 53% for shared and 41% for patient-led decision-making.

In another study which asked patients to recall their preferences for involvement and their actual involvement, 33% perceived the doctor had made the decision, 43% that the doctor had made the decision but considered their opinion, 9% recalled a shared decision and 14% recalled making the decision after considering the doctor's views (Davidson, Brundage et al. 1999). A discrepancy in 29% of cases was found, with all cases showing that patients were less involved than they would have desired. The participants recalled their actual role a median of eight months after treatment in this study.

In another study breast cancer patients who had recently undergone surgical treatment were asked to recall the role they had played in the recent treatment decision (Keating, Guadagnoli et al. 2002). Actual roles recalled were described to participants as: surgeon "decided what should be done and did it"; "presented his or

her recommendations to you to accept or reject"; "discussed alternatives with you and the two of you decided together how to proceed"; or "presented all available options and allowed you to decide". The majority (40%) recalled that they had made the decision once all options were presented - a patient-led role. A third (33%) reported a collaborative experience, whilst 27% recalled being presented with a doctor-led experience either being presented with a recommendation to accept or reject or where the surgeon outlined treatment and proceeded. Comparison of actual roles with preferred roles showed that just under half of patients (49%) reported experiencing a role which they desired in decision-making, with 25% being less active and 26% being more active than desired (Keating, Guadagnoli et al. 2002).

A study with breast cancer patients has shown that the reported involvement preferences of the patient and the perceived preference of the clinician was only matched in 42% of cases (Bruera, Willey et al. 2002).

1.10.3 Limitations in measuring shared decision-making

A number of issues are raised when measuring whether shared decision-making occurred in consultations. Coding systems described above imply expectation of a high score, but there is a lack of standard or norms for what should be expected in shared decision-making scales. Many of the studies reported above use the scale developed by Degner et al (1992) which asks who made the decision, yet there is a

view as raised by Elwyn et al (2003) that shared decision-making is not only about who makes the decision., but rather about the process of the decision making.

The evidence above clearly demonstrates that for the most part, patients' involvement preferences are not being met and a suggested reason for this is that research and interventions developed for patients have raised the patients' expectations. Clinicians have not been prepared for these new patient expectations and indeed limited evidence documents the views of doctors to involving their patients in decision-making and treatment discussions.

1.11 Barriers to shared decision-making

A number of studies have identified barriers to involving patients in decision-making. These barriers can be grouped as; practical issues, doctor competence, patient difficulties and doctor support.

1.11.1 Practical issues

The barrier most commonly reported was shortage of time. The models and competencies of shared decision-making and the steps along this process take time. Say and Thompson (2003) state that the establishment of a partnership is required for patients' views and values to be given significance. According to Sainio et al (2001) health professionals who are friendly, and with whom patients are familiar, enable patients to be more involved in their own care. However, informing patients

adequately, finding time to develop rapport and to discuss options within the consultation are cited as problems for many health professionals (Sainio, Eriksson et al. 2001; Stapleton, Kirkham et al. 2002; Stevenson 2003). In a Canadian survey of breast cancer doctors, participants were asked to report the extent to which they found listed items a difficulty to the treatment decision-making process. Insufficient time to spend with the patient was the greatest barrier with 64% reporting they encountered this often or almost always in their practice (Charles, Gafni et al. 2004).

Another study of providing information by issuing evidence-based leaflets to patients found that lack of time due to competing clinical responsibilities was one of the prevailing barriers to doctor-patient discussions and the effective use of a valued resource (Stapleton, Kirkham et al. 2002).

Finally, a study in the United States evaluated the implementation of a multi-media shared decision-making program across three hospitals. Recruitment to the program depended on referral by the clinician and over seven months only 24 patients were referred to use the system (Holmes-Rovner, Valade et al. 2000). The primary explanation for this low recruitment was the intense time pressure felt by the physicians involved in the study: supplementary staff were required to assist with identification and enrolment of patients and this was just not practicable in the already understaffed environment.

Whilst time is cited as an issue there is little evidence that this is true. Interventions to increase patient involvement have not increased consultation time (Greenfield, Kaplan et al. 1985). Some authors have asserted that in the short term, more time might be needed to conduct detailed consultations discussing risks and benefits, but that this time will be valued later when follow up consultations could be more concise due to the understanding gained initially (Edwards, Elwyn et al. 2002).

Another practical difficulty cited by some studies has been timely access to evidence required to adequately inform patients. For example, provision of accurate data was described as a difficulty by General Practitioners, who noted that particularly as a generalist, they cannot be abreast of the latest research and guidelines in all areas of their varied practice. For this reason, participants in that particular study posited that shared decision-making was more suited to specialists (Elwyn, Edwards et al. 1999). However it was suggested that provision of accurate information there and then could be overcome by follow-up consultations, as participants stated it was rare for decisions to be made within one consultation.

1.11.2 Doctor competence

Patients stated that some obstacles to being involved stemmed from the doctors, particularly their tendency to treat patients as objects and to behave in an automated manner, and their inability to effectively communicate information (Sainio, Eriksson et al. 2001). In Say and Thompson's review (2003), doctors' ability to explain

relative and absolute risk was raised. Some doctors present information in a manner which makes their treatment preference appear the best option (Lelie 2000) even if evidence of other treatments is comparable. In Charles, Gafni and Whelan's (2004) survey of breast cancer doctors, only 5% of oncologists and 3.6% of surgeons reported that they often/almost always experienced difficulties in framing treatment options for patients. Yet General Practitioners' communications skills and views towards patient involvement showed participants felt that patients misunderstood some fundamental messages of the consultations when they reviewed their own consultations (Stevenson 2003). Thistlethwaite et al's (2002) study of junior doctors in the UK reported the doctors' knowledge of treatment options or lack of knowledge may prevent options being discussed and consequently a shared process being achieved. In the study by Elwyn et al (1999), General Practice registrars suggested that shared decision-making, requiring the ability to know all the options, was especially challenging for generalists.

1.11.3 Patient difficulties

Patients who do not wish to be involved, often labelled 'passive patients' have been cited widely as a barrier to shared decision-making (Elwyn, Edwards et al. 1999; Sainio, Eriksson et al. 2001; Say and Thomson 2003). Sainio et al (2001) reported that encouragement to participate can overcome this barrier. However, insufficient information and resources to assist clinicians to increase and educate patients about involvement has also been listed as a barrier to the process (Say and Thomson 2003). These findings are supported by the results of the survey by Charles et al (2004),

which found reported that surgeons and oncologists most frequently cited patient anxiety (49%, 38%), misconceptions about their disease (41%, 39%) and lack of understanding (42%, 38%) as barriers to the successful implementation of shared decision-making.

1.11.4 Doctor support

Lack of doctor commitment to the process is an important barrier to using a shared decision-making approach. Physicians may not wish to practice in such a style due to habit or the belief that involving patients in decisions is not appropriate. A number of studies have alluded to the belief that shared decision-making is not feasible due to a lack of treatment options to choose between. Many doctors (and patients) do not recognise “no treatment” as a reasonable option, and thus consider many medical situations as not being subject to choice.

The support of shared decision-making, in particular by surgeons in the Canadian survey (Charles, Gafni et al. 2004), was suggested by the authors to be somewhat surprising, despite the barriers listed above, and may well be due to breast cancer care being a specialty in which the involvement of the patient has had a great deal of media coverage stemming from the highly motivated women’s and consumer movements in this arena (Charles, Gafni et al. 2004). It is not known whether clinicians treating other cancers have similar views to those of the breast cancer doctors in Canada. This gap and avenue for more research was highlighted in the

discussion of the results. Currently there are no data on Australian oncologists' views about shared decision-making. It is not clear whether there are cross-cultural differences in attitudes. Australian doctors may not share the views of Canadian cancer doctors. No studies have explored predictors of doctor views or practice, in order to identify sub-groups who may have either useful experience to offer, or who may benefit from intervention.

1.11.5 Facilitators

Potential facilitators or ways to overcome barriers to shared decision-making have been explored. Sainio's qualitative study with breast cancer patients identified three factors which assisted patients to be involved in decision-making, namely time, encouragement and being treated as an equal (Sainio, Eriksson et al. 2001). Eighty-four percent or more of breast cancer doctors rated emotional support from family/others, patient being accompanied in the consultation, patient being emotionally ready for a role in decision-making, patient wanting to participate, patient having adequate knowledge for the consultation and patient trust in the doctor as almost always or very helpful by (Charles, Gafni et al. 2004).

Some authors have suggested that the move towards a multi-disciplinary team approach, involving collaboration with other health professionals to plan care, has increased the opportunity and the relevance of shared decision-making (Stevenson, Barry et al. 2000). Elwyn et al (2000) concluded that development of clinician skills

and encouragement to implement these skills can be achieved through policy, education and professional development. In Charles' survey of breast cancer doctors, respondents were asked to define the meaning of shared decision-making as well as identify which of four presented examples they felt most illustrated a shared decision. The results showed that breast cancer doctors demonstrated a good understanding of shared decision-making and used the language of the framework to describe their own perception. The authors concluded that the consensus they reported is helpful in planning potential training for clinicians in a shared approach (Charles, Whelan et al. 2003; Charles, Gafni et al. 2004). It is not known what barriers Australian doctors perceive to implementing shared decision-making or what might facilitate their greater use of this approach.

1.12 Interventions to increase patient involvement

Entwistle (2000) outlines four strategies for supporting patients' participation in decisions about their healthcare: development of skills of health professionals; development of skills and comprehension of the local healthcare system by the general public; development and use of interventions to encourage active role playing by patients; and development, dissemination, supply and accreditation of information resources and services.

Collaborative relationships between patient and clinician are vital for a shared decision-making environment and achievement of this requires skilled and effective

communication between the doctor and the patient (Sepucha, Belkora et al. 2000). In the cancer context, patient anxiety and unexpressed concerns can hinder the information flow and involvement of patients in decision-making (Boyle, Robinson et al. 2004). Tools or strategies have been developed to better prepare patients for the consultation by empowering the patient to improve their communication skills (Greenfield, Kaplan et al. 1985; Greenfield, Kaplan et al. 1988) Using another approach, Sepucha, Belkora et al (2000) evaluated an intervention consisting of a preparation visit with a trained researcher who assisted the patient in organising questions and concerns, and who then accompanied the patient into the consultation, assisted the doctor and patient to create an agenda, facilitated discussion and kept a record of the consultation for the patient to take home. This pilot study showed the intervention increased the decision quality score, increased agreement between physicians and patients and increased patient satisfaction with the consultation.

1.12.1 Communication skills

Communication skills training has been a neglected part of medical education despite being considered a core clinical skill (Fallowfield, Jenkins et al. 2002). A number of programs have been devised to improve the communication skills of the clinicians in the area of treatment decision-making with their patients. Jenkins et al (2005) developed and evaluated a communication skills program for clinicians in gaining consent to clinical trials, which incorporates training in facilitating patient involvement. The course was run over two days and included four video modules depicting varying scenarios. Participants were videotaped before and after the course

in simulated consultations. A high number of communication behaviours improved significantly after the course, as did clinicians' confidence in their ability to discuss and explain clinical trials. Participants expressed a wholehearted satisfaction with the course and recommended it to fellow health professionals.

Elwyn and colleagues report a communication skills training intervention designed for General Practitioners in the UK. The training consisted of four three-hour workshops focussing on shared decision-making and risk communication (Elwyn, Edwards et al. 2004). Participating doctors were allocated to the shared decision-making and the risk communication in two phases and consultations with patients were audio-taped and analysed for skills and competencies covered in the workshops. Results of this study showed an increase in patient involvement in treatment decision-making, increased doctor perceived patient satisfaction with information and with the doctor and increased agreement between doctor and patient (Elwyn, Edwards et al. 2004).

A video-conferencing system using a trained standardised patient, who also evaluated performance, was developed and tested with orthopaedic surgeons in the United States (Clever, Novack et al. 2003). Skills examined included involving the patient in decision-making, information on clinical issues, surgery and alternatives to surgery, including risks and benefits. The 'patient' fed back to the surgeons about the five key criteria and, if certain elements were missed during the role play and suggested ways of introducing them in the scenario. 86% of participants would recommend the

program as a means of learning shared decision-making skills. The use of this conferencing technology also makes this program feasible for practitioners regardless of geographic location.

One difficulty with any training program is the ability to monitor outcomes and their durability, and to remove any barriers to implementation of newly acquired skills. In a study in Wales with General Practitioners, participants reported using the risk communication tools up to six times on average in the following month (Edwards and Elwyn 2004). Fallowfield and her group asked participants in an intensive three-day communication skill course and the control group to complete self assessment after three months and found significant and improved differences in their communication behaviours (Jenkins and Fallowfield 2002; Fallowfield, Jenkins et al. 2003). One strategy to optimise the effect of communication skills training has been the addition of consolidation sessions over a three-month period following the basic session. Significant differences were seen in assessment at six months, with the group who received the consolidation sessions showing more acknowledgements, more empathy, and more negotiation (Razavi, Merckaert et al. 2003).

1.12.2 Decision Aids

Decision aids are standardised, evidence-based tools to aid achievement of an informed, value-based choice among treatment options, one of these which could be watching and waiting (O'Connor, Graham et al. 2005). O'Connor has been at the

forefront of developing decision aids as a method of presenting and comparing treatment preferences, survival and quality of life using trade-offs for patients facing difficult decisions (O'Connor, Drake et al. 1999). Decision aids are not intended to replace the doctor, but rather to supplement doctor-patient interaction and allow patients to reflect personally on their choices and the results of these, as well as to acknowledge what is important to them and to share this with the health professional (O'Connor, Graham et al. 2005). A Cochrane systematic review identified 34 randomised trials of decision aids and reported positive outcomes compared to standard care in knowledge, patient comprehension of probable outcomes, agreement between personal values and choices made, decisional conflict and the number of patients who could not make a decision (O'Connor AM, Stacey D et al. 2003). Anxiety was not increased in those patients who participated in decision-making.

A number of studies have evaluated decision aids in a variety of practice settings. For example, a randomised trial of a decision aid for cancer patients considering adjuvant chemotherapy produced significant results in terms of improved knowledge of their disease and the treatment options available, as well as improved satisfaction with the decision-making itself (Whelan, Sawka et al. 2003). A randomised trial of 112 men in general practice with benign prostatic hypertrophy tested the efficacy of an interactive multimedia program, booklet and printed summary, and found the intervention acceptable to doctors and patients; reported participation in decision-making by the patients was higher and decisional conflict was lower in the

intervention group, whilst levels of anxiety, health status and costs showed no difference (Murray, Davis et al. 2001).

Kennedy (2003) in his review on how best decision aids should be evaluated, asserts that much of the assessment of current decision aids uses measures testing knowledge, awareness of treatment decisions and the process of decision-making rather than measuring the concordance between the treatment choice and the patients' expressed values.

1.12.3 Feeding back preferences to clinicians

A few studies have investigated the value of identifying patient preferences for information and involvement prior to consultations. A study in the UK randomised doctors to either receive, or not, questionnaires completed by their patients which covered information requirements and attitudes to participating in a clinical trial (Fleissig, Jenkins et al. 2001). Results showed no difference in the information exchange between doctor and patient in either study arm, further only one out of the 15 doctors referred to the preferences recorded by the patient in each consultation, while nine of the other doctors discussed preferences briefly and occasionally. Conclusions drawn were that doctors were unlikely to deviate from their usual manner of discussing treatments with patients, either due to difficulty or because they felt their routine ensured that all issues were covered.

Another study involved the use of a computerised intervention devised and tested with breast cancer patients to elicit information and decision-making preferences prior to the consultation in a randomised controlled trial (Davison and Degner 2002). Following completion of the assessments, participants in the computer arm were given a printout of their involvement and information preferences and coached by the nurse to encourage them to achieve their preferred role and focus information requests on those topics most important to them. Almost 75% of participants achieved their preferred participation role; however a higher proportion of the intervention group assumed a more passive role than the control group. The authors suggest this may have been due to increased expectations of the role they could play in their consultation and subsequent reporting of a more passive experience when expectations were not met.

1.12.4 Question prompt lists

Question prompt lists/sheets are simple tools designed to aid the patient in obtaining the information he or she may want by listing questions pertinent to their consultation and facilitating the patient to raise these during the consultation (Butow, Dunn et al. 1994; Brown, Butow et al. 1999; Brown, Butow et al. 2001; Clayton, Butow et al. 2003; McJannett, Butow et al. 2003). Patients who received question prompt lists asked significantly more questions, particularly about difficult and emotional subjects such as prognosis. They also rated the helpfulness of written material and communication with the doctor higher, and recorded lower anxiety scores post receipt of the question prompt list (Bruera, Sweeney et al. 2003; Clayton, Butow et al. 2003).

Endorsement of the question prompt list by the doctor was found in another study to increase the number of questions asked and improve patient recall of information; another positive outcome in terms of implementation was that the intervention decreased the consultation length (Brown, Butow et al. 2001). Bruera's study comparing a question prompt sheet with a general information sheet also found no increase in consultation duration (Bruera, Sweeney et al. 2003).

1.12.5 Audio-recording consultations

The value of audio-recording consultations has been explored in a number of studies and has been proven of value in allowing patients to clarify details of the consultation, as well as to give further opportunity to absorb the plethora of information given in any consultation (Deutsch 1992; Ford, Fallowfield et al. 1995; Scott, Entwistle et al. 2001; Tattersall and Butow 2002). Patients given an audiotape of their consultation have also been more satisfied with their outpatient visit and recalled more specific information (Bruera, Pituskin et al. 1999). A survey in Australia of oncologists and surgeons, however, showed that 79% and 89% respectively never offered an audiotape of consultations to their patients (McConnell, Butow et al. 1999). When asked if they thought audiotapes should be offered, the majority of General Practitioners, oncologists and surgeons stated that they should not (73%, 39% and 66% respectively). Reasons for these views were listed as intrusive, preventive of free discussion, cumbersome, no benefit and not supported by patients, legal and confidentiality issues, reviewing of tape by patients cannot be

monitored and pertinent points may be missed or misunderstood and non-verbal communication is excluded.

Other information interventions have included patient information booklets, summary sheets and videotapes for patients to read or view in their own time. A randomised controlled trial, comparing a video with written information for cancer patients receiving radiotherapy, demonstrated no difference in patient anxiety prior to commencing radiotherapy between the two groups (Harrison, Dey et al. 2001). Another study reported significantly better outcomes in patients who received a video versus booklet, with reduced anxiety and increased satisfaction as well as 81% of the participants in the video arm finding it helpful. However, 5% reported that the extra information caused them more concern (Thomas, Daly et al. 2000).

The majority of these interventions have demonstrated positive outcomes, yet as discussed above, many patients still fail to achieve their involvement preferences, or, as suggested by a number of authors, interventions which empower patients also raise their expectations which clinicians then fail to meet (Davison and Degner 2002; Butow, Devine et al. 2004). This hypothesis reinforces a potential barrier to shared decision-making being the lack of support for this approach from doctors. If the doctor does not endorse shared decision-making, facilitate patient involvement in the consultation, or use decision aids or question prompt lists, the likelihood of the patient achieving shared decision-making is vastly reduced, regardless of their initial preferences. Clinicians who do not wish to relinquish their power in the consultation

as regards reaching a decision pose a problem for patients who wish to be involved in discussion about treatment options (Whitney 2003). To a major extent, patient involvement in decision-making is dependent on the support of the medical practitioner (Stevenson 2003).

1.13 Doctors' views on shared decision-making

While many studies have explored patients' preferences for decision-making roles, few studies have asked doctors their views on this issue or practice, despite the fact that the support of clinicians and endorsement of tools is integral to the implementation of interventions. Much of the current literature concerning doctors' views on shared decision-making has been completed in the general practice environment or in breast cancer.

A UK study sought to identify the importance of patient-centred behaviour according to General Practitioners and patients (Ogden, Ambrose et al. 2002). Sixty-four General Practitioners and 410 patients completed questionnaires rating each element on a five-point Likert scale where 1= not important and 5= totally important. Overall the General Practitioners believed the majority of patient-centred behaviours were very important; mean scores were > 4 for all items except for "allowing the patient to make the final decision". Involving patients in decisions about treatment recorded the highest mean score, 4.46. General Practitioners in this study supported involving patients in decision-making but they were less enthusiastic about allowing patients

full decisional control. Patients in this study also rated being involved in decisions highly, with a mean score of 4.37 and had comparable scores with the doctors for items concerning patient involvement.

A small qualitative study, identifying the views of 12 pre-registration House Officers in hospital and General Practice settings regarding involving patients in management decisions and their experiences of this approach produced three themes (Thistlethwaite 2002);

- Hospital-based clinicians use a more paternalistic approach
- Using a patient-centred approach more important in primary care
- Sharing information is more likely in general practice than in hospital.

Essentially, this small group of junior doctors expressed positive attitudes towards the concept of shared decision-making, seeing it as beneficial to both clinicians and patients; however, this attitude was tempered by hesitancy regarding its successful implementation. These doctors reported that they had had little opportunity to see this approach used in practice, particularly in the acute hospital setting. Consequently they experienced few occasions to learn such skills from senior colleagues.

The attitudes of 11 General Practitioners to shared decision-making in the UK were explored in two focus groups through reference to a model of shared decision-making (Charles, Gafni et al. 1997) and analysis of previously recorded and transcribed consultations conducted by the focus group participants (Stevenson 2003). The

consultations included a discussion of medications by the General Practitioner and the patient and four key components of shared decision-making were scored, namely:

- Two participants involved, clinician and patient
- Information shared by both participants
- Both participants work to a consensus on preferred treatment
- An agreement is reached on treatment to implement

Overall the General Practitioners did not express negative comments about shared decision-making, although one focus group noted that some doctors are uncomfortable with patients expressing their own opinions about treatment or having a fixed view on what treatment they wish to receive. The General Practitioners expressed difficulty in knowing how and when shared decision-making had actually taken place and when decision sharing is appropriate and feasible.

Attitudes to involving patients in decision-making were collected in a study in the UK evaluating the effect of training General Practitioners in risk communication and shared decision-making and documenting changes as participants went through the program (Edwards and Elwyn 2004). Participants included 20 General Practitioners each with one to ten years as a principal in their practice, average age of 38yrs. Measures aimed to elicit attitudes regarding the importance of involving patients in decision-making, the importance of patients responding positively to this approach, their frequency of involving patients in the decision and the importance of the

General Practitioners own competence in this approach. Scores were on five-point scale (1= most important/highest, 5=lowest/not important). Results showed that General Practitioners reported involving their patients in decision-making prior to the training program less often (mean score 2.6) than they did post training (mean score 2.2). The importance of involving patients at baseline (mean score 2.1), increased post training (mean score 1.7), however how long this effect lasts is unknown.

A further qualitative study in the United States using semi-structured interviews with 53 academic and private practice physicians from primary care and surgical specialties identified three primary justifications for involving patients in decision-making; respect for autonomy, beneficence and self-interest (McGuire, McCullough et al. 2005). The majority of doctors in this study preferred the role of the doctor as an expert who educates patients and directs the decision-making process. Some of the participants supported a collaborative relationship with their patients, however many saw a reduced role for patients if there was only one reasonable medical choice. Treatment decisions with no clear best answer or with moral dimensions were deemed particularly appropriate for increased or full patient control.

A recent study reporting attitudes to shared decision-making is based on 41 Norwegian General Practitioners (Carlsen and Aakvik 2006). General Practitioners' preferences for their decision-making role were scored on a six point scale, a score of 6 indicating a preference for sharing. Overall the mean score for General Practitioners was 4.31, with the male GP score being slightly lower than female GP

score 4.26 and 4.41 respectively. Sixty-six percent of the sample was male. These results show a high support and preference for shared decision-making amongst Norwegian General Practitioners.

A study exploring the appropriateness of involving patients in decision-making and the skills and methods required to facilitate such practice used focus groups with six experienced General Practitioners (Elwyn, Edwards et al. 2000). The participants expressed positive attitudes to patient involvement, however they were concerned that this involvement should not be forced and that the patient's right not to be involved should be respected.

A large study of 502 doctors in Germany investigated views towards shared decision-making and compared these to patients (Floer, Schnee et al. 2004). The doctor sample comprised General Practitioners (28%) and specialists (73%), with 27% of the sample being female. Two thirds (67%) of doctors reported that decisions should be shared, 8% reported that patients should take the lead and 21% reported that doctors should make the decisions. Younger doctors (≤ 45 yrs) showed greater endorsement of shared decision-making. Differences between doctor disciplines were reported between the age groups. In the younger doctor groups, specialists reported that they preferred shared decision-making more than General Practitioners (38% compared to 28%); in doctors aged 46-54 years 27% of specialists and 42% of General Practitioners preferred shared decision-making; and in doctors aged 55 years or over,

35% of specialists and 30% of General Practitioners preferred shared decision-making.

Three studies investigating clinicians' views of patient involvement in treatment decision-making have targeted health professionals specialising in breast cancer care. One of the earliest studies was undertaken in the United States (Beisecker, Helmig et al. 1994). Oncologists, nurses and patients were all asked to complete the 15 item Locus of Decisional Authority in Decision-making survey. For each item three responses were possible, 0= doctor should make the decision, 1 = doctor and patient should make the decision, 2= patient should make the decisions. A score of 15 indicated that respondents felt all decisions should be shared. Total scores for the three groups were below 15, showing they felt that doctors should have overall decisional authority, with the doctors' group mean score being the lowest, 10.23 compared to 12.49 for the patient group and 13.74 for the nurses. Attitudes of the different clinician disciplines represented in the sample were also reported; surgical oncologists showed increased support for patient involvement compared to medical and radiation oncologists. No significant differences were found in attitude to patient involvement for patient age or physician gender, however a relationship was reported between older clinicians (both nurses and doctors) and reduced advocacy for increased patient involvement.

A qualitative study looked at understanding the doctor-patient relationship and the process of treatment decision-making over two years by observing 25 women

diagnosed with breast cancer at each encounter with one of 13 oncologists. Observation comprised recorded semi-structured interviews with patients and doctors (Freedman 2002). The researchers observed that doctors did offer patients choices, however sometimes the choices offered were those with which the particular clinician was familiar and/or were available within the health setting, while treatment options which may have been available through a different specialist were not mentioned. Also doctors reported only offering options which they felt were appropriate. However, there were instances where such assessments were based on psycho-social factors and/or age of the patients and perceived inability of the patient to manage certain treatments. The authors reported that in these instances, doctors clearly removed any active or shared role for patients in the decision-making process.

A Canadian study explored the views and understanding of surgeons and oncologists specialising in breast cancer (Charles, Gafni et al. 2004). This study comprised a cross-sectional survey inviting participants to report their use and comfort with shared decision-making and their perception of the mechanics of shared decision-making as outlined in a framework described above (Charles, Gafni et al. 1997; Charles, Gafni et al. 1999). Semi-structured interviews were conducted initially with breast cancer patients to investigate their understanding and experience when making treatment decisions with their doctors (Charles, Whelan et al. 1998). The results of these interviews were then used to develop a draft questionnaire suitable for physicians. This was developed through separate focus groups of medical and radiation oncologists and breast surgeons, leading to a questionnaire identifying

physicians' perceptions of shared decision-making and its meaning, their use and comfort with this consultation style and the existence of obstacles or aids to putting this approach into practice.

Eighty-seven oncologists and 203 surgeons answered the open-ended question concerning what shared decision-making means, and the majority responded with definitions congruent with the principles of shared decision-making. A minority described shared decision-making as information transfer alone. More than a few respondents suggested that further discussion would be warranted if the patient's preference and their own recommendation were not the same. The survey included illustrations of decision-making styles designed to depict the four common models; paternalistic, information sharing only, shared and informed. The survey asked the physicians to select the model which they thought described shared decision-making. The majority of surgeons (94%) and oncologists (87%) identified the example intended to describe shared decision-making as the one most like their own definition of shared decision-making. The example which described information sharing but clear retention of decisional authority by the doctor was selected by 28% of surgeons and 34% of oncologists as their interpretation of shared decision-making, while a similar proportion, surgeons (27%) and oncologists (21%), regarded the informed decision-making example as the most like shared decision-making. It is clear from these results that between a quarter and a third of respondents were unsure whether sharing responsibility between doctor and patient is indicative of a shared decision-making experience.

The essential ingredients of shared decision-making were further explored by asking respondents to rate the importance of seven characteristics using a 5-point Likert Scale (1= not important, 5 = extremely important). Items which were rated with either a 4 or 5 were grouped together. Surgeons reported discussion of pros and cons (100%), giving information to the patient (99%) and agreeing on the treatment to be given (86%) as very/extremely important. In comparison, oncologists reported giving information to the patient (99%), discussion of pros and cons (96.9%), and agreeing on the treatment to be given (95%) as very/extremely important.

Survey participants were also asked to select which of the four decision-making styles was most akin to their usual style. Over half (56%) of oncologists and two-thirds, (69%) of surgeons stated that their approach to a decision-making consultation was most similar to the shared decision-making example and just under a third (27%) of oncologists and under a fifth (17%) of surgeons likened their approach to the information sharing style (Charles, Gafni et al. 2004). Less than 3% of both groups reported using a paternalistic approach and 8% reported embracing an informed or patient-led approach. A discrepancy was noted between these self reported use statistics and self reported comfort with each of the four styles. Both surgeons (89%) and oncologists (87%) stated they were very or extremely comfortable with the shared decision-making approach, a difference of 20% and 31% respectively to their reported use of this style.

Overall the studies in the general practice arena show support for involving patients in decisions about treatment, but less support of a patient controlled decision-making approach. They acknowledge that actual involvement of patients is not routine. Reasons why actual practice does not conform to the shared decision-making model include doctors not feeling comfortable with patients being assertive, wishing to respect the right of patients not wanting to be involved, and asserting that the role of the patient is minimal if only one reasonable treatment exists.

In the breast cancer setting, two recent studies report clinicians offering choice to their patients. However, the authors in the qualitative study stated that the choices offered were governed by the doctor, attesting that by this process the patient's choice was limited to treatments already determined by the clinician. In the large Canadian study, self reported use of shared decision-making was high, with almost two-thirds of surgeons claiming this to be most like their own approach. The reason for this could be linked to the existence of treatment options and the acknowledgement of a clear treatment choice with similar survival outcomes e.g. mastectomy v. lumpectomy and radiotherapy. A number of these studies have reported some differences between specialties and physician age, with younger doctors in the German study reporting greater support for shared decision-making. This view was corroborated in the focus group of the pre-registration House Officers in the UK who believed shared decision-making and patient involvement to be a good idea, but they had seen little evidence of this approach during their practice placements, particularly in the acute hospital setting (Thistlethwaite and van der Vleuten 2004).

Many of the studies described above are small and do not offer a cross-sectional picture of clinician attitude or use of shared decision-making. Indeed, none of the studies reports the views of Australian clinicians although there are a number of Australian studies reporting the information preferences of patients.

1.14 SUMMARY

Shared decision-making can be viewed as the gold standard of decision-making in medicine generally, and specifically in the cancer context. While there is evidence for the benefits of this approach, available studies suggest that shared decision-making is rarely implemented. Shared decision-making is, according to the theorists, suitable for many healthcare contexts. Much work in the oncology setting indicates cancer patients express desire for involvement in decision-making. Little evidence exists to show whether oncologists outside of breast cancer use such an approach or how comfortable they are with it. The survey by Charles et al (2004) provides an interesting insight into the views of breast cancer doctors, but it is unknown whether clinicians specialising in other cancers hold similar views. Additionally, a number of authors have asserted that shared decision-making is only appropriate in particular clinical situations, where doctors feel real treatment options exist. Little is known about doctor views on shared decision-making, its use, or the barriers and facilitators that might influence their use of this approach. No Australian data are available on this issue.

AIMS AND HYPOTHESES

This study aims to survey Australian oncologists to discover their understanding of the concept of shared decision-making, their level of comfort with shared decision-making, whether and when they currently use it in their clinical practice and their perceptions of barriers and facilitators to shared decision-making. Predictors of attitudes and current practice will be explored, including demographic and practice variables. It is hoped that the results will inform the development of appropriate interventions to assist oncologists and patients to improve the quality of communication around decision-making.

Stage One: A questionnaire to identify the views and attitudes of cancer doctors to shared decision-making

Aims are to:

- i. Develop a questionnaire to survey doctors treating breast, colorectal, gynaecological, haematological and urological cancers
- ii. Retrieve information concerning consultation styles currently in practice
- iii. Identify oncologist's comfort levels with different decision-making styles
- iv. Identify usual amount and type of information given to patients by cancer doctors
- v. Identify perceived skills and qualities required to elicit shared decision-making

- vi. Identify perceived barriers to shared decision-making in practice
- vii. Identify perceived facilitators to shared decision-making in practice
- viii. Identify support for interventions designed to encourage patient participation.

Stage Two: Semi-structured telephone interviews

Aims are to:

- i. Elicit in more details views of doctors to involving patients in treatment decisions to explain and inform conclusions drawn from Stage One
- ii. Investigate issues and influences experienced by cancer doctors when reaching treatment decisions with patients.

HYPOTHESES

- There will be a difference between breast cancer doctors and other cancer doctors in their attitudes to shared decision-making
- Medical oncologists in Australia will have more positive attitudes to shared decision-making than their surgical counterparts
- Younger doctors will have more positive attitudes to shared decision-making
- The practice setting will influence the attitude of doctors to shared decision-making.

CHAPTER TWO

METHODS

2.1 Introduction

This thesis incorporates both qualitative and quantitative methodology to collect and analyse data and is described as a mixed methods design (Teddlie and Tashakkori 2003). The research follows a sequential, explanatory design, which places more emphasis on the quantitative component and then uses qualitative enquiry to delve deeper into the reasons or influences to explain findings from the quantitative data analyses (Morse 2003; Cresswell and Plano Clark 2007). Differences between quantitative and qualitative research methodology have been described as those of breadth versus depth (Patton 2002). Quantitative methods seek standardised and limited responses allowing comparison of cases and statistical analysis of the data and qualitative methods provide detailed information from a small sample. Mixed methods research has advantages over single method research in its ability to produce data that represents a superior breadth of views and therefore strengthens assumptions drawn (Teddlie and Tashakkori 2003). Mixed methods design is particularly suited to projects that seek to demonstrate relationships between variables and explore how or why that relationship exists. This thesis presents a quantitative study followed by a qualitative study. As described by (Morse 2003), the main drive of the quantitative component is deductive, to identify attitudes and behaviours of Australian cancer doctors to decision-making with patients, while the qualitative component is driven by findings of the quantitative study.

2.2 Study One Survey of Australian cancer doctors.

2.2.1 *Quantitative methodology*

Quantitative methodology evaluates evidence and tests theories and hypotheses. Scientific methods used in quantitative research may include one or more of the following methods: the generation of models, theories and hypotheses; the development of instruments and methods for measurement; experimental control and manipulation of variables; collection of empirical data; modelling and analysis of data; and evaluation of results. The aims of this research project outlined in Chapter One lend themselves to quantitative research methodology to gather empirical data and conduct analysis and modelling to determine relationships and patterns to inform conclusions.

2.2.2 *Aims of quantitative stage*

The initial aims of the first stage of this thesis were to gather information from practicing Australian oncologists concerning their usual approach and comfort with different approaches to decision-making when making treatment decisions with cancer patients. Secondary aims included eliciting information on:

- The type of information cancer doctors considered important to give to newly diagnosed or newly referred patients;
- Frequency of discussing patient participation in decision-making;
- Doctors' perception of the role their patients wish to play in deciding on treatment decisions;

- Offering of patient choice;
- Giving treatment recommendations;
- Frequency of barriers and facilitators to decision-making process with patients; and
- Support of interventions to encourage patient involvement and reflection on treatment options prior to decision being made.

2.2.3 Development of survey instrument

The survey instrument was based on a structured questionnaire developed by Charles and colleagues in Ontario, Canada in 1998 through focus groups and pilot-testing (Charles, Whelan et al. 2003; Charles, Gafni et al. 2004). The survey assessed the validity of the conceptual framework developed by Charles et al (1997; 1999), both in its description of the meaning of shared treatment decision-making (STDM) and in the agreement of practicing physicians to the key components. With permission, we used this questionnaire with some alterations. The survey presented unlabelled examples constructed from the conceptual framework presented by Charles and colleagues in earlier publications to reflect the following decision-making approaches; paternalistic, information-sharing only, informed and shared (Charles, Gafni et al. 1997; Charles, Gafni et al. 1999) (See Figure 1). Doctors were asked to select which of the examples best reflected their usual approach to treatment decision-making with their newly diagnosed or newly referred patients.

The survey included questions covering: use and comfort with decision-making approaches; usual information given; discussion of participation with decision-

making; doctors' perceived preferred roles of their patients; offering options and treatment recommendations; barriers and facilitators to decision-making.

Example 1 Paternalistic

After reviewing the medical records and examining the patient the doctor decides on a suitable treatment and presents this to the patient. The doctor gives information about the treatment including risks and benefits. The patient accepts the treatment that the doctor recommends.

Example 2 Information sharing only

After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor then recommends a treatment that the patient accepts.

Example 3 Informed

After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor asks the patient to decide on a treatment and states that s/he is the best person to make the decision. The patient decides and informs the doctor of the treatment s/he prefers.

Example 4 Shared

After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor invites the patient to ask any questions. The doctor asks what his/her preferences for treatment are given his/her lifestyle and the issues that are important to him/her. Together they decide on a suitable treatment to implement.

Figure 1 Treatment decision-making examples

2.2.3.1 *Use and comfort with decision-making approaches*

Doctors were asked to rate their comfort levels with each of the decision-making approaches on a five-point Likert scale, from not comfortable to extremely comfortable.

2.2.3.2 *Usual information given*

Ten items were listed and doctors were asked to indicate the amount of detail they usually provide from 1 = no information to 5 = a great deal of information on 10 topics related to the benefits and risks of treatment option and the impact of treatment on the patient's quality of life.

2.2.3.3 *Discussion of patient participation*

The survey asked doctors to report whether they had initiated a discussion of how much involvement their patients would want to play in the last six months, and if so, with what proportion of patients they had discussed this issue with.

2.2.3.4 *Perceived preferred roles of patients*

Doctors were asked what role they perceived their patients wanted to play in making treatment decisions. This was a three part question, with doctors reporting the proportion of patients who prefer the doctor to make the decision, those who prefer to share the decisions and those who prefer to make the decision themselves.

2.2.3.5 Offering treatment options and recommendation

Two questions elicited ‘yes’ or ‘no’ responses to whether doctors offered patients a choice when multiple options are available and whether, when options are available, doctors usually gave patients a recommendation.

2.2.3.6 Barriers and facilitators to decision-making process

Nineteen potential barriers were listed in the survey and participants were asked to rate how often they experienced these as barriers on a four-point Likert scale (never, sometimes, often and almost always). Six items considered helpful to the decision-making process were listed and doctors were similarly asked to report how frequently they encountered these in their practice.

Three additional questions were included in the surveys administered to the breast and urological cohort. These elicited views concerning which components are important to a process of shared decision-making between clinician and patient, and support for a number of interventions and initiatives aimed to encourage patients’ participation and reflection on treatment decisions. Full versions of the surveys administered are presented in Appendices 3-6.

2.2.4 *Design and procedures*

2.2.4.1 *Participants*

Medical and radiation oncologists and surgeons across Australia, whose practice is primarily in Oncology, and who specialise in managing people with one of five tumour types (breast, colorectal, gynaecological, haematological or urological cancers) were invited to participate in the study. Doctors were identified through the Australia and New Zealand Breast Cancer Trials Group, the Royal Australian College of Surgeons – Breast Section, the Medical Oncology Group of Australia, the Colorectal Surgical Society of Australasia, Australian Society of Gynaecologic Oncologists, the Australasian Leukaemia and Lymphoma Group and the Urological Society of Australasia. The invitation letter clearly stated that the survey was intended for cancer doctors. Doctors who had retired from active practice were excluded from the study.

2.2.4.2 *Procedures*

This was a cross-sectional survey. Permission was sought to obtain contact details of all group members from each representative body. If this was granted, the research team sent each doctor a package through the mail which included a letter inviting their participation and outlining that the survey intended to identify views of cancer doctors; an information sheet; a consent form; a copy of the questionnaire; and a postage paid envelope. If contact details were not provided the packages were

distributed by the representative body. Written endorsement of the survey was sought and obtained from all representative bodies.

Reminders were dispatched at six and 12 weeks if no response had been received. A modified Dillman approach was used to follow up invited participants (Dillman 1978). The second contact was by mail and comprised a letter reminding the participant of the questionnaire and the value their input would bring to the study. The third and final contact included a second copy of the questionnaire with a return envelope, a letter outlining the aims of the survey and a further reminder of the importance of their contribution and the proportion of completed surveys that had been received so far. The returned surveys were de-identified. This study was approved by the University of Sydney Human Research Ethics Committee.

2.2.5 *Data analysis*

Demographics and characteristics of the sample were analysed using descriptive statistics. Statistical Package for the Social Sciences (SPSS) for Windows Version 14 was used for all descriptive statistics and correlational analyses.

2.2.5.1 Predictors of usual approach to decision-making

Univariate analysis was completed to identify associations between variables and usual approach to decision-making and high comfort with shared decision-making. For the purposes of this study, identifying and predicting attributes which determine use of a shared decision-making approach were particularly noteworthy. Regression

analysis was used to predict usual approach of cancer doctors in our sample. Regression analyses are commonly used statistical techniques which seek to determine relationships between a dependent variable and a number of independent variables (Tabachnick and Fidell 1989). Generally, regression techniques seek to identify whether an independent variable is associated with the dependent variable.

Logistic regression analyses were completed with the usual approach, recoded as shared or not, and with comfort, recoded as low or high, as the dependent variables in multivariate analysis to identify predictors of use of and comfort with shared decision-making. Covariates for initial inclusion into the model were identified through univariate analysis: all those correlated $p < 0.25$ were included in the model. To identify the final predictive factors for retention in the model, we applied multivariable logistic regression analysis. The likelihood ratio test in a backwards elimination process, with $p < 0.05$ for a covariate to be retained in the final model was used. The extent of model fit was assessed with Hosmer–Lemeshow goodness of fit tests. All analyses were performed using SPSS for Windows Version 14.

Multiple linear regression analysis was used to assess predictors of greater reporting of barriers to treatment decision-making where more than 2 variables emerged with $p < 0.2$. A backwards elimination process, with $p < 0.05$ for a covariate to be retained in the final model, was used.

2.2.5.2 *Factor analysis*

Factor analysis was used to further explore the data collected concerning barriers to involving patients in reaching treatment decisions. To identify and explain relationships between variables Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA) were completed. Exploratory factor analysis allows conceptual thoughts to be tested and reveals loadings of items onto a number of factors, which can be more concretely classified conceptually and confirmed by CFA. Given the preliminary stage of this field it was felt appropriate to use this two-stage approach. Factor analysis was chosen as it seeks to discover whether the observed variables can be explained largely or entirely in terms of a much smaller number of variables called factors. Correlational analyses were conducted prior to all factor analyses, permitting inspection of any relationships between items. Factor analysis allows classification and description of the data collected, permitting comprehension of relationships between the independent variables and improved understanding of the information which cancer doctors regard as important in treatment decision-making consultations with their cancer patients.

Exploratory Factor Analysis

Exploratory Factor Analysis was undertaken using the MS-DOS program Common Factor Analysis (COFA 87) (McDonald and Fraser 1987). Using exploratory as well as confirmatory analyses allows discovery of features of the data that other methods may ignore. Decisions taken during EFA were based on conceptual analysis initially, and then confirmed by inspection of the correlations. Three criteria were used to

guide judgments about model fit during EFA: (1) using the Promax oblique rotated factor pattern matrix – all items with a factor loading of ≥ 0.3 were considered to be loading onto a factor (Tabachnick and Fidell 1989); (2) discrepancy values greater than 0.2 were considered indicative of need to revise the model; (3) the psychological significance of set of factors was considered.

Confirmatory Factor analysis

The MS-DOS program (CONFA) was used to perform Confirmatory Factor Analysis (McDonald and Fraser). Three indices were used to assess the model fit: (1) Steiger Lind Root mean square error of approximation (RMSEA), this is an indicator of unbiased absolute fit of a given model. A RMSEA value of less than 0.05 equals a good fit and a RMSEA value of 0.08-0.10 is considered an acceptable fit; (2) Goodness of fit index (GFI). This gives a measure of how well the model fits the data as a whole. A value of > 0.90 is considered an acceptable fit; (3) the sizes and distribution of the discrepancies between the sample correlations and the fitted values. Models are acceptable if the discrepancies are too small to support a more complex model (McDonald 1999).

Internal consistency and reliability

Internal consistency determines the certainty of factors within the variables and subsequently within the model (Tabachnick and Fidell 1989). This was measured using Cronbach's alpha. A co-efficient alpha of 0.7 or more is considered to indicate high reliability of a scale (Streiner and Norman 1995). McDonald has asserted that

the coefficient alpha frequently underestimates factor reliability and suggests that the coefficient Omega gives a more accurate estimation of reliability (McDonald 1999). Therefore, the coefficient alpha and coefficient omega are reported to evaluate internal consistency and reliability of the factor analysis. Omega is based on the parameters of the items in the factor model. Omega is determined by summing the factor loadings; summing the unique variances; and then dividing the square of the summed loadings by itself and adding the sum of unique variances. As stated above, one of the research aims of the quantitative component of this thesis is to identify predictors of usual approach to treatment decision-making with cancer patients. Factors with low or moderate reliability coefficient loadings are considered useful for such purposes.

2.2.6 *Sample size and power*

A-priori sample size calculations were conducted based on the primary outcome of use or not of shared decision-making as participants' usual approach to decision-making. The study completed in Canada gave us an anticipated proportion of approximately 60% who would report shared decision-making as their usual approach. Sample size calculations were based on the precision required for point estimates within 95% confidence intervals of $\pm 5\%$. The following calculations show the workings for the sample size calculation for the survey.

$$\begin{array}{l} 95\% \text{ CI} = \\ \text{thus} \end{array} \quad \begin{array}{l} p \pm 1.96 \times \text{SE}(p) \\ 1.96 \times \text{SE}(p) = 5 \end{array}$$

$$\text{SE}(p) = \frac{5}{1.96}$$

$$\text{that is} \quad \text{SE}(p) = 2.55$$

$$\sqrt{\frac{p(100-p)}{n}} = 2.55$$

$$\frac{p(100-p)}{n} = 2.55^2 = 6.50$$

$$n = \frac{p(100-p)}{6.50}$$

if $p=60\%$

$$n = \frac{60 \times 40}{6.50} = 369$$

The minimum sample that would be expected to achieve the required accuracy is 369.

This study proposed to identify predictors of usual approach to decision-making. Sample size and power calculations were undertaken to allow for six potential predictors for the regression model. The following calculation was conducted to establish the required sample size for the proposed regression analyses. Guidelines recommended for the minimum number of events per variable for multivariate analysis suggest 10-20 events per variable (Peduzzi, Concato et al. 1996).

Reliability of a model is considered dependent on the sample size; a sample of 100-200 participants is recommended (Streiner and Norman 1995). Cohen (Cohen 1992)

provides guidance for small, medium and large effect sizes (ES) with Power =0.80 and significant tests at $\alpha=.01$, .05, and .10. He reports that for multiple regression analyses with 6 predictors using significance $\alpha=.01$ for all tests requires a sample of 134 for an expected medium ES.

Using the predicted prevalence of 60% of the dependent variable, used of shared decision-making or not, six potential predictors, and the 10 events per variable rule of thumb, the calculated sample required equals 150.

$$\begin{array}{r} (6 \times 10) \times \frac{100}{100-60} \\ 60 \times \frac{100}{40} = 150 \end{array}$$

Results of the quantitative component of this thesis are presented in Chapters Three and Four.

2.3 Study Two: Qualitative interviews with cancer doctors

Mixed methods research is increasingly common in psycho-social research and proves itself to be a reliable method to investigate research issues. Strengths of a mixed methods approach to a research question include the ability to gain different perspectives of participants to an issue. Commonly, when using quantitative and qualitative methods, one approach supplements findings from the other (Morse 2003). For the purpose of this thesis, qualitative methodology was elected to explain and understand in more detail the findings of the quantitative component. Further, having collected data from a large sample of practicing Australian cancer doctors, it was

possible to select participants who reported divergent views and practices towards shared decision-making.

2.3.1 Qualitative methodology

Qualitative methodology allows researchers to study the meanings which people ascribe to real situations, through collection of empirical data by observation or interviews or collection of written documents (Patton 2002). The three major approaches to qualitative research are ethnography, phenomenology, and grounded theory. Ethnography focuses on the study of a culture and is chiefly viewed as an anthropological approach, although a cultural group can be an organisation or club. Participant observation is a common example of the field work which occurs in this approach, where the researcher immerses him or herself in the community or culture to observe from within. Phenomenology focuses on the desire to understand the world through the experiences and descriptions of others, using participants' subjective experiences. The grounded theory approach was established in the 1960s and research using this approach aims to generate theory from observation. Common features of qualitative research include a focus on meaning and understating, recognition of the role the researcher plays in the process, the concurrent collection and analysis of the data and the subsequent dynamic nature of the research design. The purpose of the research is important as this affects the selection of a design method, sampling and analysis. Decisions regarding those issues need to take into account whether the purpose is: to establish or contribute to knowledge or theory (basic research); to describe or bring attention to an issue (applied research); to

establish a program's efficacy (summative evaluation); to improve a program (formative evaluation); or to find a solution to a particular problem (action research).

This study uses a phenomenological theoretical base, using the experiences of cancer doctors to understand when, why and how they involve patients in reaching treatment decisions.

2.3.2 *Sampling strategy and participants*

Purposeful sampling is appropriate where the research focus is to gain a detailed understanding and this underlines the difference between quantitative and qualitative methodologies (Patton 2002). Such sampling aims to achieve information rich data. Within purposeful sampling there are a number of strategies for identifying the participants or cases which will yield the most applicable results. Some researchers may be interested in the extreme or outlier cases to learn more about distinctive or unusual views or events. A similar strategy known as intensity sampling focuses on the information rich cases which best explain or give details of a particular issue, but do not represent extreme or outlier views. Other strategies focus on a particular subgroup to maximise homogeneity, or a snowball effect by eliciting from participants recommendation for the next person or case to be included in the sample.

Grounded theorists typically use theory guided by real world observations to examine the range of issues which a concept may encompass. In exploratory research where researchers are looking to identify new patterns, sampling can lead from the

exploratory to the confirmatory phase of pattern identification. Explanatory strategies include critical case sampling or criterion sampling, where criteria which must be met are identified. Maximum variation sampling seeks to elicit detail on certain key themes across a varied sample and is particularly useful where a larger sample is available from which a representative sample is sought. Heterogeneity can be achieved across the whole sample although stratification can be used to focus on key characteristics which researchers wish to ensure are represented and aims at achieving generalisation of the whole populations whilst allowing the possibility of statistically valid comparisons between characteristics such as gender or education level (Patton 2002).

The major question of this thesis is to identify doctor attitudes to involving cancer patients in treatment decisions. We used a purposeful sampling strategy to gather data from doctors who had reported in a previous national study (Shepherd, Tattersall et al. 2007) adopting as their usual style a variety of approaches (doctor-led, shared or patient-led) and who treated a variety of cancers (breast, colorectal, gynaecological, haematological and urological cancer). It was thought that these different treatment contexts might highlight contextual factors influencing attitudes to shared decision-making.

Participants were purposefully selected using a stratified maximum heterogeneity strategy. Participants would each represent one of the three key approaches to decision-making and one of the five cancer specialties. This method would then

ensure maximum heterogeneity of the collected qualitative data in terms of the reported different approaches to decision-making and cancer practice and allow identification of different views concerning when or where patients' involvement was considered more or less appropriate.

A planned matrix was developed focusing on the usual approach and cancer types (see Figure 2). Where certain cells afforded numerous potential participants, attention was paid to the clinical discipline and gender of the participant, to maximise a representative sample for these additional attributes.

BREAST	COLORECTAL	GYNAECOLOGICAL	HAEMATOLOGICAL	UROLOGICAL
3 x Dr led	3 x Dr led	3 x Dr led	3 x Dr led	3 x Dr led
3 x Pt led	3 x Pt led	3 x Pt led	3 x Pt led	3 x Pt led
3 x Shared	3 x Shared	3 x Shared	3 x Shared	3 x Shared
9	9	9	9	9

Figure 2 Proposed Sample Matrix

It was thought a priori that 15 participants in each decision-making group and 9 within each cancer site group would be sufficient to allow saturation of themes; that is, that no new data would emerge after these numbers of participants were interviewed. Actual recruitment outcomes are described in the Results in Chapter Five.

2.3.3 *Procedure*

2.3.3.1 *Data collection*

Participants in our earlier quantitative study (Shepherd, Tattersall et al. 2007) who had agreed to a further qualitative interview were randomly contacted within the strata described above, to obtain consent to this stage of the study. Consenting doctors participated in a semi-structured telephone interview exploring their views about involving patients in decision-making. Research interviews are a common method to collect data and are described as a method of hearing the perspective of study participants with an underlying assumption that that perspective is sought, either due to the knowledge or experience or both of the participants and as a means to gather information and gain increased understanding of the research topic (Patton 2002; Gillham 2003).

The decision to use semi-structured telephone interviews was based on a number of factors. First, the data collected from Stage One of this thesis identified a number of themes that seemed important to further explore. It was therefore necessary to ensure a level of standardisation across the proposed interviews to ensure that those themes were explored consistently and to allow comparison across groups.

Second, telephone interviews were primarily used as the geographical locations of the sample spanned the breadth of Australia. Furthermore it has been suggested that the anonymity that telephone interviews provide enhances the quality of data collected by

increasing participants' willingness to speak openly and reducing social desirability bias (Carr and Worth 2001).

Our questions probed a number of themes which emerged from the quantitative data we collected previously (Shepherd, Tattersall et al. 2007). The list of semi-structured questions is provided in Figure 3 and is included in the appendices (Appendix 9). The interviews were audio-recorded and fully transcribed. This study was approved by the University of Sydney Human Research Ethics Committee, approval no. HREC7575.

1. Can you tell me what you think are the most important features of involving patients in decision making?
2. What do you think about involving patients in making treatment decisions?
 - What about it is good or bad for the patient?
 - What about it is good or bad for you?
 - What about it is good or bad for the health system as a whole?
3. GPs have said that shared decision-making is useful in some situations (e.g. AF, menorrhagia, HRT,) but not in others. Do you think there are situations where shared decision-making is more appropriate than others? If so, what are they? Which clinical scenarios?
(If respond with “where there is clear choice”) How do you determine when there is clear choice?
4. How do you determine if the patient views this in the same way you do? E.g. patients may be interested in the no treatment option?
5. Do you think it is ever appropriate not to disclose a treatment option? For example, if it is expensive and you know the patient has a limited income?
6. Are there circumstances in which you either have not or might disclose a clinically relevant option to a particular patient?” (or might not disclose an option that you would sometimes mention to other patients with the same diagnoses)
7. Can you describe how you would normally present treatment options to your patients? Do you list them in order of your preference/recommendation? Do you present equal amounts of information on each? Do you spend more time on the ones you think are more appropriate?
8. In our survey doctors who treated breast and urological cancers were more positive about shared decision-making than others. Why do you think that might be?
9. Some patients don’t want shared decision-making. To what extent do you think patients vary in terms of their preferences for shared decision-making?
10. Do you establish if your patients want to participate in decision making?
11. How do you establish whether your patient wants shared decision-making?
 - In your experience what sorts of patients tend to like and dislike shared decision-making?
 - In what senses do you think patients like/dislike shared decision-making? Or are there particular aspects which patients like/dislike?
12. Would you ever encourage passive patients to participate or do you simply accept their passivity? How do you decide which patients to push a little? How would you go about encouraging them to shared decision-making?
13. In our survey, some doctors reported that some patients are incapable of shared decision-making because they are too anxious, or lack understanding of their disease status and/or the information they receive– do you agree?
 - Can you give an example of a patient who could not share decision-making?
14. In your experience does shared decision-making take up extra time? Does it ever save time down the track?
15. Do you routinely offer a patient a follow-up consultation so they have time to think about the treatment choice?
 - What might prohibit this approach?
16. How, if at all do you think shared decision-making impacts on your own and the patient’s responsibility for the decision? Does shared decision-making shift the ultimate decision responsibility? How easy or difficult is this for you and for the patient?
 - For you? How?
 - For the patient? How?

Figure 3 Questions for semi-structured telephone interviews

2.3.4 *Qualitative data analysis*

Analysis of qualitative data requires researchers to make sense of large amounts of data, identifying data that are significant, in a similar vein to quantitative data analysis. Numerous guidelines for qualitative analysis exist, however there are minimal fixed rules, each study has unique elements, and interpretation by the analyst is governed by experience, skill and ability. According to Patton (2002) it is important to identify a framework for organising data, establishing whether findings are guided by an individual case and variation between individual cases (case analysis) or whether a topic is the main issue and answers and responses to questions or themes by individual cases are what will be reported (cross case analysis). Thematic analysis is described as a flexible analytical method which is able to provide a detailed and complex account of data (Braun and Clarke 2006). Thematic analysis can be inductive or theoretical depending on whether the researcher seeks to identify themes and patterns from the data alone (inductive) or whether the researcher is guided by theoretical or analytic interest (theoretical); however it is important to note that themes are guided by the researcher and more importantly by the research question. Cross case analysis can then be used to compare or contrast themes with experiences across individuals (Patton 2002).

In this study, a theoretical thematic analysis approach was used to identify key themes from the data. These themes were guided by intentions to answer questions which had emerged from stage one of this project. Following this thematic analysis approach, the data collected were analysed using cross case analysis, focussing on

doctors reported usual approach to decision-making and the type of cancer treated. The first four transcripts were read and themes and subthemes identified by the research team, HS, PB MT. These themes were discussed, differences in coding decisions were discussed until a common approach was agreed upon and a coding tree was developed. The remaining transcripts were coded (HS) by listening to the audio files and by reading the transcripts. Additional subthemes were coded and the final coding tree was discussed and reviewed by the research team. These themes were then described and compared across cases. All transcripts were then recoded in a different order to minimise possibility of coding fatigue on the last transcripts. Data were organised using NVivo7, an established computer program which assists management of large amounts of qualitative data. Finally the completed analysis was reviewed by HS and PB and small changes in coding were agreed upon.

Results of the qualitative component of this thesis are presented in Chapters Five, Six and Seven.

SECTION TWO

STAGE ONE RESULTS AND DISCUSSION

Chapters Three and Four present the results of Stage One of this thesis and some discussion regarding their meaning and implications. Chapter Three, the results of surveying Australian cancer doctors regarding their usual approach to decision-making and their reported comfort levels with different decision-making style, has been published in the British Journal of Cancer in 2007. The pdf document of this manuscript is included in the appendices (See Appendix 9).

Chapter Four presents the reported barriers and facilitators to involving patients in decision-making. These results have published in the Journal of Clinical Oncology in April 2008. (See Appendix 10).

CHAPTER THREE

USUAL APPROACH AND COMFORT WITH SHARED DECISION-MAKING, AND INFORMATION EXCHANGE IN THE CONSULTATION

3.1 Sample

Of 1198 total surveys mailed, 136 were returned and regarded as being ineligible (doctor retired, deceased, not clinically active, overseas, incorrect address). From the remaining 1062 eligible participants, 632 surveys were returned, a response rate of 59%. Eight respondents declined to participate. This response rate is comparable to the mean response rate of 54% for physician surveys (Asch, Jedrziewski et al. 1997). Twenty of the surveys were completed by clinicians who reported that they did not treat patients in the five targeted tumour groups; therefore these data were excluded from statistical analysis.

The response rate was higher in the groups where the researchers contacted the participants directly, perhaps because the mailing list being used by the professional society did not exclude retired or non-practicing doctors. Within the non-respondents, tumour specialties were; breast 30%; colorectal 10%; gynaecological 2%; haematological 9%; urological 42%, 7% unknown. The high non-responders in the urological cohort may reflect the mail out method in this group. Excluding the urological cohort on whom we had no information, 89% of the non-responders were

male. Comparison of these characteristics with the study sample reveals no notable differences.

Table 1 shows the demographics of the 604 participating clinicians. Males (83%) made up the larger proportion of the sample. The mean age of the sample was 50 years and the mean time since medical qualification was 26 years. The majority (68%) worked >20 hours per week in direct patient care. The majority (59%) worked in community sizes of >500,000.

Table 1 Demographics of sample

Variable	N (%)[#]
Cancer type treated	
Breast	308 (51.0)
Colorectal	79 (13.1)
Gynaecological	27 (4.5)
Leukaemia/lymphoma	83 (13.7)
Urological	107 (17.7)
Physician discipline	
Medical Oncologist	126 (20.9)
Radiation Oncologist	51 (8.4)
Surgeon	354 (58.6)
Haematologists	61 (10.1)
Paediatric Oncologist	12 (2.0)
Gender	
Male	503 (83.3)
Female	101 (16.7)
Country of medical school attended	
Australasia	552 (91.7)
UK/Europe/Canada & South Africa	40 (6.6)
Asia/SE Asia/Middle East	10 (1.7)
Direct pt care per week	
< 20hrs	170 (31.2)
20hrs or more	375 (68.8)
Community size	
<100,000	41 (7.5)
100,000-500,000	184 (33.8)
More than 500,000	319 (58.7)
Caseload of new pts per month	
0 to 6	313 (52.3)
7+	285(47.7)
Median	3-6 new pts per month
Age - Mean	50yrs (32-79yrs)
Years since graduation - Mean	26yrs (4-56yrs)

[#] percentages based on valid cases only; with specified cancer

3.2 Usual approach to decision-making

The majority reported that their usual approach to decision-making with cancer patients was most like the shared decision-making approach (see Table 2). The paternalistic approach and the informed decision-making approach were selected by fewer doctors.

Table 2 Usual approach to decision-making and comfort levels with each approach

	Usual approach	Not comfortable 1	Somewhat comfortable 2	Neutral 3	Very comfortable 4	Extremely comfortable 5
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Paternalistic (Example 1)	6 (1.0)	198 (37.1)	144 (27.0)	85 (15.9)	60 (11.3)	46 (8.6)
Information sharing (Example 2)	138 (23.2)	39 (7.3)	95 (17.8)	135 (25.3)	154 (28.9)	110 (20.6)
Informed (Example 3)	49 (8.2)	73 (13.7)	118 (22.1)	115 (21.5)	145 (27.2)	83 (15.5)
Shared (Example 4)	372 (62.4)	11 (2.1)	23 (4.3)	49 (9.1)	133 (24.8)	320 (59.7)
None of these	1 (0.2)					
Other	30 (5.0)					

Most doctors (82%) reported initiating a discussion about participating in decision-making with their patients; however only 62% instigated this dialogue with more than half of their patients. Offering treatment options when available was almost unanimously supported (98%).

3.3 Comfort with different approaches to decision-making

Comfort levels with each of the four decision-making approaches are shown in Table 2. The model with which most doctors (84%) reported being most comfortable was the shared decision-making approach, 37% reported being least comfortable with the paternalistic model.

3.4 Information giving

The amount and type of information doctors routinely gave to newly diagnosed or newly referred patients varied according to specialty (Table 3). Items which doctors gave the most information about were extent of disease, treatment procedures and benefits and risks. Items about which doctors gave the least information were effects of treatment on family, sexuality and mood. The amount of information given was scored out of 50; the mean score was 37.38, std. dev 5.372.

Table 3 Amount of information given to new patients

	No information 1 N (%)	A little information 2 N (%)	Some information 3 N (%)	Quite a bit of information 4 N (%)	Great deal of information 5 N (%)	Mean (SD)
Extent of the disease	1 (0.2)	4 (0.7)	37 (6.2)	233 (38.8)	326 (54.2)	4.46 (0.658)
Details of treatment procedures	1 (0.2)	0 (0)	22 (3.7)	193 (32.1)	385 (64.1)	4.60 (0.578)
Benefits of treatment	1 (0.2)	0 (0)	18 (3.0)	234 (39.1)	346 (57.8)	4.54 (0.573)
Risks (side effects) of treatment	1 (0.2)	2(0.3)	36 (6.0)	237 (39.5)	324 (54.0)	4.47 (0.640)
Impact of treatment on sexuality	34 (5.7)	128 (21.4)	189 (31.6)	136 (22.7)	111 (18.6)	3.27 (1.158)
Changes in appearance due to treatment	22 (3.7)	63 (10.5)	197 (32.9)	218 (36.4)	99 (16.5)	3.52 (1.006)
Effects of treatment on mood	41 (6.8)	135 (22.5)	247 (41.1)	133 (22.1)	45 (7.5)	3.01 (1.010)
Effects of treatment on family	51 (8.5)	179 (29.8)	223 (37.1)	107 (17.8)	41 (6.8)	2.85 (1.033)
Effects of treatment on social activities	22 (3.7)	114 (19.0)	233 (38.8)	178 (29.7)	53 (8.8)	3.21 (0.972)
Effects of treatment on patients' ability to care for themselves at	15 (2.5)	72 (12.0)	194 (32.4)	229 (38.2)	89 (14.9)	3.51 (0.969)
Total information giving score						37.38 (5.372)

SD: standard deviation

Comparing the mean scores of amount of information given by clinicians according to their usual approach to decision-making revealed that doctors using shared decision-making gave significantly more information (mean score 38.27) than doctors who reported not using shared decision-making (mean 35.86), $p < 0.001$. (See Figure 4) This may reflect the emphasis on information exchange and attendance to patient preferences in shared decision-making, although the difference translates into less than one additional information item and is unlikely to have clinical implications.

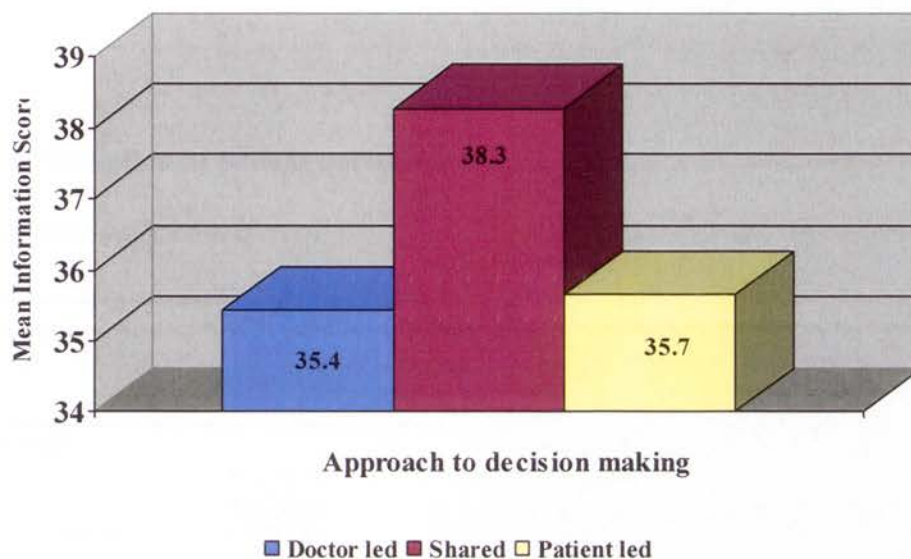


Figure 4 Information giving and usual approach to decision-making

3.5 Clinician perception of patient role preference

Forty-five percent of doctors reported that more than half of their patients preferred to share decision-making responsibility with their doctors (see Table 4). When this response was examined by specialty and doctor discipline, more urological (55.1%) and breast (53.4%) cancer doctors reported that more than half of their patients wanted to share responsibility than colorectal (33%), haematological (22%) and gynaecological (19%) cancer doctors. Similarly more medical oncologists (58%) than other disciplines reported that more than half of their patients wanted to share decision-making responsibility. The other disciplines stated that the majority of their patients wanted the doctor to take the decision-making responsibility. Very few

clinicians (<10%) felt that the majority of their patients wanted to take the lead in this process.

Table 4 Perception of patient preferred role (% of doctors who reported the role >50% of their patients preferred)

	Doctor takes full responsibility N (%)	Share responsibility N (%)	Patient takes full responsibility N (%)	Chi square χ^2 (df)
Cancer specialty				$\chi^2(4)=17.16^{**}$
Breast	80 (26.8)	159 (53.4)	4 (1.3)	
Colorectal	41 (52.6)	26 (33.3)	1 (1.3)	
Leukaemia / Lymphoma	43 (53.8)	18 (22.5)	1 (1.3)	
Gynaecological	16 (61.5)	5 (19.2)	0 (0.0)	
Urological	22 (20.6)	59 (55.1)	2 (1.9)	
Dr Type				$\chi^2(4)=31.13^{**}$
Medical Oncologists	29 (24.2)	70 (58.3)	2 (1.7)	
Radiation Oncologists	22 (44.0)	15 (30.0)	0 (0.0)	
Haematologists	31 (52.5)	11 (18.6)	0 (0.0)	
Paediatric Oncologists	5 (45.5)	4 (36.4)	1 (9.1)	
Surgeons	115 (33.0)	167 (47.9)	5 (1.4)	

df: degrees of freedom, ** $p < 0.01$

3.6 Predictors of usual approach to decision-making

The original 4 category response to usual approach to decision-making was collapsed into 2 categories, shared decision-making or not. This decision was taken as only example 4 describes shared decision-making fully, incorporating sharing of decision-making responsibility, encouragement of patient involvement and discussion of patient preferences and values relevant to the situation.

We analysed the data using crosstabs and chi square to identify significant predictors of usual approach to decision-making. Univariate analysis results are presented in Table 5.

More medical oncologists (66%) and surgeons (66%) reported using a shared approach than other doctors. The duration of direct patient care per week and the size of the community in which the doctors practiced did not influence approach to treatment decision-making. More doctors specialising in breast or urological cancer reported using a shared approach than doctors specialising in colorectal, gynaecological or haematological cancer. To further explore these results the clinicians were grouped into those treating cancers with well known preference-sensitive decisions and those where there are not. Breast and urology cancer doctors (prostate cancer) were combined to form the preference sensitive group (n=415) and colorectal, gynaecological and leukaemia/lymphoma doctors were grouped as the non-preference sensitive group (n=189). This variable was included in the multivariate analysis reported below.

Table 5 Univariate analyses of usual DM approach by doctor characteristics.

	Non-Shared	Shared	Chi square χ^2 (df)
	N (%)	N (%)	
Dr type			$\chi^2(4)=15.240^{**}$
Medical Oncologists	42 (33.9)	82 (66.1)	
Radiation Oncologists	24 (48.0)	26 (52.0)	
Surgeons	118 (33.8)	231 (66.2)	
Haematologists	32 (52.5)	29 (47.5)	
Paediatric Oncologists	8 (66.7)	4 (33.3)	
Tumour type			$\chi^2(4)= 37.256^{**}$
Breast	99 (32.9)	202 (67.1)	
Colorectal	42 (53.8)	36 (46.2)	
Leukaemia / Lymphoma	44 (53.0)	39 (47.0)	
Gynaecological	16 (59.3)	11 (40.7)	
Urological	23 (21.5)	84 (78.5)	
Cancer specialty			$\chi^2(1)=32.538^{**}$
Breast and urological	122 (29.9)	286 (70.1)	
Colorectal, gynaecology and haematology	102 (54.3)	86 (45.7)	
Gender			$\chi^2(1)= 6.873^{**}$
Male	198 (39.9)	298 (60.1)	
Female	26 (26.0)	74 (74.0)	
Age			$\chi^2(2)=2.802$
Under 40yrs	25 (29.4)	60 (70.6)	
40-55yrs	125 (39.2)	194 (60.8)	
Over 55yrs	73 (38.2)	118 (61.8)	
Country of medical training			$\chi^2(1)=2.313$
Australia	195(36.4)	341 (63.6)	
Other	27(46.6)	31 (53.4)	
New pt Caseload per month			$\chi^2(3)=10.345^*$
2 or less	38 (47.5)	42 (52.5)	
3-6	90 (39.6)	137 (60.4)	
7-10	56 (38.4)	90 (61.6)	
11+	37 (27.0)	100 (73.0)	
Direct pt care hrs/week			$\chi^2(1)=0.694$
<20hrs	63 (38.0)	103 (62.0)	
20hrs+	127 (34.2)	244 (65.8)	
Community size			$\chi^2(2)=7.06$
<100,000	12 (30.0)	28 (70.0)	
100,000-500,000	63 (34.8)	118 (65.2)	
500,000+	115 (36.5)	200 (63.5)	

(df) degrees of freedom * $p<0.05$, ** $p<0.01$

Binary logistic regression was performed of usual approach to decision-making (shared or non-shared) using independent variables with chi squares of $p < 0.25$. Variables entered in the model were cancer type (breast and urological doctors v. colorectal, gynaecological and haematological doctors, gender, age (3 groups), new patient caseload per month (2 or less, 3-6, 7-10 or >11) and country of medical training (Australia versus elsewhere). A backward stepwise likelihood ratio model was used; non-shared was the reference category of the dependent variable. The final model has a chi square of 51.31, $df = 5$, $p < 0.001$. Goodness of fit is supported by the Hosmer-Lemeshow Test; chi square 4.62, $df = 7$, $p = 0.71$.

Doctors practicing in breast or urological cancer were three times as likely to use a shared approach compared to colorectal, gynaecological or haematological doctors ($p < 0.001$, OR 3.02, 95% CI 2.08–4.37). Doctors reporting the highest numbers of new patients per month had 2.8 times the odds of using a shared approach ($p < 0.005$, OR 2.81, 95%CI 1.54-5.16). Female doctors had 1.9 times the odds of using shared approach compared to their male colleagues ($p < 0.001$, OR 1.87, 95%CI 1.13-3.10). Variables not independently associated with usual approach to decision-making were: country of medical training and age. (See Table 6)

Table 6 Multivariate logistic regression predicting usual approach to decision-making

Independent Variables		β (SE)	Wald chi square (χ^2) (df)	AOR (95%CI)
Age		0.00 (0.14)	χ^2 (1) = 0.00	1.00 (0.75- 1.33)
Country of training	Australia	0.42 (0.30)	χ^2 (1) = 1.98	1.52 (0.85- 2.74)
	Other			
Caseload	0-2		χ^2 (3) = 11.33*	1-
	3-6	0.53 (0.27)	χ^2 (1) = 3.78	1.71 (1.00-2.92)
	7-10	0.57 (0.29)	χ^2 (1) = 3.74	1.77 (0.99-3.14)
	>11	1.03 (0.31)	χ^2 (1) = 11.23**	2.81 (1.54-5.16)
Cancer specialty	Colorectal, Gynae & Haematological Breast & Urological	1.10 (0.19)	χ^2 (1) = 33.94**	3.02 (2.08– 4.37)
Gender	Male			1-
	Female	0.63 (0.26)	χ^2 (1) = 5.99*	1.87 (1.13 – 3.10)

SE: standard error; df: degrees of freedom; AOR: adjusted odds ratio; 95%CI: 95% confidence interval
* $p < 0.05$, ** $p < 0.01$

3.7 Predictors of comfort with shared decision-making

Univariate analysis was undertaken for high comfort with shared decision-making (See Table 7). Shared decision-making was rated with the highest comfort levels by doctors treating breast or urological cancers, (88%). Medical (89%) and radiation oncologists (78%) and surgeons (84%) reported being most comfortable with the shared approach.

Table 7 Univariate analyses of high comfort levels with shared decision-making[#]

	High comfort with SDM N (%)	Chi square χ^2 (df)
Dr type		$\chi^2(4)=4.95$
Medical Oncologists	105 (89.0)	
Radiation Oncologists	39 (78.0)	
Haematologists ^a	4 (66.7)	
Paediatric Oncologists	9 (81.8)	
Surgeons	296 (84.3)	
Cancer specialty		$\chi^2(1)=12.74^{**}$
Breast and urological	360 (87.6)	
Colorectal, gynaecology and haematology	93 (74.4)	
Gender		$\chi^2(2)=4.56^*$
Male	372 (83.0)	
Female	81 (92.0)	
Age		$\chi^2(2)=0.42$
Under 40yrs	65 (86.7)	
40-55yrs	241 (83.4)	
Over 55yrs	146 (84.6)	
Country of medical training		$\chi^2(1)=0.00$
Australia	412 (84.4)	
Other	39 (84.8)	
Caseload per month		$\chi^2(3)=6.65$ P=0.084
2 or less	62 (81.6)	
3-6	162 (80.6)	
7-10	111 (86.7)	
11+	113 (90.4)	
Direct pt care hrs/week		$\chi^2(1)=0.70$
<20hrs	137 (82.5)	
20hrs+	315 (85.4)	
Community size		$\chi^2(2)=1.27$
<100,000	34 (85.0)	
100,000-500,000	158 (86.8)	
500,000+	259 (83.0)	

[#] Percentages here represent respondents who reported comfort levels of 4 or 5 on the 5 point Likert scale, 1=not comfortable, 5=very comfortable.

* $p<0.05$ ** $p<0.01$

^a An initial decision to shorten the survey for participants other than breast cancer specialists, excluding the question concerning comfort levels with each of the four decision making examples was reversed mid way through sending the survey to second cohort (haematologists) and explains the small number of responses in this group for these questions.

We performed binary logistic regression of comfort with shared decision-making (low comfort or high comfort) using independent variables with chi squares of < 0.25 . Variables entered in the model were cancer type (breast and urological doctors v. colorectal, gynaecological and haematological doctors), doctor gender and new patient caseload per month. A backward stepwise likelihood ratio model was used; low comfort was the reference category of the dependent variable. The final model has a chi square of 23.55 $df = 5$, $p < 0.001$. Goodness of fit is supported by the Hosmer-Lemeshow Test; chi square 10.55, $df = 6$, $p = 0.10$.

In multivariate regression analysis doctors practicing in breast or urological cancer were $2\frac{1}{2}$ times as likely to be very comfortable with shared decision-making compared to colorectal, gynaecological or haematological doctors ($p < 0.001$, OR 2.53, 95% CI 1.52–4.24). Female doctors had 2.3 times the odds of being very comfortable with shared decision-making compared to their male counterparts ($p < 0.05$, OR =2.31, 95% CI 1.01–5.27). Overall caseload did not produce a significant result however doctors reporting the highest numbers of new patients per month showed 2.3 times the odds of being very comfortable using shared decision-making ($p = 0.05$, OR 2.33, 95%CI 0.10–5.44). (See Table 8)

Table 8 Multivariate logistic regression predicting high comfort with shared decision-making

Independent Variables		β (SE)	Wald chi square (χ^2) (df)	AOR (95%CI)
Cancer specialty	Colorectal, Gynae & Haematological Breast & Urological	0.93 (0.26)	χ^2 (1) = 12.58**	2.53 (1.52–4.24)
Caseload	0-2			
	3-6	0.10 (0.35)	χ^2 (1) = 0.80	1.11 (0.55-2.22)
	7-10	0.56 (0.40)	χ^2 (1) = 1.95	1.76 (0.80-3.88)
	>11	0.84 (0.43)	χ^2 (1) = 3.82	2.33 (1.00-5.44)
Gender	Male			1-
	Female	0.84 (0.42)	χ^2 (1) = 3.97*	2.311 (1.01–5.27)

SE: standard error; df: degrees of freedom; AOR: adjusted odds ratio; 95%CI: 95% confidence interval
* $p < 0.05$, ** $p < 0.01$

The results show a discrepancy between reported usual practice of shared decision-making and high comfort with that approach. This mismatch is highest in the gynaecological doctors (48%) and in the paediatric oncologists (53%). (See Table 9)

Table 9 Discrepancy between high comfort level and reported use of shared decision-making

	Usual approach N (%)	High level of comfort N (%)	Mismatch
Tumour type			
Breast	202 (67.1)	266 (86.9)	19.8
Colorectal	36 (46.2)	51 (67.1)	20.9
Leukaemia / Lymphoma	39 (47.0)	18 (81.8)	34.8
Gynaecological	11 (40.7)	24 (88.9)	48.2
Urological	84 (81.6)	94 (89.5)	7.9
Dr type			
Medical Oncologists	91 (65.0)	105 (89.0)	24.0
Radiation Oncologists	26 (50.0)	39 (78.0)	28.0
Haematologists	29 (47.5)	4 (66.7)	19.2
Paediatric Oncologists	4 (28.6)	9 (81.8)	53.2
Surgeons	231 (69.2)	296 (84.3)	15.1

3.8 DISCUSSION

We investigated usual practice and comfort levels with treatment decision-making across cancer care in Australia. Our expectation that differences would exist between tumour specialties and between doctor disciplines was supported. Since a clear treatment choice is available in the management of early breast cancer and because of the breast cancer consumer movement, we expected more positive attitudes to shared decision-making to be evident in surgeons treating this disease. Demographic differences were apparent in Australian clinicians' approach to decision-making, not only in their usual practice but also in their comfort with the styles presented in the survey.

Comfort with and use of shared decision-making

Respondents reported high levels of comfort with shared decision-making and discomfort with a paternalistic model. These results reflect the changes over recent years in the expectations and information preferences of patients and suggest that clinicians are responding to an increasingly consumerist model of healthcare. A UK study which used focus group interviews with General Practitioners also reported positive attitudes to patient involvement (Elwyn, Edwards et al. 2000). Doctor use of shared decision-making in our survey was associated with reported greater information giving compared to colleagues who did not use a shared approach.

Our hypothesis that doctors treating breast cancer would involve patients in decision-making was supported. Breast cancer doctors in Australia strongly endorsed shared decision-making as found in Canada (Charles, Gafni et al. 2004). Indeed there were strong similarities between the decision-making practices of Australian and Canadian breast cancer doctors (Charles, Gafni et al. 2004), suggesting a similar culture surrounding treatment decision-making in the two countries. Shared decision-making was also strongly supported by the urological specialists. Conversely, support for shared decision-making was low in paediatric oncologists and haematologists. Paediatricians may feel parents of seriously ill children need to be informed of options, but led to the preferred treatment because of the extremely emotional context. Other clinicians however, may feel more able to share decision-making where a treatment decision is a real choice between two options with similar survival outcomes (Whitney, McGuire et al. 2003), such as mastectomy versus breast

conservation or radical prostatectomy versus hormone therapy and brachytherapy for prostate cancer. The surgical treatment options in breast cancer may explain the higher proportion of surgeons (who have a clear choice to offer) compared to medical oncologists (who may feel that systemic therapy is definitely indicated) who reported sharing decision-making with their patients. Similarly, colorectal, gynaecological oncologists and haematologists may also feel that their patients need more direction due to lack of treatment options available. This interpretation is supported elsewhere with family physicians asserting that shared decision-making is most appropriate when clinical equipoise exists (Elwyn, Edwards et al. 2000; Whitney, McGuire et al. 2003). Respondents were not asked to identify a particular decision, nor did the questionnaire stipulate that the questions should be answered in contexts where equitable treatment options existed, yet our results indicate that context and existence of equitable treatment options may play a part in doctors' comfort and readiness to use shared decision-making.

The consumer movement and public awareness of surgical treatment options in breast and prostate cancer may also have contributed to these results. The doctors in these specialties may be responding to this shift as their patients demand more information and a role in discussing and deciding about treatment. Breast and urological cancer doctors believe more of their patients wish to be involved in decision-making. Indeed, studies which have investigated the information and involvement preferences of patients demonstrate that breast cancer patients prefer a more active role than other

cancer patients (Beaver, Luker et al. 1996; Degner, Kristjanson et al. 1997; Bruera, Willey et al. 2002).

The small differences according to caseload in support of shared decision-making may suggest a relationship with practice setting and multi-disciplinary relationships. Doctors who treat fewer patients with a particular cancer may be less comfortable with involving patients in decision-making due to their reduced familiarity with treatment options. Those with a large caseload are perhaps more likely to be a multi-disciplinary team member where shared decision-making is fostered, and more likely to feel confident in offering a number of options.

Discrepancy between reported comfort levels and usual practice

The discrepancy in the reporting of comfort with shared decision-making and the use of this approach in practice mirrors the Canadian results. For all surveyed clinicians except those treating colorectal cancer, over 80% reported high levels of comfort with shared decision-making, yet, with the exception of the breast and urological cohorts, less than 50% reported using this approach for the majority of their patients. Interpretation of this discrepancy affords varying standpoints. Some commentators may interpret this discrepancy as evidence that in certain oncology clinical situations choice does not exist and therefore doctors would not use a shared decision-making approach. Whitney discusses the issue of no treatment as a non-viable option and cites the example of a life threatening gunshot wound and the inappropriateness of

shared decision-making in this context. Yet in oncology observation without treatment could be seen as medically reasonable in many instances where treatment reduces risk but does not eliminate it, and carries serious side effects. This interpretation opens up the debate on what constitutes a medically reasonable option and whether this always includes intervention. More generally however, these criteria for shared decision-making may be refuted by those who comment that shared decision-making is always appropriate even in circumstances where a treatment choice is obvious, as patients need to be involved in the decision to understand the logic. There may also be other barriers to implementation of shared decision-making which we as yet do not understand.

Similar discrepancies have been reported internationally. General Practitioners in the UK also professed support for shared decision-making but when their own consultations were analysed the participating doctors agreed components of shared decision-making did not occur (Stevenson, Barry et al. 2000). Braddock and colleagues analysed 1057 consultations of primary care physicians and surgeons in 1993 and found that only 11% included discussion of alternative treatment options and just 8% included pros and cons (Braddock III, Edwards et al. 1999). An Australian study in 2001 of consultations with advanced cancer patients showed that only 27% of patients were offered a choice, and 44% were given information on an alternative course of action to anticancer therapy (Gattellari, Voigt et al. 2002). In a Dutch study of advanced cancer patient care acknowledgement of the medical oncology options of palliative chemotherapy or watchful waiting, occurred in half of

the consultations, with just 27% receiving extensive explanation of the watchful waiting option (Koedoot, Oort et al. 2004). These results lead us to conclude that the discrepancy between reported high comfort and actual shared decision-making practice may be greater than our self-reported data shows. It is important to explore barriers to implementation which might explain this discrepancy.

3.9 CONCLUSIONS

Despite shared decision-making being lauded as the gold standard for discussion of treatment options and reported high levels of comfort with shared decision-making, Australian clinicians are not currently reporting that this is their usual practice. Cancer specialty, clinician gender and higher caseload of new patients influence cancer doctors' use of shared decision-making. Breast and urological cancer patients can expect a consultation where their involvement and information preferences are more likely to be explored. Clinician attitudes and use of shared decision-making can be influenced by the clinical situation in which they practice. Further work is required to establish whether clinicians in cancers other than breast and urological cancers recognize clinical scenarios where they support and use shared decision-making.

CHAPTER FOUR

PHYSICIAN IDENTIFIED FACTORS WHICH AFFECT PATIENT PARTICIPATION IN REACHING TREATMENT DECISIONS.

4.1 Sample

The sample for this analysis is identical to that reported above for Chapter Three.

4.2 Perceived barriers to treatment decision-making

Experience of items perceived as barriers to treatment decision-making is presented in Table 10. Response categories were on a four-point Likert scale; never, sometimes, often and almost always. Items experienced by the most physicians as difficulties 'almost always' were; the physician having insufficient information to make a decision at the first consultation (7%); and insufficient time to spend with the patient (5%). Items perceived by the most physicians as 'never' a hindrance to treatment decision-making were; the doctor experiencing difficulty in framing the treatment options for the patient (48%); and the patient's family overriding the decision-making process (44%). Most common difficulties reported 'often' or 'almost always' were; the physician having insufficient information to make a decision at the first consultation (29%); insufficient time to spend with the patient (28%); patient having other health problems (28%); patient having misconceptions about their disease or

treatment (27%); patient being indecisive (24%); patient being too anxious (24%); and patient not understanding the information given (21%).

Table 10 Items experienced as difficulties or helpful to decision-making process

Items experienced as difficulties N=604	Never N (%)	Sometimes N (%)	Often N (%)	Always N (%)
I have insufficient information to make a decision about treatment at the first consultation.	58(9.6)	371(61.5)	134(22.2)	40(6.6)
Insufficient time to spend with the patient	87(14.4)	345(57.2)	138(22.9)	33(5.5)
The patient has other health problems. (E.g. heart disease)	28(4.7)	406(67.4)	157(26.1)	11(1.8)
The patient has misconceptions about the disease or treatment.	11(1.8)	428(71.1)	154(25.6)	9(1.5)
The patient is indecisive.	22(3.7)	432(72.1)	139(23.2)	6(1.0)
The patient is too anxious to listen to what I have to say.	32(5.3)	428(71.1)	132(21.9)	10(1.7)
The patient does not understand the information I have given.	12(2.0)	467(77.4)	116(19.2)	8(1.3)
The patient has difficulty accepting s/he has cancer	96(15.9)	458(76.0)	43(7.1)	6(1.0)
The patient comes expecting a certain treatment rather than a consultation.	115(19.1)	443(73.5)	43(7.1)	2(0.3)
There are cultural differences between the patient and me.	121(20.1)	440(73.1)	37(6.1)	4(0.7)
The patient has received conflicting recommendations from various specialists.	59(9.8)	505(83.7)	34(5.6)	5(0.8)
The patient requests a treatment not known to be beneficial.	65(10.8)	500(83.3)	31(5.2)	4(0.7)
The patient brings too much information to discuss.	130(21.6)	441(73.4)	28(4.7)	2(0.3)
The patient wants to make a decision before receiving the information from me.	243(40.3)	343(56.9)	14(2.3)	3(0.5)
The patient wants to participate more than I would like him/her to.	231(38.4)	357(59.3)	10(1.7)	4(0.7)
I experience difficulty knowing how to frame the treatment options for the patient.	291(48.3)	304(50.5)	7(1.2)	0(0)
The patient's family overrides the decision-making process.	263(43.7)	332(55.1)	5(0.8)	2(0.3)
The patient refuses a treatment that may benefit him/her.	30(5.0)	566(93.9)	3(0.5)	4(0.7)
Items experienced as helpful				
The patient trusts me.	0(0)	11(1.8)	231(38.5)	359(49.7)
The patient has someone with them at the consultation.	0(0)	51(8.5)	267(44.4)	284(47.1)
Providing written information to the patient.	2(0.3)	117(19.4)	217(36.0)	267(44.3)
The patient wants to participate in making the treatment decision.	1(0.2)	107(17.8)	300(49.9)	193(32.1)
The patient is emotionally ready for decision-making.	2(0.3)	134(22.2)	271(44.9)	196(32.5)
The patient is prepared (knowledgeable about disease and treatment) for the consultation.	4(0.7)	245(40.7)	231(38.4)	122(20.3)

Based on conceptual analysis and the correlational findings, exploratory factor analyses were conducted. Two items, cultural differences and patient receiving conflicting recommendations, were removed due to statistical reasons. The items of insufficient information and patient co-morbidity were removed due to their relatively low factor loadings and as they did not fit conceptually with the other items loaded onto the patient difficulties factor. Confirmatory factor analysis produced a four factor model, conceptually defined as: patient difficulties; preference for a not recommended treatment; system difficulties; and agenda-setting patient. The patient difficulties factor included items which covered misunderstanding or lack of understanding, anxiety, denial, withdrawal and indecision. The patient preference for a not recommended treatment factor included items which indicated the patient did not want to accept the physician-recommended treatment, through refusal or request for another treatment. System issues included lack of time, misunderstanding of the nature of the consultation and the decision-making process and physician difficulties in framing options. The fourth factor included items which reflected a patient who was agenda-setting; either by bringing too much information or by wishing to be more involved than the doctor was comfortable with. The factor loadings for this analysis confirmed the four factor exploratory analysis. The analysis gave a χ^2 of 199.99 on 84 degrees of freedom, with a RMSEA of .05, a RMR of .04 and a GFI of .98. These values indicate that the model provides a good approximation to the data. Factor loadings are presented in Table 11.

Table 11 Factor Analysis

Item	1	2	3	4	Unique variance	N	Mean	Std Deviation	Range
Factor 1 – Patient difficulties						596	12.9	1.8	8-24
The patient does not understand the information I have given.	.48				.77				
The patient does not want to participate as much as I would like.	.42				.82				
The patient is indecisive.	.50				.49				
The patient has difficulty accepting s/he has cancer.	.59				.66				
The patient is too anxious to listen to what I have to say.	.58				.66				
The patient has misconceptions about the disease or treatment.	.42				.82				
Factor 2 – Patient prefers a not recommended treatment						600	3.9	0.6	2-8
The patient requests a treatment not known to be beneficial.		.71			.49				
The patient refuses a treatment that may benefit her		.62			.62				
Factor 3 – System difficulties						601	8.8	1.7	5-17
Insufficient time to spend with the patient.			.32		.90				
The patient wants to make a decision before receiving the information from me			.58		.66				
The patient's family overrides the decision-making process.			.58		.67				
I experience difficulty knowing how to frame the treatment options for the patient.			.38		.86				
The patient comes expecting treatment rather than a consultation.			.50		.75				
Factor 4 – Agenda-setting patient						600	3.5	0.9	2-8
The patient wants to participate more in deciding on his/her treatment than I would like him/her to.				.45	.80				
The patient brings too much information to discuss.				.78	.66				

Note: All loadings for each item, are provided with the salient loadings in bold face

4.3 Predictors of barriers to treatment decision-making.

To further explore the reported barriers, the variables relating to each factor were summed and a score was computed for each of the four factors. A higher score represented greater reporting of the factor as a difficulty. Mean scores are presented in Table 11.

Results of univariate analysis, comparing demographic and clinical characteristics with each of the factor scores are presented in Table 12. Urological cancer physicians had the highest mean score for the patient difficulties factor. Breast cancer physicians had the lowest mean score for the preference for a not recommended treatment factor. Haematologists and gynaecological physicians had the highest mean score for system difficulties. Surgeons reported the highest mean score for patient difficulties and haematologists reported the highest mean score for system difficulties. Mean scores for each of the factors were comparable regardless of physicians' reported usual approach to decision-making. Physicians whose initial medical training was completed in Asia, SE Asia or the Middle East had higher mean scores for 3 of the 4 factors: patient difficulties; system difficulties; and agenda-setting patient. Physicians reporting less direct patient contact per week and fewer new patients per month showed a higher mean score for the patient difficulties factor.

Table 12 Univariate analysis of factor scores

	Factor 1		Factor 2		Factor 3		Factor 4	
	Patient difficulties		Patient prefers a not recommended treatment		System difficulties		Agenda-setting patient	
	Mean	Std dev	Mean	Std dev	Mean	Std dev	Mean	Std dev
Cancer type treated								
Breast	12.85	1.78	3.82***	0.59	8.64**	1.69	3.41	0.82
Colorectal	13.05	1.64	3.96***	0.44	8.72**	1.58	3.42	0.86
Gynaecological	13.04	1.51	4.04***	0.98	9.11**	1.45	3.44	0.85
Haematological	12.78	1.42	3.98***	0.42	9.40**	1.60	3.62	0.70
Urological	13.26	2.48	4.14***	0.70	8.92**	2.12	3.66	1.06
Breast and Urological	12.96	1.99	3.90 [†]	0.64	8.71 [†]	1.81	3.47	0.89
Colorectal, Gynaecological & Haematological	12.93	1.52	3.97 [†]	0.54	9.07 [†]	1.59	3.51	0.79
Physician discipline								
Medical Oncologist	12.59***	1.42	3.98	0.51	9.09***	1.44	3.50	0.81
Radiation Oncologist	12.12***	1.18	3.94	0.31	9.27***	1.39	3.31	0.73
Surgeon	13.23***	2.07	3.90	0.70	8.55***	1.87	3.49	0.93
Haematologists	12.75***	1.42	3.95	0.47	9.51***	1.60	3.52	0.72
Paediatric Oncologist	12.83***	1.59	4.00	0.00	8.73***	1.74	3.75	0.45
Physician gender								
Male	12.99	1.92	3.92	0.63	8.77 [†]	1.77	3.50	0.87
Female	12.74	1.50	3.95	0.48	9.08 [†]	1.68	3.41	0.81
Usual approach to decision-making								
Doctor-led	12.81	1.67	3.93	0.60	8.82	1.71	3.58	0.79
Shared	12.96	1.88	3.92	0.59	8.83	1.75	3.47	0.84
Patient-led	12.85	1.43	3.88	0.56	8.78	1.82	3.44	0.97
Medical student training								
Australasia	12.97	1.90	3.92	0.59	8.81	1.76	3.48	0.86
UK/Europe/Canada & South Africa	12.62	1.21	4.00	0.78	8.85	1.63	3.45	0.85
Asia/SE Asia/Middle East	13.50	1.65	4.00	0.67	9.20	2.39	4.00	1.12
Years of postgraduate experience								
<25yrs	12.84	1.76	3.95	0.57	9.15***	1.63	3.42	0.88
≥25yrs	13.04	1.93	3.90	0.64	8.53***	1.81	3.54	0.84
New patient caseload per month								
≤6 pts	13.03	1.87	3.86*	0.62	8.75	1.80	3.48	0.84
≥7 pts	12.86	1.83	3.99*	0.59	8.90	1.71	3.48	0.89
Direct pt care per week								
<20hrs	13.14 [†]	2.09	3.85 [†]	0.75	8.63	1.96	3.40 [†]	0.94
20hrs or more	12.89 [†]	1.80	3.96 [†]	0.55	8.84	1.67	3.52 [†]	0.84
Community size								
<100,000	13.02	2.16	3.83	0.54	8.27 [†]	1.73	3.39	0.83
100,000 - 500,000	13.07	2.01	3.90	0.66	8.71 [†]	1.81	3.51	0.90
>500,000	12.90	1.79	3.95	0.60	8.88 [†]	1.74	3.47	0.87

[†]p<0.2, *p<0.05, **p<0.01, ***p<0.001,

Our data showed a high correlation between the variables age and years of experience ($p<.01$) and physician discipline and type of cancer treated ($p<.01$). We included only years of experience and type of cancer treated in regression analyses. Bivariate correlation of cancer, years of experience, doctor gender and community size showed significant correlation with system difficulties (See Table 12). New patients seen per month, cancer type treated and hours of practice per week showed significant correlation for the patient preference for a not recommended option.

Predictors of greater reporting of system difficulties were identified using linear regression. Three variables included had a significant association with a higher system limitation score. Variables included in the model were years of experience, cancer type treated and community size. The final model ($R^2 = .035$) showed that physicians with less experience ($p<0.001$) reported greater frequency of system difficulties as barriers to decision-making with patients.

Table 13 Linear Regression

Model	R²	df	F-statistic	p-value
Higher system difficulty score	.035	3,536	7.536	0.000
Individual predictors	B	SE	β	p-value
Constant	9.291	.296		.000
No. of years qualified	-.033	.008	-.174	.000
Breast & Urological vs. Colorectal, Gynaecological & Haematological	.154	.178	.037	.385
Community size 100K, 100-500K, >500k	.194	.120	.069	.105

4.4 Facilitators to treatment decision-making

Six possible facilitators were listed and the frequencies with which physicians found these helpful obtained. As responses were skewed the original four categories on a Likert scale were collapsed into a dichotomous score. Those reported by physicians as experienced as helpful ‘never’ or ‘sometimes’ were recoded as not helpful, and those reported as experienced ‘often’ and ‘almost always’ helpful were recoded as helpful. The majority of physicians (98%) reported that the patient trusting them was helpful and that the patient being accompanied in the consultation (91%), the patient wanting to participate (82%), and providing written information were helpful (80%). (See Table 10)

4.5 Interventions to encourage patient involvement and reflection.

Most of the breast and urological cohort, (81%) supported offering patients written information concerning available treatment options; 69% supported a third person being at the consultation, and 50% endorsed input from a senior cancer nurse prior to the consultation. There was less support for six other interventions to encourage involvement. Three of six possible interventions for encouraging patient reflection after the consultation were well supported. A follow-up appointment to make the decision was supported by 96%, as was written information highlighting treatment options (90%) and encouragement for the patient to speak with the treatment team and their general practitioner (73%). Worksheets to assist the patient to articulate their values and preferences were supported by one fifth (19%). (See Table 14).

Table 14 Interventions which physicians would support to encourage patient involvement and reflection.

N= 415*	Yes N (%)
Offering the patient written information about the treatment options available	321 (81.1)
Having a third person in the room	273 (68.9)
Input from Cancer Nurse Coordinator/CNC prior to consultation	196 (49.5)
Booklet explaining clinical decision-making.	135 (34.1)
Preparing patient for a greater role in decision-making, by offering question prompt lists prior to the consultation.	124 (31.3)
Booklet about patient roles explaining shared decision-making.	111 (28.0)
Access for medical practitioners to training to enhance skills in meeting patients' preferences for SDM	99 (25.0)
Explicitly negotiating shared decision-making	89 (22.5)
Input from Cancer Nurse Coordinator/CNC post consultation	50 (12.6)
Follow up appointment to make a decision	381(96.2)
Giving written information highlighting treatment options	356(89.9)
Encourage pt to talk to treatment team and general practitioner	288(72.7)
Worksheets for the patient to help him/her articulate what is important for him/her.	77(19.4)
Audio-taping consultation	64(16.2)
Telephone follow up to discuss treatment decision	54(13.6)

* Breast and urological cancer physicians only

4.6 DISCUSSION

We examined the reported barriers and facilitators to treatment decision-making of a large sample of practicing cancer physicians across Australia. We hypothesized that physician characteristics including discipline and the type of cancer treated may influence experience and perception of factors as barriers to shared decision-making.

Lack of time was reported as one of the more frequently experienced barriers to treatment decision-making by Australian cancer physicians. Physicians with less experience reported system issues as difficult more often. This may be because physicians with greater experience are more patient-centred in their approach to consultations or have become skilled at overcoming system issues. A number of studies have reported that collaborative decision-making does not increase consultation time and may save time in the long run as thorough initial discussion enables subsequent consultations to be more succinct (Greenfield, Kaplan et al. 1985; Edwards, Elwyn et al. 2002; Say and Thomson 2003). Moreover addressing patient concerns may shorten initial consultations.

Patient misunderstanding was considered one of the key difficulties when reaching treatment decisions. Quirt et al (1997) explored the level of agreement between patients and their physicians about diagnosis, treatment aims, and risks and benefits. They reported that many lung cancer patients did not fully comprehend their situation and that this was underestimated by their physicians. If this discrepancy between the patient understanding and physician awareness of patient understanding is duplicated

in Australia, this barrier may be higher than reported by our participants. Participating physicians reported that patient anxiety and misconception of their disease or treatment were two of the most frequent barriers to sharing decision-making. This is not surprising as emotion has a negative effect on many requirements for collaboration, making it more difficult for patients to take in information, and consider their options. In Gravel's review of barriers to implementing shared decision-making in clinical practice, lack of applicability of the process due to patient characteristics, such as anxiety, and characteristics of the clinical situation, such as lack of any real choice, also featured strongly (Gravel, Legare et al. 2006).

Our data show cancer physicians' perceptions of what assists them when making treatment decisions. Patients' trust was regarded as the key facilitator. Patients also nominate trust in their physician as one of the most important factors when reaching a treatment decision (Salkeld, Solomon et al. 2004). As patient involvement and the consumer role in healthcare grows (Coulter 1999), the importance of physicians gaining the their patients' trust may increase. Previous studies suggest that trust develops through excellent communication and by responding to patient preferences for information and involvement (Thom and Physicians 2001; Keating, Green et al. 2002; Trachtenberg, Dugan et al. 2005). However, difficulties in defining and measuring trust complicate research into its effect on doctor decision-making style (Entwistle 2004).

A patient being accompanied at the consultation was viewed as helpful. This may reflect recognition of the two-fold benefit a companion brings for the patient, as a second pair of ears and as emotional support. However the presence of a third person as a facilitator to patient involvement was supported less, implying that physicians are more comfortable with patients bringing a significant other to the consultation than having a third person present, perhaps a nurse or patient advocate. Perceived differences in the roles that a patient's family or significant other might play compared to that of a nurse practitioner are unclear.

Perceived patient willingness to participate in the decision-making process was viewed by the majority of physicians as a facilitator and reflects the notion that for a shared approach both parties have to be willing to participate (Charles, Gafni et al. 1997; Charles, Gafni et al. 1999).

Some written information given to patients is not balanced or complete (Braddock III, Edwards et al. 1999; Coulter 2003), yet our findings imply that patients and physicians may benefit from patients receiving written evidence-based information to reflect on the treatments being recommended.

We found little support for interventions designed to prepare patients to be involved in decision-making, with less than a third of respondents embracing booklets explaining clinical decision-making, patient roles in decision-making or use of question prompt lists (QPLs). Audio-recording consultations was supported by only

16% of physicians. A review of the effectiveness of providing consultation audio-recording or written summaries showed the majority of patients found them to be very useful and that recall and satisfaction with information received were improved. Anxiety or depression were not influenced by receipt of an audio-recording or summary (Scott, Entwistle et al. 2001). Our findings suggest this review's recommendation that physicians should consider offering patients audio-recordings appears not to have been adopted in Australia.

Translating research evidence into practice remains a challenge for researchers keen to implement effective communication tools. An investigation of barriers to uptake of patient decision aids in clinical practice reported that physicians' lack of awareness and of the skills to use the tools effectively inhibited implementation (O'Donnell, Cranney et al. 2006). Training programs targeted at health professionals are recommended to address the issue of lack of familiarity (Charles, Gafni et al. 1997; Charles, Gafni et al. 1999; Gravel, Legare et al. 2006), yet our data reveal that Australian cancer physicians have minimal interest in access to training in order to meet patient preferences for shared decision-making.

The difficulties identified in our survey and the limited support for strategies and interventions echo the views of Entwistle and Watt (2006) who state that the clinician's motivation to involve patients is influential and that success in facilitating involvement is inextricably linked to this. The difficulties we report emphasize system and patient attributes which prove challenging for physicians. Insight into the

difficulties which may be physician driven and reasons why physicians may be less supportive of patient involvement should be sought in further research. Changing established practice and successfully implementing evaluated communication interventions remains a challenge. Perhaps greater implementation success will be realized by aiming strategies at patients or at the system (Holmes-Rovner, Valade et al. 2000).

4.7 CONCLUSION

Our survey sought to identify physician perceived barriers and facilitators to the treatment decision-making process in cancer consultations and to explore support for interventions to increase patient involvement and reflection on treatment options presented to them.

What hinders? System issues, particularly time, are a barrier to shared treatment decision-making, particularly for less experienced physicians. Patients who refuse the recommended treatment or wish to pursue a treatment not considered optimal are also seen as a barrier to shared decision-making.

What helps? A patient trusting their doctor is important, although how to create and build trust is not clear. The value of the patient being accompanied during a consultation and being provided with quality written information is strongly endorsed by surveyed physicians.

Successful implementation of interventions to encourage patient involvement in decision-making is a challenge. Interventions which physicians support need to be developed, as well as increasing physician access to and awareness of interventions already available.

SECTION THREE.

STAGE TWO RESULTS AND DISCUSSION

Chapters Five, Six and Seven present the findings from the qualitative interviews conducted with Australian cancer doctors treating breast, colorectal, gynaecological, haematological or urological cancer. As described in more detail in Chapter Two, the doctors were a subset of the larger sample from stage one, selected to give perspectives from doctors reporting each of the three different approaches to decision-making with their patients.

Chapter Five presents a detailed description of the sample as well as results and discussion concerning features of the cancer consultation which encourage or discourage doctors to involve patients in reaching treatment decisions.

Chapter Six describes the features which doctors identified as critical to involving patients in treatment decisions. The discussion of this chapter shows how these features reflect current models of shared decision-making in the literature.

Chapter Seven presents themes concerning the consequences for doctors and patients of patient involvement in decision-making; the effects on the consultation and changes that involvement brings about for the parties concerned.

CHAPTER FIVE

FACTORS WHICH MOTIVATE CANCER DOCTORS TO INVOLVE THEIR PATIENTS IN REACHING TREATMENT DECISIONS

5.1 Participants

Forty-five doctors were invited to participate, nine treating each of five cancer types, and three within each set of nine who professed a doctor-led approach, three a shared approach and three a patient-led approach. Sixteen of the 45 agreed to participate. One of the 45 had since retired and therefore was excluded. A further 22 doctors were invited to participate; the researchers targeted the decision-making approaches and cancer types treated which were not represented in the matrix. Six of the 22 doctors agreed to participate, giving a total of 22 interviews, an overall response rate of 34%.

The matrix with the final sample by usual decision-making approach and cancer treated is shown as Figure five. Seven doctors professed that their usual approach to decision-making was doctor-led, nine a shared approach and five a patient-led approach, one did not select a single usual approach. Doctor-led and shared usual approaches to decision-making were represented in each cancer type and a usual patient-led approach was represented in breast, urological and gynaecological cancer doctors. Only six colorectal doctors and one haematologist selected a patient-led as

their usual approach in the original quantitative survey, all were invited to participate in the interviews and all declined or did not respond to the invitation. Nevertheless, theoretical saturation was apparent in the data, with no new themes emerging in the later interviews; thus it was felt to be reasonable to cease recruitment.

	Dr led	Shared	Pt led	Other
Breast	3 (2xMO, 1xsurgeon)	1 (surgeon)	1 (surgeon)	
Colorectal	2 (surgeon)	4 (1xMO; 2xsurgeon)		
Gynaecological	1 (surgeon)	1 (surgeon)	2 x surgeon)	
Haematological	1 (haematologist)	2 (MO*)		1 (haematologist)
Urological	1 (surgeon)	1 (surgeon)	2 (1xMO; 1xsurgeon)	

MO= Medical Oncologist

Figure 5 Final sample matrix

The final sample consisted of 14 surgeons, six medical oncologists and two haematologists. Demographic and practice data are shown in Table 15. Ages ranged from 39 to 63 yrs (mean 50.3, SD 7.9 years). Number of years since graduation from medical school ranged from 12 to 40 years (mean 25.6 years, SD 9.0 years). Five participants (23%) were female, representative of the gender distribution of our larger survey. Five of the doctors worked less than 20hrs per week in direct contact with patients. Two doctors worked in communities of less than 100,000 and two doctors

worked in communities of 100,000 – 500,000. All five major states of Australia were represented.

Table 15 Demographics of sample

Variable	N (%)
Dr type	
Medical Oncologist	6 (27.3)
Surgeon	14 (63.6)
Haematologist	2 (9.1)
Gender	
Male	17 (77.3))
Female	5 (22.7)
Age – Mean	48. yrs (37-61yrs)
Years qualified – Mean	24yrs (10-38yrs)
Direct pt care hrs/week*	
<20hrs	5(26.3)
20hrs+	14 (73.7)
Community size*	
<100,000	2(10.5)
100,000-500,000	2(10.5)
500,000+	15(78.9)
*n=19(3 missing values)	

5.2 Thematic analysis

In the telephone interviews we conducted with Australian cancer doctors (for Methods, see Chapter Two) we sought to further explore the discrepancy found between doctors reported comfort with shared decision-making and their reported use of this approach, as well as the barriers and facilitators they experienced when making treatment decisions with their cancer patients. A number of questions in the interview schedule (see Figure 3, Chapter Two) specifically sought responses from the participants regarding this topic:

- *GPs have said that shared decision-making is useful in some situations (e.g. AF, menorrhagia, HRT,) but not in others. Do you think there are situations where shared decision-making is more appropriate than others? If so, what are they? Which clinical scenarios?*
 - *(If respond with “where there is clear choice”) How do you determine when there is clear choice?*
 - *How do you determine if the patient views this in the same way you do? E.g. patients may be interested in the no treatment option?*
 - *Do you think it is ever appropriate not to disclose a treatment option? For example, if it is expensive and you know the patient has a limited income?*
 - *Are there circumstances in which you either have not or might disclose a clinically relevant option to a particular patient?” (or might not disclose an option that you would sometimes mention to other patients with the same diagnoses)*
 - *Can you describe how you would normally present treatment options to your patients? Do you list them in order of your*

preference/recommendation? Do you present equal amounts of information on each? Do you spend more time on the ones you think are more appropriate?

- *In our survey doctors who treated breast and urological cancers were more positive about shared decision-making than others. Why do you think that might be?*

- *In our survey, some doctors reported that some patients are incapable of shared decision-making because they are too anxious, or lack understanding of their disease status and/or the information they receive— do you agree?*
 - *Can you give an example of a patient who could not share decision-making?*

- *In your experience does shared decision-making take up extra time? Does it ever save time down the track?*

Four main themes emerged from the data regarding factors which influence when Australian cancer doctors considered it appropriate to involve patients in decision-making appropriate. These were described as characteristics of the disease, the patient, the doctor and of society. Doctors described situations in regard to each of these themes referring to whether patients' involvement was appropriate or not and whether they encouraged it.

5.3 Disease characteristics.

When discussing whether or not they involved patients in decisions doctors talked about five features of the disease: decision context; existence of treatment options; impact of treatment; disease culture; and stage of disease.

5.3.1 *Decision context*

A clear distinction was made between black and white decisions where there was only one treatment choice (where patients were less likely to be involved) and situations described as grey, where more than one option was considered potentially appropriate (where patient involvement was considered important). Clear cut decisions included those in an emergency situation or where the evidence for one treatment pathway was strong and the chance of success was high, the assumption being that patients wanted to live.

“I say look if you have appendicitis you are having your appendix out at 5 o’clock today. Whether you’re ready or not. Whether you’ve got meetings or other things on, we don’t really care. You’re having it out and the surgeon rolls her eyes at you if you think there’s anything to discuss or so ... Um, so there, there is no shared decision-making that thing. It’s very black and white type of thing.” (Medical oncologist)

“someone turning up with peritonitis, um and due to a ruptured appendix. I mean, they really only have two alternatives. They’re not very well ... to share in the decision, and there’s really not much sharing to be done. And ah, you know, so, so the sort of urgent intervention ... it’s fairly irrelevant.” (Breast surgeon)

“It depends on the disease so that if it’s a disease where I think there’s a, clearly the best therapy. ... I’ll probably even in some ways try to steer them against um sharing the decision because I would have made my mind up from the scientific evidence that is the best”.
(Haematologist)

Examples of grey decisions were; low grade lymphomas, which involved deciding between a watch and wait approach or treatment; in more aggressive lymphomas deciding between stem cell transplantation or chemotherapy, (one with a higher chance of cure and an associated greater risk of morbidity/mortality); deciding about adjuvant chemotherapy in breast cancer, where the actual survival benefit is small; or in colorectal cancer deciding between different chemotherapy regimens.

5.3.2 Existence of treatment options

Involving patients was considered important and more likely to happen where evidence for one treatment option compared to another was not conclusive. A key

indicator for involvement was described as options where survival is similar, such as the surgical options in early stage breast cancer, or in prostate cancer where contention surrounds the choice of surgical or radio-therapeutic intervention.

“So there are many decisions of the breast. Often, the fundamental one is O.K. we can do a, wide excision and radiotherapy ... or we can do a mastectomy. The results with many are pretty much equal in terms of survival ... there is a, there’s a choice between the deformity of the mastectomy, whilst avoiding 5 weeks of daily radiotherapy which knocks them about bit and it’s totally disruptive of their life. ... And in almost every breast is a, a multi-choice discussion and then very few is it cut and dried”. (Breast surgeon)

Existence of treatment options clearly featured highly although this was mitigated when patients' individual circumstances made some options inappropriate.

Treatments which were just as likely to result in death as they were to result in survival were not considered a real option, nor were treatments not based on evidence, or no treatment when treatment offered a significant advantage.

“It depends on the disease too you know. If it’s one where I think there are several options and very much needs the patient’s input into what’s right for them”. (Haematologist)

“Haematology’s a different kettle of fish ... say if someone has a, a diagnosis of acute leukaemia, their life expectancy without treatment is a month ... a haematologist would not be sort of very keen to um, muck around too much, like spend too much time in making people have a have a chance to consider all their options, because there aren’t very many.” (Medical oncologist)

Some doctors mentioned established protocols or guidelines for disease management and that these prohibited discussion about options, whereas scenarios which included clinical trials added to the number of options and the need for discussion.

“And I suspect that, that management of the lymphoma is more, is better than the management of the urology malignancy or the breast cancer, so you’ve got a more defined treatment path”. (Haematologist)

The notion of uncertainty in breast, prostate and lymphoma treatment was often contrasted with the situation in colorectal or gynaecological surgery where contention was ruled out. For example, the contention surrounding prostate cancer options was

described as forcing doctors to involve patients and this made doctors more comfortable using this approach.

“we’ve been thrust into it that’s why, we’re used to it. ... certainly in prostate I mean ah, it’s an area where we just don’t know what the right answer is, so you have to involve the patient. You’re fool if you don’t.” (Urologist)

However other issues clearly impacted on the doctors’ views that involvement was necessary.

5.3.3 *Impact of treatment on patient*

The impact of a treatment option on a patient’s life style and self-image was often mentioned as influencing the appropriateness of shared decision-making. The more impact a treatment had, the more likely shared decision-making was to be supported. For example, many doctors felt patients should be involved in decision-making about potentially mutilating surgery for gynaecological and breast cancer, and treatments for prostate cancer which impact on sexual function. In these contexts doctors overwhelmingly supported involving patients in decisions.

“I think that it’s a very personal thing for women when ... they’re having breast surgery and I think that they do need to be involved in

what's going on ... there are lots of different ways of managing breast cancer in particular, reconstruction ... then they do have to be involved in the, in the treatment options, choices, because it does impact so much on their ... self identity.” (Gynaecological oncologist)

“Sex. Yeah, ah so yes I'm being a bit provocative but I mean the impact of um, of, of taking off a breast is significant to a woman and therefore, for me to disfigure, if, if I were a breast surgeon, to disfigure somebody in that way I'd have to have the support of the patient. They have to say; yes I want my breast off I don't want to feel that I've imposed. And for a lot of prostate cancers and loss of sexual function, the impotence and things like that, and for me to take that away from somebody I think that probably I have to have them ask me to do it rather than me impose it on them ... that, crudely and maybe simplistically, [is] what I think it is.” (Urologist)

Issues of fertility were also included in this context. Some doctors clearly did not want to impose such decisions on their patients and found involving patients in these decisions beneficial.

“the advantage to us is that it's shares a bit of the burden because some of our treatment decisions involve taking away fertility ... to do

that ah to a young woman is ah you know, fairly disastrous on their lifestyle ... it's a big burden to carry without having them on board."

(Gynaecological oncologist)

5.3.4 Disease culture

Disease culture (the social, consumer and public profile of the disease)) was mentioned as influencing the appropriateness and likely use of shared decision-making. This was raised in regard to breast cancer particularly, but also for prostate cancer. In both cancers, it was felt that the existence of active consumer groups encouraged patients to be more educated about their disease and to play an active role in treatment decisions. Involving patients was described as patient driven in these cancers, influenced by the amount of information in the public arena about treatment options.

"I think the men with prostate have probably followed, less so than the breast, but have ... followed that lead ... empowering men, to have decision-making about their breast, about their prostate because there's so much literature and publicity on it." (Haematologist)

"Breast cancer I think was largely driven, there was probably more than any other cancer, there is an incredibly affective patient ah, ah, ah

patient focus and lobby group, telling doctors what they wanted, and I think the NBCC did a great job in that regard.” (Medical oncologist)

“I mean if you take the adjuvant 2%, most ladies will say no to chemotherapy and that’s a right answer and some will say yes, that’s a right answer. ... so I think in the type of stuff I do it’s ah, shared decision-making is, you know, I think we actually do it without even really thinking ... about it.” (Medical oncologist)

In contrast to breast and prostate cancer, patients diagnosed with leukaemia often knew nothing about the disease and had no or far-fetched expectations of outcomes or what treatments would entail.

“when someone gets leukaemia well they’ve often never heard of it or hardly heard of it and got all sorts of strange preconceptions and it’s such a foreign entity that they ... say, and doctor I don’t know nothing about leukaemia but you tell me what to do. Whereas with breast cancer women and with prostate they might say yeah, um I know a lot about this, it’s in the news...” (Haematologist)

5.3.5 *Stage of disease*

Some doctors suggested that shared decision-making was more appropriate, or more beneficial for the doctor-patient relationship, at different stages of the disease. For example, some doctors suggested that shared decision-making facilitated the difficult discussion of the changing goals of treatment when disease progression had occurred, and withdrawing anticancer treatment had become an issue.

“The second scenario I guess would be in advanced disease where often people have had a number of treatments, and so the chances of further treatments working is getting increasingly small ... the chance of just feeling worst because of side-effects is narrowing. ... the chances of benefit might be 10%, and chances of getting some side-effects are 30 – 40%. And, it’s your call as to whether you just want us to treat symptoms as opposed to give you a treatment that may improve the disease but probably won’t.” (Medical oncologist)

One doctor commented that discussion around alternative treatment options, while discouraged in early disease was more common in advanced disease, where evidence-based medicine had little to offer.

“there are other diseases like um; refractory acute leukaemia’s that there’s really very little I can do. And I’ll, I’ll even sometimes

encourage them to explore alternative health options.”

(Haematologist)

Indeed, a doctor's caseload, and the disease type and stages of the majority of his or her patients, were considered to often explain his or her approach to decision-making. The implication was that those doctors who work with patients whose prognosis is good will practice quite differently to those whose patients generally have a worse outcome.

“you might talk about people for whom minimal therapy will still end up with someone surviving decades. It's quite different to someone who spends their time looking after acute leukaemia, particularly advanced acute leukaemia” (Medical oncologist)

However, it was also noted that effective options for adjuvant and palliative chemotherapy in colorectal cancer have increased in recent years requiring more discussion and challenging perceptions that discussion is more suited to early stage or advanced stage or vice versa.

“before the options was really yes or no ... now with more options in the adjuvant setting and ... in the palliative setting it does require more discussion” (Medical oncologist)

5.4 Doctor characteristics.

Characteristics of doctors themselves were grouped into four subthemes: practice area culture; communication styles; doctor perceptions; and support for involvement.

5.4.1 *Practice area culture*

Practice area culture (the norms and expectations which surround individual specialties) was also thought to influence attitudes to shared decision-making. For example, different specialties were thought to have different approaches to the issue of how long to continue anti-cancer therapy in the context of a poor prognosis. The image of haematologists was described as “fairly gung-ho” (haematologist), but not based on a cavalier-type attitude but rather the belief that the next treatment might be effective, or that this time an initial response to therapy might be sustained. This approach was thought to lead haematologists away from shared decision-making.

In a somewhat stereotypical response, surgeons were described as perhaps less likely to support patient involvement because their skills lay in manual dexterity rather than communication. One participant noted this was particularly true of those surgeons who,

“...just chop everything ... they are operators, not really oncologists”

(Gynaecological oncologist)

Breast and gynaecological surgeons were often described as an exception to this rule, in part because of the multidisciplinary approach to breast cancer care and their female clientele. One doctor described the difference they saw between surgeons working in breast and gynaecology and those working in the colorectal field as follows:

“people who go into gynaecology are ... more physician like than surgeon like ... colorectal surgeons tend to be more authoritarian”

(Gynaecological oncologist)

Some doctors mentioned their awareness of the power of their own recommendation to influence patients' decisions and thus limit patient involvement. This was often raised in the context of discussing expertise bias (another example of practice culture). Expertise bias is defined as a clinician's preference for or stronger recommendation of a treatment or procedure which they commonly perform. Expertise bias was mentioned by some doctors as a strong influence on the recommendation or options they discuss with their patients. Some doctors stated that they make this clear to their patient, and some stated that perhaps this bias towards treatment or options they as practitioners felt more comfortable performing or administering was unconscious.

“you tend to discuss the things that you think are treatments you can offer, or treatments, that you think you’re good at, or you would be ... feel are appropriate. ... I suppose that’s almost an unconscious thing that you may not mention treatments that are outside your ... area of comfort.” (Colorectal surgeon)

“I guess I’m aware that you know I’m the surgeon and I’m aware that I am biased towards surgery as a treatment option. I think most people if they were honest would actually admit that they are probably biased towards the treatments that they use” (Urologist)

5.4.2 *Communication style*

Doctors talked about their own ability to communicate with patients and the effect certain strategies can have in developing an environment where open discussion can occur.

“it’s my ability to um communicate. ... You see, I tell some people too much because they don’t want to know, they, they get upset when I tell them everything, then other people ah, you can, you can never win, all you can do is your best.” (Colorectal surgeon)

“I’m a great believer in trying to get the patient up to speed with, with what we’re doing. And so I um, I tend to be I guess, a little brutal ah. Not brutal but, but I believe honesty is the best policy. ... Say for example I’ve got someone who’s got a, ah comes with a breast lump I try and get the empathy going early on. ... I usually say to a patient at some stage during their first or second interview ... that it must be pretty frightening coming to see a surgeon with a breast lump. ... Or with rectal bleeding or whatever it might be. ... I feel that openness ... and transparency gives us ah a good starting point to ah to then evaluate and to ah further investigations and also the discussion of treatment”. (Breast surgeon)

Communicating effectively to promote shared decision-making was described as challenging with some patients, particularly those who are passive.

“I guess that’s the skill of the consultation ... trying to work those people out ... whether you need to bring them back a couple of times, whether you need to get other people involved or whether they’re truly just passive and happy to leave you be. I mean at the bottom, the bottom line is that, again I’m confident with my advice, but I want to know how they’re going to react if it doesn’t go well. So if they’re gonna stay passive and ... accept the problems that are there, and keep going, well that’s fine, but if problems occur and they become

aggressive and, and blameful, well then um, I'm going to push them to be much more ah active. [Mmm, Mmm] Ah now, God only knows how you sort that out. ... I guess that's seat-of-your-pants stuff sometimes isn't it?" (Urologist)

5.4.3 Doctor perceptions

Many of the doctors alluded to their perception that ultimately cancer patients wanted treatment with the best chance of survival and that this mutual understanding overrode concerns about pushing patients to be more involved in any decision process.

"Now I must say most of these patients because they are malignant. ... most of them in our experience in gynaecology are not that keen to go away and give it a lot of thought. They want to plan and they want it dealt with. That's my impression." (Gynaecological oncologist)

"I'm assuming that they want to survive and live and that there's clear evidence with clinical trials, that this gives the best survival rate so I'm not too worried if they are so anxious they can't under, they can't make the, the appropriate decision.. Although, I've made a judgement that ... this is going to give them the best survival, based on the evidence"
(Haematologist)

5.4.4 *Support for involvement*

Some doctors spoke about their own belief and support for involving patients in decision-making. At one end of the spectrum, some doctors believed that not allowing patients to make a decision if there is a choice is a sign of arrogance, while at the other extreme, some felt that shared decision-making mostly resulted in patients making the wrong decision. Some doctors stated that they would always try to involve patients, that it was important to do so and that by doing so they could reduce patient anxiety. Although they acknowledged that involving patients is not always easy and requires skills in negotiating how much patients want to know and what role they want to play.

“I think most people have a view ... usually they express a preference for a particular course of action ... it’s reassuring that you’re embarking on a course ... they feel is appropriate for them” (Colorectal surgeon)

5.5 **Patient characteristics**

Doctors discussed eight key patient characteristics which influenced whether or not they involved patients in treatment decisions: anxiety; age; gender; cultural background; personality; occupation; understanding; and involvement preferences.

5.5.1 *Anxiety*

Many of the doctors mentioned patient anxiety as a key barrier to involving patients in decisions and to patients' understanding of the information they discuss in their consultations. Anxiety was described as preventing logical thought, recall, ability to prioritise and be objective, and ultimately to make the most appropriate decision.

*“a lot of my patients ... they've just been diagnosed with cancer ... taking in that one piece of information on its' own is difficult enough”
(Urologist)*

Some doctors talked about ways to manage this and that involving patients can in fact be helpful in reducing anxiety.

*“anxiety paralyses a lot of people but often if you engage in the decision process, sharing process that dissolves a lot of the anxiety”
(Urologist)*

“I guess some people may argue that it creates undue stress etc. I think that's probably being overly paternalistic, and I don't think patients are children, ... they need to be involved in their decision-making” (Medical oncologist)

5.5.2 *Age*

Many doctors mentioned age as a predictor of how much involvement patients would want in any decision-making. Older patients were often described as those who would ascribe to the “*whatever you reckon Doc*” (*Medical oncologist*) mantra. Younger patients were perceived to want more involvement particularly young female breast cancer patients, where the surgical options impact on appearance, self-image and may initiate concern of a partners’ reaction.

5.5.3 *Gender*

Gender appeared to override age in women with some doctors describing their older female patients as very assertive. As one medical oncologist noted,

“[...] they always tell me exactly what I can do with my chemotherapy or not” (Medical oncologist)

5.5.4 *Cultural background*

Patients’ culture often gave doctors a clue as to the amount of discussion they would want to have. Not telling some patients about their diagnosis due to the wishes of other family members was something which doctors found difficult and uncomfortable.

Older patients with a Mediterranean or Central/Eastern European background were often identified as a group who prefer the doctor to make decisions, either because they expect the doctor to tell them what to do, or due to their lack of confidence in their ability to speak English.

“the culture of certain countries does vary enormously from Australia. What they expect of doctors, how they behave to doctors, how much respect they have for doctors ... will involve how much involvement they want in the decision-making”. (Urologist)

5.5.5 *Personality and occupation*

A few doctors felt that personality features predicted involvement preferences. For example, patients with very little trust or those used to being in control were thought to prefer involvement, while those who lead busy professional lives or who have a medical background themselves were thought to be more likely to prefer non-involvement. One doctor noted that the latter will often tell their doctors to “shut-up” (colorectal surgeon) and just tell them what to do.

5.5.6 *Understanding*

Cognitive impairment and psychiatric illness were described as situations where patients were not able to make decisions and so were not offered involvement. Patients described as of lower intelligence or limited educational background

sometimes caused the doctors some angst, as involving them was deemed impossible, or even detrimental.

“I mean sometimes you’re worried even though you think you are using plain English they’re lost. I mean some people don’t know where their stomach is, I mean they’re really generally don’t know where it is and then they’re kind of embarrassed and it’s kind of like how can they?”
[make a decision] (Medical oncologist)

Whereas doctors ensured they involved patients identified as educated, intelligent and questioning.

“I would say more highly educated or more widely read people would prefer to be involved because they actually want to hear about – and often read a lot of stuff”. (Medical oncologist)

5.5.7 *Involvement preferences*

Most of the doctors alluded to the spectrum of involvement preferences they saw in their patients; those who wanted the doctor to make any decision, those who weren’t able to make decisions and those who came to the consultation armed with information and a plan.

“most people um are obviously as you would be aware. You have a set of people who say whatever you say doctor... another set who will um, ah very small subset who in cancer patients, who have their own plan. ... You have to sort of present to them the options, and then it’s up to them, and then the ones in the middle who are very reasonable and you explain why you think a course of action is the best and get them to come on board with it” (Gynaecological oncologist.)

Working out the role patients want to play was described by some doctors as easy and by others as less obvious.

“Some people will do that (make a decision) very easily. And some people never do it. And ah you know, some patients are very much more um dependent. And so you just got to pick the patient. ... and run with it.” (Breast surgeon)

“usually to be honest, usually patients will tell you what they want very quickly. They’ve already made decisions before they even come in to see you” (Medical oncologist)

“I think it’s a ... bit of mixture. It surprises you who says, I’ll just try on what you think I should do, and the people that say no, no, I need, I

*need all the information to make a decision. ... I don't think I can say
oh one group, I can't generalise that well with them I don't think"
(Medical oncologist)*

There was a general feeling that the patients who came with their own plan were in the minority however. Some doctors noted that despite patients being of the “I’m in your hands Doc” mentality, it was always possible to help them understand on some level. Doctors felt it was important that a certain amount of time was spent explaining what was happening and what would happen in terms of their illness and treatment to all patients regardless of their involvement preferences or their educational or comprehension ability.

*“I’ve got to explain it to you ... you may now or in the future want to
understand a little bit more ... I don’t want to upset you ... even if it was
your car, you’d ask me what was going on with it.” (Colorectal
surgeon)*

5.6 Society characteristics

Subthemes identified in doctors’ comments on the influence of society included, patient expectations of today’s healthcare, and the consumer and information driven society.

Some doctors described the expectations of patients in today's healthcare climate as necessitating involvement in decision-making. There was a general feeling that the days of paternalistic care are either long gone or certainly changing with the generations. Some doctors noted that involving patients was,

“the way things have to be these days” (Breast surgeon).

Another doctor noted that:

“it's the baby boomers who want control over everything” (Urologist)

Use of the term “consumers” was challenging for some doctors. Consumerist views were also thought to encourage 2nd and 3rd opinion seeking, as patients sought the answer they wanted to hear, rather than accepting a poor prognosis.

Others found it difficult when patients attended consultations having already identified available and preferred treatments (including alternative treatments) which may or may not be recommended, which prevents them from accepting any suggestion that their oncologist might make. This experience was described by doctors as,

“they just come with an agenda and that is extraordinarily frustrating”

(Breast surgeon)

“Well she didn’t embrace the treatment which was quite clear that it would help her, because ... she had swallowed some line about alternatives, and you know, so there, there you go” (Medical oncologist)

5.7 Subgroup differences

Despite our purposive sampling we found no consistent difference in opinions between doctors who reported different approaches to decision-making with their patients, or between doctors coming from different specialties. Tables 16 and 17 show the number of issues covered by participants by reported usual approach to decision-making and cancer specialty.

Table 16 Overview of themes vs. usual approach to decision-making

Themes	Usual decision-making approach			
	No. in each DM approach who mentioned theme			
	Doctor led n=7	Shared n=9	Patient led n=5	Other n=1
Disease characteristics				
• Decision context	5	7	2	1
• Existence of treatment options	7	9	4	1
• Impact of treatment	6	7	3	1
• Disease culture	6	7	4	1
• Stage of disease	6	4	3	1
Doctor characteristics				
• Practice area culture	6	7	3	1
• Communication style	2	4	4	1
• Dr perceptions	6	3	5	1
• Support for involvement	3	4	4	0
Patient characteristics				
• Anxiety & distress	6	6	3	1
• Age	5	5	4	0
• Gender	1	2	0	0
• Culture	4	4	4	1
• Personality	4	3	4	1
• Occupation	1	3	0	0
• Understanding	5	9	4	0
• Involvement preferences	5	7	4	0
Society characteristics				
• How healthcare is now - current expectations	3	3	1	0
• Information & consumer driven society	5	2	3	0
• Fear of litigation	0	1	0	0

Table 17 Overview of themes vs. tumour speciality

Themes	Tumour speciality				
	No. in each speciality who mentioned theme				
	Breast n=5	Colorectal n=5	Gynaecological n=4	Haematological n=4	Urological n=4
Disease characteristics					
• Decision context	5	4	3	2	1
• Existence of options	5	5	4	4	3
• Impact of treatment	5	3	3	4	2
• Disease culture	5	4	2	4	3
• Stage of disease	4	1	3	4	2
Doctor characteristics					
• Practice area culture	4	4	2	4	3
• Communication style	3	2	2	3	1
• Dr perceptions	3	3	3	3	3
• Support for involvement	4	6	2	4	3
Patient characteristics					
• Anxiety & distress	4	5	2	2	3
• Age	4	4	4	0	2
• Gender	2	0	1	0	0
• Culture	2	2	2	4	3
• Personality	4	1	3	1	3
• Occupation	0	2	1	1	0
• Understanding	5	5	3	2	3
• Involvement preferences	3	5	4	2	2
Society characteristics					
• How healthcare is now	3	1	0	0	3
• Information & consumer society	4	0	2	1	3
• Fear of litigation	0	0	0	1	0

5.8 DISCUSSION

This qualitative study of Australian cancer doctors sought to explain the differences found in the earlier study of clinician use of shared decision-making with their patients.

The existence of treatment options appeared to be the most influential factor over doctor support for involvement. Most doctors in our study commented that shared decision-making is most appropriate in situations of uncertainty or controversy, where there is no one right answer. These types of decision have been labelled preference-sensitive situations (Llewellyn-Thomas 2006). In contexts where clinical guidelines or protocols with a clear best option existed, they were less likely to involve patients. This finding reflects the views of Whitney et al (2004) where shared decision-making is considered appropriate in situations where two or more medically reasonable alternatives exist. Similarly, a qualitative study of academic and private primary care and surgical practice physicians in the United States found that situations with no clear best answer or with moral dimensions were considered particularly appropriate for increased or full patient decisional control while many of the physicians saw a reduced role for patients where there is only one reasonable medical choice (McGuire, McCullough et al. 2005). Llewellyn-Thomas (2006), noted that much of the research into both patient and doctor preferences has not made it clear to respondents whether they are answering the question in a preference sensitive situation or a clear-cut clinical scenario and this reduced the validity of the findings.

Many doctors saw the impact of treatment on lifestyle and self-image as an indicator for involving patients in decision-making, particularly when the treatment would affect gender defining qualities. This may go some way to explain the differences found in the earlier study, where doctors treating breast and urological cancer were much more likely to use a shared decision-making approach than those treating colorectal and haematological cancers (Shepherd, Tattersall et al. 2007). Studies of the decision-making preferences of breast cancer patients have identified body image as one of the major influencing factors on which patients base their decisions (McVea, Minier et al. 2001). Similarly for prostate cancer patients, the majority wanted to play an active role in any decision-making and rated information on sexuality as important (Davison, Gleave et al. 2002). The comments of doctors in this study's sample show that doctors are aware of and responsive to these concerns and allow patients to play a greater role when these situations occur.

The doctors in this sample did reflect prior findings in general practice and oncology that older people are less likely to want to be involved in decision-making either through their acceptance of the doctors' authority or unfamiliarity with the notion of involvement (Blanchard, Labrecque et al. 1988; Wetzels, Geest et al. 2004). However the discussion of whether or not to have chemotherapy for older female patients was reported to evoke an assertive negative response, rather than a passive accepting one, suggesting that age did not always indicate a preference for non-involvement. These comments reflect the findings of (Chouliara, Miller et al. 2004) that older people place equal importance on their quality of life when considering

whether or not to undergo cancer treatment. This example is illustrative of changing preferences patients have along their cancer journey and supports the need for doctors to reassess patients' preferences regularly.

In the quantitative study findings doctors' support for and practice of involving cancer patients in decision-making differed between cancer contexts (Shepherd, Tattersall et al. 2007). Explanations of these findings in this qualitative work lead to the hypotheses that three factors are responsible for the increased use of a shared decision-making approach by breast and prostate cancer doctors. First, for both these cancers multiple treatment options are considered to be clinically equivalent. Second, treatments for both these cancers impact on gender issues and require patients to accept potential changes to either their sexual function or their body image. Third, both cancers are supported by high profile consumer groups who, particularly for breast cancer have raised the profile and expectations of cancer patients and empowered them to be active in their care, and which have increased knowledge of the general public about the treatment options available.

Meeting the preferences of patients was described as a challenge by many of the doctors in our study, particularly in light of the range of their patients. Doctors saw the need to identify the different personality types, anxiety levels and levels of understanding of their patients and acknowledged that this guided them in their encouragement to involve patients in decisions. Some doctors mentioned that their communication strategies or perceptions were often instinctive and not always right.

These sentiments are supported in the literature by a number of studies which report a mismatch between patients reported preferences for shared decision-making and doctors' perceptions of patients preferences for shared decision-making (Bruera, Sweeney et al. 2001). It is these skills which may reduce the mismatch between patient involvement preferences and reported actual involvement often reported in both general practice and cancer consultations (Gattellari, Butow et al. 2001; Ford, Schofield et al. 2003).

Raised patient expectations for information and involvement and the increasingly consumer and information driven society were factors which all doctors acknowledged as increasing the involvement which patients expect in consultations and in treatment decisions. Explanations of information which patients have gathered from the internet or discussion to change a patient's mind necessitated more consultation time. However in a similar vein to identifying patient characteristics which encourage or discourage doctors to involve patients, shared decision-making was portrayed by some as a method to allay patient anxiety rather than increase it. The identification of patient and doctor characteristics by this sample of doctors showed their awareness that both parties have a role and an influence on the communication and involvement in cancer consultations. Patients who are more active influence their doctors to display more patient-centred or partnership behaviours (Street, Krupat et al. 2003).

5.9 CONCLUSION

Promoting shared decision-making as the optimum way of discussing treatment options with patients presents some challenges and contradictions for clinicians. Clearly in doctors' views there have to be treatment options available, which is why this approach is more likely to occur in these situations. Added to this the impact of patients' awareness of options increases the likelihood of doctors involving patients in decision-making. This is particularly true in breast cancer, where the consumer groups have motivated patients to take an active role in any treatment decisions. Prostate cancer appears to be a slightly different scenario, with the notion of controversy and uncertainty driving the doctors to acknowledge and encourage their patients to consider management options, which unlike in breast cancer surgery means referring their patients or informing their patients about an equivalent non-surgical option. What is common however for both these cancers is the impact of the treatments on the patients' self image, with the potential of sexual function impairment due to mechanical complications or disfigurement to gender defining organs.

Australian cancer doctors are aware of the demand for involvement in decision-making by cancer patients and comprehend a number of different factors which influence their consultation style with their patients. Clearly the clinical situation is of foremost importance, the patients' perceived wish to survive and the existence of treatment options and consequent possibility of real choice is fundamental. There are however other issues of which cancer doctors are aware; particularly the emotive

impact treatments may have, although the motivation to involve patients in these scenarios is unclear. It seems that patients can expect their cancer doctors to attend to their preferences in situations of uncertainty or where treatment will have a severe impact on them.

CHAPTER SIX

CRITICAL FEATURES OF INVOLVING PATIENTS IN DECISION-MAKING

6.1 Introduction

In the postal survey whose methods were described in Chapter Two, we identified the typical decision-making style of doctors, their comfort levels with different styles and key barriers which they encountered when attempting to share treatment decisions with their patients. These results are reported in Chapters Three and Four of this thesis and in the published manuscripts Shepherd et al (2007; 2008).

In the subsequent telephone interviews we conducted with Australian cancer doctors (for Methods, see Chapter Two) we sought to further explore these doctors' perceptions regarding the key features of involving patients in decision-making. Doctors described what they felt involving patients required and what attributes it brought to consultations and how they managed this process and the issues that influenced the content of their consultations. A number of questions specifically sought responses from the participants regarding this topic:

- *Can you tell me what you think are the most important features of involving patients in decision making?*

- *Some patients don't want shared decision-making. To what extent do you think patients vary in terms of their preferences for shared decision-making? Do you establish if your patients want to participate in decision making? How do you establish whether your patient wants shared decision-making?*
 - *In your experience what sorts of patients tend to like and dislike shared decision-making?*
 - *In what senses do you think patients like/dislike shared decision-making? Or are there particular aspects which patients like/dislike?*
 - *Would you ever encourage passive patients to participate or do you simply accept their passivity? How do you decide which patients to push a little? How would you go about encouraging them to shared decision-making?*

6.2 THEMES IDENTIFIED

Three main themes emerged from the data regarding what doctors felt to be the critical features of involving patients in decision-making. These themes were; the doctor-patient relationship; eliciting preferences; and information exchange.

6.3 Doctor-patient relationship

Under this theme, doctors talked about how a good doctor-patient relationship was essential to shared decision-making, and vice-versa. Aspects of the doctor-patient

relationship raised in this context included trust, honesty, clarity of roles and a sense of being part of the same team.

6.3.1 *Openness, trust and honesty*

Many of the doctors talked about developing an arena where open discussion was welcomed as a key feature of involving patients in decision-making. Having an open forum for many doctors engendered increased trust in them from their patients.

“I feel that openness, and transparency gives us ah a good starting point”

Trust was important to most doctors; with many stating that patients need to have confidence in their doctor and that a relationship built on trust then allowed both parties to be honest.

“I think personally they should also have confidence of the person with whom they are dealing, i.e. the doctor. has the expertise, has the credentials... to be able to guide them ah to a degree in what, what should be ah decided”. (Urologist)

“by getting a trusting relationship going at least the patient can speak to you honestly about their concerns. I think that’s, that’s where the advantage of the shared decision-making is. Is that the patient does have a concern that you may not have come up with then they are more likely to talk to you about it., than in a, a more dogmatic sort of approach”. (Surgeon)

6.3.2 *A partnership role*

Defining the role of the doctor in the relationship was important and a discussion where involvement and open discussion was supported allowed doctors to do this. Some doctors talked about their partnership with the patient, that they would accompany them on their cancer journey.

“I think particularly with chemotherapy, you take a patient by the hand and say I will take you in harms way. You know I think you will get through, there are risks but I’ll be with you through the journey.”
(Medical oncologist)

Shared decision-making and the relationship which then develops by using this approach was declared to be easier for doctors, illustrated by one participant,

“if you want to get their co-operation I guess it’s pretty important to have them on side isn’t it And it, it um, it makes life so much easier dealing with people if you’re open and honest with them, then, and you’ve got ah, an adult dialogue.” (Gynaecological oncologist)

Other doctors noted that it was the feeling of sharing decisions that was important, not how informed or expert the patient had become. In other words, the impact shared decision-making had on the doctor-patient relationship and the patient’s sense of being part of a team was more critical than informed consent. One doctor stated that;

“..shared decision-making is, is not to get that patient up to the same level as understanding as you. Shared decision-making is about making the patient feel that they shared the decision. Now whether they do that with a little bit of information or a lot of information doesn’t matter.” (Urologist)

Other methods doctors suggested for enhancing an open discussion and subsequent involvement included using empathy and self-disclosure, for example talking about cancer experiences within the doctor’s own family.

“my eldest sister died of rectal cancer at age 31... and my mother had colon cancer 5 years ago, I actually do quote that a lot ... because when I actually add that they then actually change and say oh he may actually have some idea he’s not this, just the technician.. So I’ve always noted it adds an extra dimension, and they almost tend to believe me a bit more... it’s incredible how when I mention that. They go oh, so you’re not just quoting from a textbook.” (Colorectal surgeon)

6.4 Eliciting preferences

Many doctors felt that eliciting and respecting patients’ preferences for decision-making was an essential component of shared decision-making. When discussing identifying patient preferences for information and involvement doctors talked about four subthemes; identifying involvement preferences, skills and strategies to elicit treatment preferences; respecting preferences; and understanding preferences.

6.4.1 Identifying preferences

Knowing what level of involvement or information patients wanted was thought to be a critical part of shared decision-making by many of the doctors.

“I mean you have to gauge what the person, the patient wants. Or, or is capable of taking I think” (Haematologist)

“we do make judgements about people all the time ... you make decision that there’s a seriously intelligent, questioning person ... sitting across the table. ... With those women I make absolutely certain I involve them in everything.” (Gynaecological oncologist)

Some doctors talked about it being easy to tell what level of involvement a patient would want, either because of their own inherent skill;

“I think you just get a feel for it.” (Gynaecological oncologist)

*“you get a feeling when people hit the door that they are inquiring. They often come with a lot of information, they often tell you at the start, they’ve read all about it. Or they come with extreme anxiety and those people need actually to have much more information.”
(Gynaecological oncologist)*

Or because patients tell them what they want;

“Oh oh that’s easy. I mean, you know, usually they tell you beforehand. Or often people come in and say you know I’ve only come

to see you because my Doctor made me come or my daughter forced me and I'm just letting you know that I've had this done before and I don't want to have it again. ...Some people are very upfront."

(Colorectal surgeon)

Some doctors noted that as they got to know their patients they picked up cues regarding how much involvement or information they would want to have.

"So I think it often is apparent just as you're talking to people what, which type of personality I suppose, or what background, they bring and then when you talk, when you start talking to them about specifics. I don't think it's hard to tell people. People usually make it pretty apparent if they're interested in participating or not." (Colorectal surgeon)

"I through the, you know, interview and you know history taking, I try to work out how the woman feels about the whole thing. You know, and you will have different and every woman will be different." (Breast surgeon)

In contrast doctors mentioned those times when they find it impossible to tell what role their patients want to play;

“God only knows how you sort that out. I can tell ya but... that’s seat-of-your-pants stuff sometimes isn’t it?” (Urologist)

“..there will be some patients where, you know occasionally where you know you couldn’t predict what they actually. You know what, they, they’re just unreadable patients. You know, whatever you say it just they raise their eyebrows and you think oh God I’m not winning here at all.” (Breast surgeon)

6.4.2 Skills and strategies to elicit treatment preferences

Some doctors talked about specific language skills they used to help patients express preferences. These included use of the 3rd person to suggest how patients might feel about one option or another, using open questions to encourage patients to respond freely, or repeating pros and cons back to patients once they have been expressed.

Several doctors talked about the value of the patients being accompanied by a loved one in the consultation; that this helped patients feel more at ease with the situation, helped them to understand better the decision and treatment options but also allowed the doctor to make it clear that the patient’s voice needs to be heard. Some doctors also noted that decisions are rarely made just between the patient and doctor, particularly for patients with a spouse.

“I guess my observation is often it’s the partner and the patient that have made the decision, rather than just the patient.” (Urologist)

Other doctors mentioned the wider health team, General Practitioners, nurses, other specialists, as all having a role in treatment decisions.

Doctors’ awareness of patients’ reactions to information was mentioned by some doctors. Noting body language and responses to information gave good cues about where a patient might sit on the involvement spectrum; this skill was something which experience brought.

“at the end of the day it comes down to a savvy operator, some savvy consultant. And that’s the difference between when I was 30 and now that I’m 50.” (Urologist)

6.4.3 *Respecting preferences*

Most doctors felt that it was important to respect a patient’s preferences for involvement, even if this did not accord with the doctor’s own views. For example, most doctors said they would respect a patient’s wish to play a passive role. Reasons included not wanting to raise anxiety of those already anxious, and discomfort with forcing their own ideas on patients. It seemed for some that forcing more involvement on patients than they wanted was similar to paternalism.

“I think you have to [accept a patient’s passivity] because again you’re forcing your ideas on somebody else aren’t you?” (Gynaecological oncologist)

“I mean you must have come across these patients. It’s up to you doctor, whatever you reckon recommend. They do not wish to know, they want you to get on with it and make them better. And I think, you know, we, we have to. I think, I, I, I have no problem with that actually.” (Gynaecological oncologist.)

“I guess really you have to be ah aware that not all patients are going to react in the same way. ... so you really need to let them decide how much they want to do. And I think that really is the bottom line, forcing your ideas down somebody’s throat, um are the perfect way to end up um ah with poor satisfaction for both sides.” (Gynaecological oncologist)

One doctor acknowledged he was happy to go ahead with treatment even if the patient had not taken in much information, justifying this action by his own expertise and altruistic intent;

“to me it’s a journey. ..., I’ve got no problems starting people on essential therapy if they don’t know anything. As long as I know in my heart-of-hearts it’s the right thing for them”. (Medical oncologist)

Other doctors found it difficult to act in accordance with patient preferences, particularly for passivity. Some doctors felt shared decision-making helped them feel that their patients really understood the risks and benefits which certain treatment options presented, and that knowing that patients fully understood these helped the doctor to accept the option the patient wished to pursue. Such doctors were quite discomfited when patients preferred a passive role,

“occasionally a patient will say to me. You do whatever you think is best. And, and in some ways that’s, that’s then a difficult situation because I usually like them to be involved.” (Urologist)

6.4.4 *Understanding preferences*

Some doctors mentioned it was important to be aware of what was behind patients' preferences. This was particularly true for patients who stated they just wanted the doctor to get on with treatment, which was felt often to be based on fear of treatment or death, or previous experience with cancer, particularly having cared for a loved one, or just that patients weren't familiar with a participatory style. Addressing these

issues allowed patients to play a greater role. As one doctor said about patients who say they don't want to know anything,

"I say well yeah hang on that's fine. You know, look if you really don't want to know, I'll look after you which ever way you want to do this, but you know, what it is you're frightened to know. And you know if you sit back and relax and ask that question. It usually comes out that they, and usually it's fear of dying, chemotherapy complications they nursed their husband who had a terrible experience. There's something in that." (Medical oncologist)

Some doctors noted that understanding patient's priorities helps explain their preferences.

"we can't judge for a person what may be important to them, that they may rather keep their hair and risk a couple of percent. ... And we can't make a decision for them as to what their priorities are ... the person who's having the treatment...knows their priorities better than anybody else." (Medical oncologist)

6.5 Information exchange

The third important component of shared decision-making raised by doctors was information giving. This was divided into two main subthemes: discussing information with patients; and presenting options to patients.

6.5.1 *Discussing information*

Doctors raised four issues under this subtheme: the critical role information played in preparing patients for shared decision-making, the legal requirement embodied in the concept of informed consent for information giving, the external factors which enforce information exchange during medical consultations and the importance of distinguishing information giving and actual decision-making.

6.5.1.1 *Provision of information* was considered fundamental to any notion of involving patients. Many of the doctors talked about their first goal being to transfer information and knowledge about the patient's diagnosis and treatment options.

"basically they need to have enough knowledge to make a decision."

(Gynaecological oncologist)

"I think the single most important thing is providing them with adequate information" (Urologist.)

“I think that it is important...because I think for involvement you know they understand better the, the disease process and what’s happening.”
(Breast surgeon)

Doctors talked about ways in which they tried to ensure that they increased the likelihood of patients’ understanding the medical terminology.

“I think when you first see them you have got to ask them what they really understand is going on.” (Gynaecological oncologist)

Some doctors noted that when patients understood information shared decision-making became easier.

“I find ... once the patient has sat down and gone through the information. You can actually come up with a shared decision”
(Urologist)

6.5.1.2 *Informed consent and medico-legal issues* were mentioned by some doctors, with patient involvement in decision-making assisting doctors to meet legal requirements.

“We... have to lay the options out in front of them. It’s a legal requirement, apart from anything else.” (Breast surgeon)

Not providing information to patients was seen as negligence, morally, ethically and legally.

“People need to be aware of all of their options so that they can make an informed decision, and if you just give them one really you, morally, ethically and medico/legally you, you haven’t done the job you are meant to be doing.” (Urologist)

6.5.1.3 Many doctors talked about *external factors* which enforced information exchange in consultations. Because information is much more available on the web and through the media, patients were often misinformed, and this required correction. The Internet was mentioned by many doctors, with some portraying it negatively and some positively. The negative sides included the confusion it may bring and the necessity then to spend time explaining why certain treatments are not appropriate.

“And the other thing is you are, I sometimes find that patients log on to the internet, look up I guess prostate cancer in particular find there are 10,000 sites. And you get patients coming in with basically A4

binders full of information. Totally confused as to what they should be doing.” (Urologist)

“They do a quick scan of the Web or a couple of mates or, or they glean some sort of information, and it maybe um about a context, it may be inapplicable to their particular situation, and they think they have become an authority, because the world is ah perpetuating this view that if you want to find out anything. Well you can find that information and, and you know, sort of be in control of your own destiny.” (Urologist)

Some doctors also talked about the media, TV personalities and the fact that patients talk to each other, and that being armed with information prior to consultations has a similar effect as arriving with reams of paper from the internet.

“People very, people are very resourceful. They find out information. They speak to people. They search the net. They you know, ring Chat shows. They find out information anyway. I think they should hear if from us” (Medical oncologist)

So, so ah we're pretty realistic about that [patients talk to each other] and answering questions about why they got this and I didn't." (Medical oncologist)

6.5.1.4 Some doctors noted that there is an important *distinction between information exchange and actual decision-making*. Some felt that the former was more critical to shared decision-making than the latter, while others felt that information giving alone was not enough.

"I think, well. The, the most important aspect is ah to ensure that the patient has adequate information to participate in the discussion but not feel that they need to make a, ah life and death decision at any point." (Medical oncologist)

"[the patients] quickly say well I don't want to talk about [the options], you do, I wouldn't call that shared decision-making...their decision is to leave it to me and take my preferred option, you know, I'm penning my preferred option, so there's still a sharing of information but not decision" (Breast surgeon)

6.5.2 *Discussing options*

The idea of options available to cancer patients and how to discuss this featured frequently in the data we collected. Discussing options was seen as a vital part of shared decision-making and the doctors' skills in doing so, critical also. On the other hand doctors discussed scenarios where they felt that open disclosure of all options was detrimental to patient well-being. Others felt it was important to reassure patients that while making them aware of different options the doctor would also make a clear recommendation to guide their thinking.

6.5.2.1 *Presenting the idea of options*

Doctors felt that when treatment options existed, it was important to inform patients of them and involve them in decision-making.

“I think in oncology especially there are lots of um options to patients...and there may be two, three, four right answers of what to do....so I think for treatment options in oncology. It's ah, it's very important that the patient is involved.” (Medical oncologist)

6.5.2.2 *Strategies for presenting options*

How doctors presented this idea to patients was explained by one doctor in the following way;

“..then we get to the point of you know, options for care. And what’s, what’s available and at that point I usually tell them that there are two or three options for [their] management. You can do nothing, you can have this, you can have this, this and that. And these are the relative advantages and disadvantages and then discuss it with them, you know, what do you feel about that?” (Gynaecological oncologist)

Some doctors talked about language strategies useful in presenting the idea of options to patients, such as giving patients examples of why some people might opt for one choice over another.

“I present um, the options. And I usually give them um my opinion. And where I think you know, there are, you know there are two ways around it, I, I tell them that. Stating you know, I think this could be approached ah via A or B...and the way I put it to them is um. Some people in your situation ah will be so against surgery that they will go - opt for A, and some of them will be so scared of a second cancer or

recurrence, so they will opt for B for treatment.” (Gynaecological oncologist)

Some doctors were keen to communicate to their patients that they understood they had come to see them for an opinion, and that whilst they would present options to them they would also make a recommendation.

“I do actually say to patients look you’ve come here for my opinion. There are alternatives here, I will tell you my opinion if I can. If it’s a really grey area I’ll let you know that and we’ll decide that together. But I find most patients accept that. I don’t accept the modern idea that...you try, like I don’t turn my patients into a haematologist ... in a 1 hour initial consultation.” (Medical oncologist)

“I’ll say look there isn’t a right way to manage this. These are the options. What do you think? And if they say I really don’t know. I’ll say well my suggestion would be.” (Breast surgeon)

6.5.2.3 Reasons for NOT presenting options

Doctors noted that there were a range of scenarios where they did not always disclose all treatment options.

The issue of whether or not to mention *expensive or unfunded drugs* was often raised in this context, with varying views expressed. Some doctors stated this was not an issue in their field of practice as all recommended or standard treatments were available to all patients.

“I guess the other question is where a treatment isn’t funded. I mean if, if, if you can’t get the treatment because it’s not available then it’s not a treatment option ... You can’t say, you know well this might work but we can’t get it.” (Medical oncologist)

“I think that’s in, very inappropriate...not to, not to give the patient all options. And I think we’ve had a very good example of that recently with Herceptin, a very expensive drug. ... I felt very strongly that we should discuss that with the patient whether they can afford it or not. In fact I, I think it, in my mind you are being negligent because [you are] assuming that that particular patient can’t afford it.” (Medical oncologist)

Some doctors talked about reasons other than expense for not disclosing all options to patients. These included treatments which the doctor believed would not work – and which they therefore did not feel were real options.

“I don’t go and talk about experimental treatment available in America ... subject to tests through experiment. I mean that’s not the go, but if they say to me look what about this? I’ll say well it’s not recommended in your cancer full stop.” (Gynaecological oncologist)

“I think it is completely appropriate not to disclose an unrealistic treatment option.” (Medical oncologist)

Some doctors also talked about needing to talk about some options in order to dismiss them, as patients had expected to be told about a particular course of treatment and were surprised or confused when the doctor didn’t offer it to them. One doctor described explaining why surgical treatment for an 83yr old with prostate cancer was not appropriate,

“surgery is one option for select patients but you’re not one of those select patients buddy. Um, and so you can, you can mention to dismiss it. There are circumstances where you know, ah an option is not appropriate. And it will either not be mentioned or mentioned to dismiss it.” (Urologist)

6.6 FREQUENCY OF THEMES

While frequencies in qualitative studies cannot be interpreted in the usual quantitative sense, they can give an indication of majority and minority views and suggest possible group differences. The frequency with which different themes were raised by participants according to their reported usual decision-making approach is shown in Table 18 and by speciality in Table 19. Irrespective of usual approach to decision-making, most doctors commented on patient understanding and information provision as key features of involving patients in decision-making. The issue of external influences and the dilemma of disclosing expensive options were raised by the more paternalistic and sharing doctors. All the doctors who had previously reported using shared decision-making as their usual approach gave a type of definition of what patient involvement meant for them.

Some differences were noticeable when looking at the spread of issues according to cancer specialty. The issue of expensive drugs was expanded on by doctors treating breast or haematological cancer, probably reflective in breast cancer of recent controversies in breast cancer related to the funding of Herceptin for patients.

Table 18 Overview of themes vs. usual approach to decision-making

Themes	Usual decision-making approach			
	No. in each DM approach who mentioned theme			
	Doctor led	Shared	Patient led	Other
	n=7	n=9	n=5	n=1
Doctor/Patient relationship				
• Openness, trust and honesty	2	2	1	0
• Partnership role	2	3	2	0
Eliciting preferences				
• Respecting preferences	4	5	3	0
• Understanding preferences	3	4	1	1
• Skills & strategies to elicit preferences	7	8	4	1
• Identifying preferences	5	6	4	1
Information				
• Information provision	7	9	4	1
• Informed consent & legal issues	3	4	1	0
• External influences	5	6	2	1
• Information provisions vs. DM	5	4	2	0
Presenting options				
• Presenting idea of options	7	9	4	1
• Strategies for presenting options	7	8	4	0
• Not disclosing options	6	7	5	0
• Expensive drugs	6	5	3	1

Table 19 Overview of themes vs. tumour speciality

Themes	Tumour speciality				
	No. in each speciality who mentioned theme				
	Breast n=5	Colorectal n=5	Gynaecological n=4	Haematological n=4	Urological n=4
Doctor/Patient relationship					
• Openness, trust & honesty	2	3	0	0	0
• Partnership role	1	2	1	1	2
Eliciting preferences					
• Respecting preferences	2	2	3	2	3
• Understanding preferences	1	3	1	4	0
• Skills & strategies	5	4	3	4	4
• Identifying preferences	3	4	4	2	3
Information					
• Information provision	5	5	3	4	4
• Informed consent/law	3	1	2	1	1
• External influences	1	4	3	3	3
• Information vs. DM	4	2	1	3	1
Presenting options					
• Presenting idea of options	5	5	4	4	3
• Strategies	5	5	3	2	4
• Not disclosing options	4	4	4	3	3
• Expensive drugs	4	3	2	4	2

6.7 DISCUSSION

The data collected in the interviews elicited some information about features doctors felt were critical to involving patients in reaching treatment decisions. Participants discussed three critical components of shared decision-making the doctor-patient relationship; eliciting preferences; discussing information.

For many it was difficult to separate the idea of the doctor-patient relationship from shared decision-making. In their explanation of what was important to involving

patients in decision-making doctors stated that patients being involved in a decision and an open transparent relationship are co-dependent. Models of shared decision-making also place importance on communication between health professional and patients (Charles, Gafni et al. 1997; Siminoff and Step 2005). Qualities of a good doctor-patient relationship have been identified elsewhere and include elements of good manners, and courtesy, establishment of mutual trust, empathy, openness, transparency and honesty. Many of the themes common to the literature arose in our data.

A review of information giving and decision-making in advanced cancer patients also concluded that involving patients in decisions was helpful to the doctor-patient relationship (Gaston and Mitchell 2005). This two-way process suggests that it may be important to address both shared decision-making and general communication skills in programs designed to improve doctors' skills in this arena. Focusing on one without the other may inhibit change.

The components of shared decision-making identified in this study mirror theories of shared decision-making and empirical data from other studies. Models of shared decision-making generally include five core components: partnership; information exchange; eliciting preferences; negotiation and agreement; and future planning (Charles, Gafni et al. 1999; Siminoff and Step 2005; Makoul and Clayman 2006; Montori, Gafni et al. 2006). Table 20 compares the themes which our interviews

elicited with core components in models of shared decision-making current in the literature.

Table 20 Aspects of the SDM models which doctors discussed

Charles et al (1999)	Mentioned by Aus doctors
Two people at least are involved in the decision making process	Yes
Both patient and doctor take part in the treatment decision making	Yes
There is a two-way flow of information between the clinician and the patient	Yes
A treatment decision is made when both the clinician and the patient agree on the most appropriate treatment.	Yes
Makoul and Clayman (2006)	
Define explain problem	Yes
Present options	Yes
Discuss pros /cons (benefits/risks/costs)	Yes
Patient values/preferences	Yes
Discuss patient ability/self-efficacy	Yes
Doctor knowledge/recommendations	Yes
Check/clarify understanding	Yes
Make or explicitly defer decision	Yes
Arrange follow-up	Yes
	Yes
Ratzen (1996) Conflict resolutions shared negotiation model	
Communication	
• identify interests	Yes
• establish an agenda	Yes
• listen and understand other side	Yes
Options	
• brainstorm	
• dialogue	Yes
• strengthen opportunities	
Alternatives	
• know your best alternatives,	Yes
• explore competitive realistic ideas,	Yes
• inform parties of various alternatives	Yes
Standards	
• locate and share objective criteria	Yes
Trust	
• be honest and open,	Yes
• develop a compliance-prone agreement	Yes
• build relationships	Yes
Siminoff and Step (2005) Communication Model of Shared decision-making	
Patient-Physician Communication Antecedents	
• socio-demographic characteristics	Yes
• personality	Yes
• communication competence	Yes
Communication Climate	
• Information and decision preferences	Yes
• Disease severity	Yes
• Emotional state	Yes
• Role expectations	Yes
• Treatment decision	Yes

These concepts also mirror some commonly used measures of decisional adequacy and difficulty, such as the Decisional Conflict Scale (O'Connor 1995). This measure includes subscales which cover information, uncertainty, values clarity, support and effective decision. It is perhaps fair to suggest that these subscales do reflect the issues (doctor-patient relationship; eliciting preferences; information giving; and involving patients), which doctors identified as critical to the decision-making process. The uncertainty subscale touches on issues which concern doctors of overburdening patients with difficult decisions, the values clarity subscale teases out whether preferences have been explored and communicated, the support and information subscales reflect the importance placed on the quality of information that patients receive and the support patients receive both from their significant others and from the professional support they receive. The final subscale is the only one which does veer from the critical elements identified in the interviews, in that the wording implies that the patient makes the choice or decision, a view which most of the doctors felt was not vital to the notion of involving patients in treatment decisions. Perhaps these similarities may warrant the use of this scale as a measure of whether a patient has experienced a shared decision-making consultation in which they have been involved, rather than using measures designed to identify preferences, such as The Cassileth Information Styles Questionnaire (Strull, Lo et al. 1984), to measure the role the doctor or the patient played in the actual decision.

Doctors in our study suggested that these consultation skills come with experience. Competencies have been proposed by Towle and Godolphin (1999) and Elwyn,

Edwards et al (2000) and Table 21 shows whether or not these competencies were discussed in the Australian data (see Table 21).

Table 21 Competencies for shared decision-making

Towle and Godolphin (1999)	Discussed by Australian cancer doctors
establishing a partnership,	Yes
eliciting preferences for information and involvement,	Yes
acknowledging and responding to patient's views,	Yes
outlining choices	Yes
providing the research evidence to support or refute these	
discussion of possible outcomes, good and bad,	Yes
decision negotiation	Yes
further planning	Yes
Elwyn, Edwards et al (2000)	Discussed by Australian cancer doctors
Implicit or explicit involvement of patients in decision-making process	Yes
Explore ideas, fears and expectations of the problem and possible treatments	Yes
Portrayal of clinical equipoise	Some
Identify preferred format	
Provide tailor made information	Yes
Checking process <ul style="list-style-type: none"> ▪ understanding of information and reactions ▪ acceptance of process and decision making role preference ▪ involving patients to the extent they desire 	Yes Yes Yes
Make, discuss or defer decisions	Yes
Arrange follow-up	Yes

Whilst most of these were covered by doctors in the interviews, difficulties with them were noted. A qualitative study of General Practitioners, hospital doctors, academics and lay persons to explore their views of the key components of an evidence-based

patient choice consultation identified six key themes : establishing the nature of the problem; the doctor-patient relationship; the decision-making process; time issues; research evidence; and patient perspectives (Ford, Schofield et al. 2003). The three main themes which emerged from Australian cancer doctors (the doctor-patient relationship; eliciting preferences; information provision) reflect these earlier findings. Ford's study also listed consultation skills which doctors require for evidence-based shared decision-making. Skills which were reported as the most difficult were, explaining complex information, keeping up to date with the latest evidence and according to the lay people in the sample, doctors' ability to listen and not talk over patients.

Establishing and identifying patient preferences was a feature which most doctors identified as integral to facilitating patient involvement. Models of shared decision-making include this as a core component (Charles, Gafni et al. 1997) and doctors surveyed in other studies have also identified this as a key feature of shared decision-making. Over 93% of oncologists and surgeons in Charles et al study reported that they believed it to be very or extremely important for patients to communicate what issues were important to them for a shared approach to be evident (Charles, Whelan et al. 2003). Bruera et al 2002 concluded that doctors' understanding of patients' preferences has a positive effect on communication and outcomes such as patient satisfaction with treatment decisions.

Our data shows that doctors sometimes find it difficult to identify the roles patients may wish to play. This is reflected in studies which report discrepancies between the roles doctors perceive patients want and the roles patients report they prefer. Other studies report wide discrepancies between doctors' perceptions of what treatments patients would choose and the treatments patients report they would choose, suggesting that treatment preferences are also difficult for health professionals to identify.

Doctors placed value on knowing patient preferences; however there is scant evidence of how doctors elicit this information. In this study, many doctors saw this as an innate skill, while others suggested that these consultation skills come with experience. Some doctors felt that patients gave cues which doctors could perhaps be taught to recognise. This may be a fruitful component of communication skills training programs in this area.

Information exchange and understanding is vital to patient involvement. Many doctors asserted that they aimed to assist patients to understand their situation and that without this, involvement in any decision was difficult. Additionally the consensus that information exchange is vital may reflect wide acceptance of the principle of informed consent, and legal rulings in recent years determining a minimum standard in information provision for patients prior to consent.

In discussions of involvement and decision-making, sharing information was clearly thought of as involvement on some level. This reflects the findings of the Canadian survey where approximately one third of participants identified an example of decision-making which included information sharing only, as a shared decision-making approach (Charles, Whelan et al. 2003). Doctors often seemed to see shared decision-making as a process, rather than an outcome. Having both parties feel they were sharing information, views and preferences was the critical issue, the actual decision, or outcome, was not. This is also in accordance with studies of patient preferences which often report a high proportion of patients desiring maximum information but a much lower proportion of patients desiring active involvement in decision-making (Strull, Lo et al. 1984; Ende, Kazis et al. 1989; Degner, Kristjanson et al. 1997; Vick and Scott 1998). Whether patients need to be actually involved in decision-making for shared decision-making to be said to have occurred remains a contentious issue and one which should be explored further in future research.

Doctors also identified explicit discussion of treatment options as an important component of shared decision-making. However, doctors also commonly spoke of situations where disclosure of options might not be appropriate. As reported in the previous chapter, the existence of treatment options is an incentive for doctors to involve patients in reaching a treatment decisions. This issue is further explored in this chapter as doctors commented on what constitutes a realistic option. Most doctors felt that not disclosing unrealistic options was justified, especially those treatments whose efficacy has not been proved. Additionally many doctors pointed

out that whilst on the surface a number of options may seem appropriate, individual patient circumstances dictate those options that are realistic and that the doctors would recommend in a given situation. This view somewhat endorses the status of doctors as the experts, that patients seek medical advice and a treatment recommendation, and justifies occasions when doctors do not disclose all options. Further it could be commented that doctors are responding to the preferences of patients, for information but not necessarily control of decision-making. However not all doctors expressed this view with others raising the ethical dilemma of not disclosing options, regardless of their effectiveness, or their expense. These doctors suggested it was not their role to determine which options their patients should be told, that patients should have the right to decide whether or not they wanted to pay for an expensive treatment. This view was supported by doctors who suggest that patients find out about options anyway, either through talking to other patients or via the media and the Internet. Patients' views about disclosure of expensive treatment options are unclear and research into this issue may assist doctors in deciding whether disclosure or not is the best option. Doctors' views of when to disclose expensive options have not been extensively sought, although one study from the Netherlands reported that doctors would continue treating individual patients with a treatment they considered expensive when the average probability of success was less than 12% (Wouters, Timmermans et al. 1997). Other studies have shown that doctors often do not predict which treatment patients would opt for, placing more emphasis on survival than other consequences of treatment (Solomon, Pager et al. 2003), or poorly

predicting patients' views on their wish to receive cardio-pulmonary resuscitation (Covinsky, Fuller et al. 2000).

Shared decision-making suggests that patients should be made aware of all options, yet clearly doctors perceive options differently in different contexts, endorsing the views of Whitney (2003). Doctors' motivations for disclosing options are equally diverse. Judging whether a patient has experienced shared decision-making is difficult in light of these conflicting views.

Interestingly, very few communication skills training programs have been reported which target both specific and general skills. A number of successful programs have been developed and evaluated which target generic skills in eliciting and responding to patient emotions and concerns (Razavi, Merckaert et al. 2003). Others have reported positive results from training programs designed specifically to improve shared decision-making (Elwyn, Edwards et al. 2004). Outcomes measured in these studies tend to reflect the focus of the training. It is still to be demonstrated whether targeting both specific and general skills results in much better patient and doctor outcomes.

Training programs have been developed and evaluated to develop doctors communication skills and improvements were noted; however sustained improvement beyond three months has only been reported in one study (Fallowfield, Jenkins et al.

2003). Given that many doctors discussed the difficulty of implementing shared decision-making, it is interesting that support for interventions such as decision aids, which are designed to assist patients to be more involved or more active in consultations and decisions (O'Connor, Drake et al. 1999), are not better supported by the medical profession. Support and use of these interventions was found to be limited in the survey reported in stage one of this thesis (Shepherd, Tattersall et al. 2008).

In discussions of involvement and decision-making, sharing information was clearly thought of as involvement on some level. This reflects the findings of the Canadian survey where approximately one third of participants identified an information sharing example of decision-making, which included information sharing only, as a shared decision-making approach (Charles, Whelan et al. 2003). Studies which report patients' experiences of treatment decision-making report recollection of who made the decision. Yet doctors appear to interpret information sharing as involvement, perhaps because for patients other than breast or prostate cancer patients, they are attending to the needs of patients which are generally reported to be high for information but less demanding for a major role in decision-making. Additionally the consensus that information exchange is vital may reflect the issue of informed consent and legal rulings in recent years concerning how much information patients need to be told prior to consent.

6.8 CONCLUSION

According to the cancer doctors in this study involving patients in treatment decisions requires the development of a good relationship, the sharing of information and the eliciting of patients preferences, in line with models of shared decision-making. These findings show that doctors are aware of these core components and give some insights into how doctors go about achieving these when discussing treatment decisions. While specific strategies were presented by doctors, many had difficulty articulating exactly what they did, feeling that it was an innate skill, or somehow intuitive. This presents a challenge to those proposing to develop effective training programs in shared decision-making. Discussion of options was more controversial as a component of shared decision-making, and more research is required to determine how critical this is.

CHAPTER SEVEN

CONSEQUENCES OF INVOLVING PATIENTS IN DECISION- MAKING

7.1 Introduction

In the postal survey whose methods were described in Chapter Two, key barriers were identified which cancer doctors encountered when attempting to share treatment decisions with their patients. These barriers are reported in chapter Four of this thesis and in the published manuscript (Shepherd, Tattersall et al. 2008).

In the subsequent telephone interviews with Australian cancer doctors (for Methods, see Chapter Two) these doctors' perceptions regarding the consequences of involving patients in decision-making were further explored. A number of questions specifically explored this topic:

- *What do you think about involving patients in making treatment decisions*
 - *What about it is good or bad for you?*
 - *What about it is good or bad for the health system as a whole?*
 - *What about it is good or bad for the patient?*
- *In your experience does shared decision-making take up extra time? Does it ever save time down the track?*

- *Shared decision-making involves sharing responsibility for the decision as well as information about the options and consequences of these. Is this difficult?*
 - *For you? How?*
 - *For the patient? How?*

- *How, if at all do you think shared decision-making impacts on your own and the patient's responsibility for the decision? Does shared decision-making shift the ultimate decision responsibility? How easy or difficult is this for you and for the patient?*

7.2 Themes identified

Four main themes were identified from the data: effects on decision responsibility; effects on doctors; effects on patients; and effects on the health system. We also gathered some information from doctors on strategies they employed to involve patients in decision-making.

7.3 Effects on decision responsibility

During the interviews doctors discussed the impact of involving patients in decision-making on who accepted responsibility for the decision made. Doctors gave us instances where they felt that the patient took on the responsibility, where the responsibility was shared or where the responsibility remained with the doctor.

7.3.1 *Patients take on the responsibility.*

A patient who has all the information was considered by some doctors to be responsible for the treatment decision.

“you know a fully informed patient makes their own decision, as it should be I think, and if it’s their decision, my responsibility is to give them correct advice, to ensure they understand it. The decision is their responsibility. I am happier with that than the passive patient.”

(Breast surgeon)

Patient responsibility was considered particularly appropriate under three conditions; for grey decisions where no one right treatment path is obvious; when patients choose a path contrary to their doctor’s recommendation; and when the patient has time to fully consider the information and return at a later consultation with a decision.

“where there’s a grey area then ah all you can do is present the evidence and really give them the responsibility for the decision.”

(Gynaecological oncologist)

“If a patient says oh I, I, I hear the two options but I don’t to loose my hair and I don’t that to happen. So neither option is possible. I will then say well there is may be a third option that’s even less effective. ... [If] the patient doesn’t want the recommendations; I’ll make the next best recommendation. I think then they have taken responsibility because they have declined your(my) recommendation, And so you then make your next best recommendation, but you tell them this isn’t the optimal thing but within your (the patient’s) parameters of wanting this and that and not wanting the other ... it’s the optimal treatment.”
(Medical oncologist)

“I guess in my practice [responsibility does shift] because often I have spoken to patients about their diagnosis, given them the information to read and they will come back and say this is what I want to have done, and then it’s just a matter of, making sure they’re fully informed about the decision they’ve made and going ahead. So often it really does shift the decision in that the patient comes back having already made a decision as to what treatment they have. So it frequently does shift the decision ... and the responsibility to the patient.” *(Urologist)*

Participants who felt that patients take on (or should take on) responsibility during shared decision-making saw their own role as one of advising.

“we are here to offer advice not decisions so this is what we advise. This is the reasons for it [the treatment] this is the pros, this is the cons. This is the alternatives. And you know, really it’s, it’s their decision, we’re the ones who share it.” (Breast surgeon)

7.3.2 *Responsibility is shared with the patient*

Sharing the decision for some doctors did imply that responsibility was shared.

“if we [the doctor and the patient] have the joint decision, we both decided to go down this path, and we both understood what this path could hold, and unfortunately, we have got a pot hole in the road, and you got an intermediate complication or a bad complication, well we both made the decision, we both know, knew we could get here, and we both take partial responsibility for having gotten here to a degree. So it does, it does sort of – you spread the load of responsibility, yes.”
(Urologist)

As demonstrated in the quotes above and below, in discussing the possibility of patients taking on some decisional responsibility, doctors did sometimes raise the notion of blame-sharing if things do not turn out as well as the doctor and the patient might have hoped. The degree to which such blame was shifted to the patient varied amongst respondents.

“it’s not a matter of shifting it[the responsibility] to the sense that you’re blaming them if they don’t make a particular decision, but I’ll write for example, we discussed the nature of this, that and the other, and Mr. So-and-so has indicated he does not wish to have this done at present. Or I’ve recommended a colonoscopy or I discussed the options and he is not keen to have this procedure done but I’ve encouraged to come, him to come back if his symptoms change. ... To me that implies that I’m shifting some responsibility onto them and it’s not with the intent of blame. ... I think people can make their own choices but I certainly do feel then that afterwards I can say to them if they come back well we did discuss this and as I recall you know you weren’t keen to have such and such done at the moment”. (Colorectal surgeon)

*“I feel more comfortable if I think the patient has been involved because I guess to a degree it, it defers responsibility for that, to both of us. You know, well we both decided this is the way to go.”
(Urologist)*

7.3.3 *Doctors retain responsibility*

Some doctors were clear that sharing a decision did not deflect responsibility away from them. Some saw themselves as the “captain of the ship” who would always be the one responsible.

“ultimately, I am responsible for the management of that patient and as long as I’m happy that they’ve made an informed decision and they understand the consequences of that. The responsibility is mine.”

(Gynaecological oncologist)

“I guess I at the end of the day, I’m the captain of the ship so, all the responsibility would have to fall on my shoulders.” (I: So you don’t think it shifts the ultimate decision responsibility?) “No.”

(Medical oncologist)

“I make the analogy that they own a ship, they’ve employed me as the Captain. They can still basically decide where to go, but I’m not going to let them off on a reef or do something like that and they know there’s someone at the helm that they can trust. I think that is still what people want, at least people in my practice.” (Medical oncologist)

Others felt that even if they wanted to give away responsibility, patients would never be willing to accept it.

“I think that if ... a patient is unhappy with the outcome they’ll put it back on to you. I think that is because they are so unhappy as to what happened [they] will really not remember or really think that they were sort of part and it all gets wiped out, because there is grief and someone’s got to be blamed. So because you’re the person who obviously knows more, I think that you [the doctor] will be responsible.” (Breast surgeon)

The context of these discussions made this issue difficult for some doctors, with the nature of cancer and the potentially life threatening nature of the disease influencing their views. One doctor used an example of deciding to withdraw treatment from a patient in intensive care to illustrate his understanding of shared decision-making and responsibility.

“We are going to turn this patient off because it’s the right medical thing to do but we wanted you to understand why we are doing it, and you can ask all the questions you like. To me that’s shared decision-making but it’s not moving any of the responsibility to make that decision.” (Medical oncologist)

7.3.3.1 Doctors who felt they should retain responsibility for decision-making often reflected on their role as *the expert who has responsibility for guiding patients to the 'right' decision.*

"I think one of the problems is doctors these days too often abrogate our responsibility. They think patient decision making is, is a way to cop out of the hard decisions I do actually say to patients look you've come here for my opinion." (Medical oncologist)

"And so while shared decision-making works well, the patient will never have the, all the knowledge that someone like myself [has] accumulated in 30 years." (Breast surgeon)

"I mean what I would actually hate is if the patient [was] to make what I thought was a wrong decision ... how would I feel for the patient then [to] carry that? I think you've got to steer the patient in the right direction" (Colorectal surgeon)

"the young guy (who) says no to chemo, because he had advanced testicular cancer. I still think the responsibility is mine ... I'd be rightly criticised if I didn't attempt to chase them down the corridor. Ring him at home and speak to the GP and speak to the urologist and speak to

the wife or the mother or the whatever. I would expect my colleagues to have shown that they tried more than just shrug their shoulders as he walked out the door.” (Medical oncologist)

7.3.3.2 Power to coerce

Some doctors noted that whether consciously or subconsciously, they did influence the choices patients made and therefore could not abdicate responsibility.

*“you make a diagnosis, you, you lay out the options. I might be selective in which options I give because I think one is completely and utterly inappropriate for this particular individual ... I probably would in some way bias some of the options, to try and direct the choice. You know, let me make you make the choices that I think you should make.”
(Urologist)*

“you know the bottom line is at the end of the day, you know you can mould them (patients) whichever way you want” (Urologist)

“You can’t help but add a personal bias to what you’re saying you’ll probably downplay some of the side-effects of one treatment option it may be consciously, may be subconsciously. At the end of the day you’ll have an idea of what you think is best, you’ll probably bias your

presentation of that in such a way that will influence the individual. I think its both human nature and unavoidable. You either put them in order or you over or under emphasise particular consequences, to make it the obvious choice.” (Urologist)

*“I mean the whole thing ends up being the way you promote whatever you’re promoting in terms of treatment to that patient.”
(Haematologist)*

“there’s all sorts of literature showing how a doctor can spin information to actually make a patient give the answer you want to them to answer.” (Medical oncologist)

“I’ll say on this side (...) these are the things against it and this is the things for it, very keenly aware that I’m influencing the patient for the guise of shared decision-making,” (Colorectal surgeon)

*“the whole process is extremely interesting ... we [doctors] can all think that we say things the same way but if the patient sees 3 different people they will come out making 3 different decisions.”
(Gynaecological oncologist)*

7.4 Effects on doctors of sharing decisions

During the interviews doctors mentioned issues which impacted negatively and positively on them as a consequence of involving patients in cancer treatment decisions. These included the impact of shared decision-making on their time, the increased complexity of discussions, the impact on patients' confidence in their doctors, the challenge to the doctor's authority, poor decision-making.

7.4.1 *Negative effects*

7.4.1.1 *Time*

Information sharing and explanation of options are core components of a shared decision-making approach and most of the doctors noted that this required increased consultation time.

"I think the single most important thing is providing them with adequate information, which, becomes difficult given the time constraints everyone has. It often takes ... two consultations and occasionally three or four consultations to come up with a decision that the patient is comfortable with." (Urologist)

"it may take a long time to explain to the patient and the relatives all the pros and cons ... and help them come to what we perceive is a correct decision. (Breast surgeon)

“it can be more time consuming, I mean that doesn’t matter, I’m not saying it’s a negative thing. ... It can take longer to involve them, rather than saying I’ve got all your results back and, and I think that the best thing for you is to ... have you know, treatment ‘A’ rather than saying well we have all your results back and, yeah the options of management are A, B, C and D. Let me tell you about ‘A’, let me tell you about ‘B’, let me tell about ‘C’, let me tell you about ‘D’ and then together we can choose a pathway to manage your particular problem. That’s certainly more time consuming and promotes more questions.”

(Urologist)

The negative impact of extra time depended on how much and how many consultations ensuring patient understanding and patient involvement took. Some doctors commented that they became frustrated when patients were unable to come to a decision and doctors felt they were having the same discussion over and over.

“I’ve had some patient, making a decision over 6 months whether to have surgery or not have surgery or what to do ... and it’s very frustrating because you have the same consultation over and over.”

(Breast surgeon)

"patients are by and large pretty wilful. ... you’ll involve them in certain, lead them gently over, say a long consultation, take an hour or

so for a certain point of view, ah and then they'll come back and want to go through it again and come to a different conclusion" (Medical oncologist).

Some doctors noted that the extra time taken was not always without some benefit. Taking extra time initially and ensuring patients knew what treatment and what to expect made later discussions easier and possibly shorter.

"in the big picture it's time well spent, ... they do take long[er] but I think in the bigger picture you can make decision(s) faster with them in the future." (Medical oncologist)

7.4.1.2 *Increased complexity*

Many doctors stated that presenting different options and choosing between them requires extra skills on their part to establish what patients want to know and what preferences they may have, particularly when talking with patients who have no medical knowledge whatsoever.

"certainly when you are talking about different surgical approaches it's sometimes very difficult to have people understand exactly what you mean and what's going to happen." (Gynaecological oncologist)

“In general involving patients as a physician. tends to increase the work load and the time involved ... and is more demanding on explanatory powers I guess.” (Medical oncologist)

“To have shared decision-making you have got to be a good communicator and therefore it hones your skills in. good communication, you’ll get feedback if you’re not.” (Haematologist)

“communication with patients is a bit like knowing what chemotherapy to give, if you don’t know how to do it, go and learn ... I’ve taken lots of courses in communication ... you can [learn] there are efficient ways” (Medical oncologist)

7.4.1.3 *Reduced patient confidence in doctor expertise*

Some doctors raised the issue that offering choice or discussing options occasionally led to patients questioning whether in fact the doctor was competent.

“Some patients interpret ... it that you [are] not sure of what they should have. I think there’s always a risk that the patient will go home and think gee, the doctor doesn’t know what I should have, what good is he? “(Urologist)

Further, with the increased access to information from the internet a couple of doctors asserted that they felt patients armed with pages of print out were challenging their expertise.

“Someone comes in with a 200 page Internet printout and says, here this is what I know, what do you know? And almost challenge you”
(Colorectal surgeon)

7.4.1.4 *Challenge to the doctor’s authority*

Some doctors noted that involving patients in treatment decisions and greater access to information increased their assertiveness and they can challenge the authority of the doctor. Doctors mentioned this with a note of amusement, but also with some concern that patients may be basing their view on poor quality information.

“people are wandering in to the clinic with their results tucked under their arm and saying, I want treatment ‘A’ because I’ve heard it’s the best, and I’ve seen it on the Web and you know I’m informed and I’m educated and I know what I want, and I think I know what’s the best”
(Urologist)

“They’ve come with their own agenda. They’ve got Channel 9 and the Age telling them what to do and we are just you know, putty in their hands.” (Medical oncologist)

7.4.1.5 *Poor decision-making*

Involving patients in decisions allows patients to make decisions which doctors may not agree with. Doctors noted that this was their prerogative, but was sometimes hard to accept.

“Where there’s a large body of expert opinion and evidence and the patients sometimes will bring along their internet gained opinions which may not have much credence ... there are people ... who will go away determined to try herbal remedies no matter what you say. Then, ah you know that’s their prerogative.” (Gynaecological oncologist)

“people come along with preconceived ideas and they don’t understand the, the subtleties and consequences, and, and why this is not particularly appropriate for them. It can be quite a challenge to talk somebody out of a treatment they think that they’ve decided they want to have done, if it’s not in their best interests.” (Urologist)

7.4.2 *Better patient outcomes*

A number of doctors felt that involving patients in treatment decisions produced benefits. These included benefits to their relationship with the patient, to their own practice, improved patient outcomes, and reduced fear of medico-legal issues.

7.4.2.1 *Reassurance that the decision is the right one*

Some doctors commented that involving patients in decisions reassured them that they had made the right choice with which the patients agreed. Additionally one doctor noted that shared decision-making required doctors to keep abreast of new advances in treatments.

“well good is the feeling that they are participants and that they’re involved ... in their treatment and ... if you give people options usually they express a preference for a particular course of action ... I think it’s reassuring that you’re embarking on a course of action which they feel is appropriate for them. So it affirms my own comfort with a recommendation.” (Colorectal surgeon)

“It’s good; it puts you on your toes. You make sure you have the latest information which is always difficult, but I think it’s generally a good thing. ... it’s good for doctor’s to know what they are talking about to

have the skills to explain things in detail to a patient.”

(Haematologist)

Some doctors noted that understanding patients' priorities helps explain their preferences.

“we can't judge for a person what may be important to them, that they may rather keep their hair and risk a couple of percent. ... And we can't make a decision for them as to what their priorities are ... the person who's having the treatment ... knows their priorities better than anybody else.” (Medical oncologist)

7.4.2.2 Improves doctor-patient relationship

A number of the doctors suggested that they found involving patients in decisions was a pathway to a good relationship. They commented that sharing decisions was rewarding and allowed good relationships to build regardless of the how the cancer journey might continue.

“Involving a patient enhances the outcome because ... it's very hard to manage a patient when there's angst between you.” (Medical oncologist)

“often if you engage in the decision process, sharing process that dissolves a lot of the anxiety and they come on board.” (Urologist)

“I guess the positive side [is] it does to give you a chance to actually develop good rapport with the patient, and give you a chance to ... ensure that the patient is making the decision that hopefully is the right decision for them.” (Urologist)

“I may not have expressed that very well. I like to be very close to them (patients) and to have them trust me and I like the idea that we solve problems and work together.” (Colorectal surgeon)

“I think my patients need to understand what the intention of ah our treatment is, I think from a decision point of view, if the patient is on the same wavelength from an intention point of view that I am, then it goes much smoother over the rest of the relationship.” (Medical oncologist)

7.4.3 Reduced fear of medico-legal issues

Some doctors asserted that involving patients in decisions about treatment was advantageous in ensuring patients understood the reasons for treatment and reducing the risk of medico-legal complications.

“when there are other situations where a doctor’s uncertain about a treatment, if the patient’s keen, this concept that it’s their decision, doctors find sometimes that it might give some medico-legal protection if things go wrong.” (Haematologist)

“You make [a] decision that there’s a seriously intelligent, questioning person sitting across the table. With those women I make absolutely certain I involve them in everything. So there’s no question, they can come back later on and say well you didn’t tell me about this.” (Gynaecological oncologist)

“should a patient have chemotherapy for adjuvant breast cancer or not the benefit might be 2% ... so, if a patient said look this is what I want to do, I really think it’s worth doing. I’ll kind of say that back to them so it’s a confirmation you know you are going ahead because you believe 2% is worth doing. And then you kind of make it like a declaration in front of the family. And I jot that down in a letter saying that they were keen, so when they die of a septic shock a month later, I guess that theory makes life a little bit easier.” (Medical oncologist)

7.5 Effects on patients

Doctors felt that shared decision-making could have both positive and negative effects on patients themselves.

7.5.1 *Difficult decisions for patients to make*

A number of the doctors talked about the difficult decisions which cancer patients face. Uncertain outcomes, weighing up pros and cons, and complex survival and recurrence risks are difficult issues to understand, quite independent of the emotional burden of a new diagnosis.

“I think it is hard for people to make decisions. ... the first time they’ve heard it(their diagnosis) and they’re being asked to consider ... a very complex thing, that even people who are very familiar with the issues find difficult. I mean, pre-operative radiotherapy is a great example and rectal cancer, practitioners argue about it. How can you expect a patient in 10 minutes, when they’re dealing with their cancer diagnosis and the thought of everything else happening in their life to, to really appreciate the issues.” (Colorectal surgeon)

“Where there are no black and white, right and wrong decisions and there are often 3 or 4 treatment options all with similar out comes, it

becomes quite difficult I think for the patient to know what decision to make.” (Urologist)

7.5.2 *Patient anxiety*

Eleven of the doctors noted that involving patients in decisions can raise anxiety and that this was something to be avoided. In these instances doctors would often reduce options offered and make clear recommendations. These doctors stated that they could recognise patients who did not want autonomy and preferred their doctor to make their decisions.

“there are people who get thrown into a bit of a spin by actually being offered a choice. So that’s the bad side I guess ... when they’ve said they’re uncomfortable with deciding and they’d rather have my hand than pushing them into it [deciding]. I think [it’s] not going to help it’s just going to increase or create anxiety if they are already anxious”
(Medical oncologist)

One doctor talked about how he managed those patients who became anxious when asked to share in the treatment decision.

“I think it can increase their anxiety and um, I um then tend to shift over to a more directive role. But you try and do it cleverly, not

sneakily but cleverly. You try and direct them more perhaps but still keep them involved in the process.” (Urologist)

Others asserted that involvement can reduce anxiety and saw this as a positive outcome of a move away from paternalism.

“often if you engage in the decision process, sharing process, that dissolves a lot of the anxiety and they come on board.” (Urologist)

“it will save angst and I think that’s an important aspect, particularly when you’re dealing with very ill people.” (Medical oncologist)

7.5.3 *Increases confusion and overwhelms patients*

Many of the doctors talked about the increased likelihood of confusing patients with detailed information about risks and benefits of treatment. For most cancer patients treatment decisions are made at the beginning of the cancer journey when many feel overwhelmed by their diagnosis. The amount of information accessible to patients was also highlighted as contributing to the confusion that patients feel.

“I really do think that we have not learnt to control the information revolution in medicine, and what you can end up doing is confusing the life out of patients.” (Medical oncologist)

7.5.4 *Patients can make the wrong decisions*

Three of the doctors expressed the view that some patients are not able to make the right decisions for themselves due to the circumstances they find themselves in. One was quite clear that involving patients in decision did not give good outcomes.

“It’s more frustrating, it leaves people to fuck up their lives good and proper sometimes, i.e. to die.” (Medical oncologist)

7.5.5 *Decisional regret*

Some doctors felt that patients who were involved in decisions might be vulnerable to later regret. That is, if something went wrong, patients may feel it was their own mistake which had led them to that pass. A distinction was drawn between participation and decision-making, where regret was seen as a possible consequence of actually making the decision, but not of participation.

“... if it’s thrust upon them they’ll always then look back later, well not always, but often and say you know was that the right thing? Was that necessary and did I do the best thing etc?” (Breast surgeon)

“some people are happy to be guided and do get scared about having to choose in case ... they choose the wrong thing. ... They find it’s a testing question that they are being asked to choose the best treatment

and if it doesn't work, [that] may be because they made the wrong decision.” (Medical oncologist)

*“the important thing is avoiding future regret, and if there really is a decision to be made then you must clearly flag that to the patient”
(Medical oncologist)*

However others suggested that by involving patients in decisions patients would have less reason to wonder why they had undergone a particular treatment.

“the good aspects of it [shared decision-making] are that, that there's, there should never be a question at the end about why a particular treatment pathway was made and there's never the possibility of, I would never have done that had I known ... that's the most positive aspect.” (Medical oncologist)

7.5.6 *Increases understanding, autonomy and empowerment*

A number of doctors talked about involving patients as empowering patients and giving them some control in the consultation. These doctors saw this as a positive attribute as it enabled patients to better understand their disease and its' treatment.

“I think the positive side of it is that most patients actually feel involved in their care. And that gives them some form of control over a situation where they can otherwise feel fairly helpless. Ah they just sort of, in some ways you know, you almost feel as if they’re along for the ride, rather than being involved in their care. So I think the positives are it gives them a chance to be involved in their care to make a decision. And also be informed about what they’re doing.” (Urologist)

“I think if they understand why they’re having something done and have been part of that process, they don’t feel disenfranchised when something happens to them, [they won’t] say well I didn’t realise that was going to happen” (Gynaecological oncologist)

“given the complexity you know, of modern medicine the decisions can be quite difficult, they are not always black and white and patients themselves have increasing knowledge of their diseases. But on the other hand ... their expectation is there’s a clear black and white answer and they want certainty and reassurance that nothing will happen. I think that involvement in the decisions makes them understand the process better.” (Breast surgeon)

7.5.7 *Increased patient satisfaction*

A few doctors noted that they felt patients were more satisfied with their care when they were given more information and were more involved in decisions.

“So they feel really happy that they’re actually part of it and they feel that ... they did make a decision even though indirectly it was predetermined. So I think it, it enhances patient care.” (Breast surgeon)

“patients (who) are better informed are generally more satisfied afterward, and accepting (when) complications occur ... rather than being very un-accepting and potentially very unhappy for lots of reasons.” (Urologist)

“They’d think well gee that doctor listened to me and. he seemed to present me all the options and I felt as though I was involved in the decision making. I guess that’s the positive thing.” (Medical oncologist)

A number of doctors also suggested that greater patient empowerment resulting from shared decision-making was beneficial to the doctor-patient relationship and subsequently increased patients’ tolerance and compliance with treatment regimens.

“the good part for the patient is ... that they feel involved in their care and they are more likely to comply, that’s the upside of it.”
(Gynaecological oncologist)

“if they share in the decision making they share in the progress of their illness, I think they feel more empowered. Um, they’re more likely to um be open with their problems.” (Urologist)

7.6 Effects on health system

The main impacts on the health system that doctors commented on was linked to the issue of consultation time, that involving patients in decisions demands more consultation time. A further consequence alluded to by some doctors was the possibility of increased costs as patients may choose options which cost the health service more, even though a cheaper option may have an equivalent outcome.

“even though the outcome may not be better, a more resource consuming option maybe chosen, because that’s what the patient wants to do ... there is a possibility that that more empowerment, that we, if you want to look at it that way, more, more involvement or empowerment of the patient may end up in the consumption of more resources.” (Urologist)

Some doctors noted that understanding patients' priorities helps explain their preferences.

“we can't judge for a person what may be important to them, that they may rather keep their hair and risk a couple of percent. ... And we can't make a decision for them as to what their priorities are ... the person who's having the treatment...knows their priorities better than anybody else.” (Medical oncologist)

7.7 DISCUSSION

From the qualitative interviews with Australian cancer doctors some insights into the effects of involving patients in treatment decision-making were elicited. A key issue was the effect that sharing decisions has on the responsibility for the decision. Does giving patients more control over which treatment they have shift the responsibility for that treatment choice and the outcome of that choice to them?

Decision responsibility

Most doctors in our sample asserted that they were ultimately responsible for their patients' welfare if they were prescribing the treatment. However a shift of some responsibility to patients occurred when patients chose independently or when they opted for a treatment which was not the treatment preferred by the doctor. There is minimal commentary in the literature of shared decision-making concerning the effect sharing decisions or patients leading decision-making has on decisional responsibility. Entwistle and Watt (2006) outline a broader conceptual framework of

patient involvement in decision-making beyond preferences and doctor-patient communication, and the issue of responsibility appears to fit within the two domains which reflect the clinician's and patient's feelings about their role.

The end of medical paternalism has been championed in healthcare, with patient-centred care heralded as the way forward. Shared decision-making has come to the fore and is founded upon the notion of the doctor and patient as partners in the consultation, with information exchange, and negotiation leading to mutually agreed decisions (Charles, Gafni et al. 1999). Description of the modern patient ascribes attributes of autonomy and self-responsibility, reflective of human rights, although the reality for patients is that this idealised image is set in an environment of illness (Dieterich 2007).

The doctors in our sample gave a variety of consequences of involving patients in decisions. It is not clear that patients accept that being more involved in decisions and in some instances making the decision, signals that the doctor is absolved of decision responsibility. Nor is it clear whether doctors think patients should take on some responsibility. Some doctors stated they recorded when patients chose a different treatment option so that they could remind patients of this if and when circumstances changed. How these consultations play themselves out is unknown as the doctors talked about these conversations in a hypothetical manner.

Differing motivations for involvement, such as benevolence or self protection, are suggested by Entwistle and Watt (2006) in their discussions of the conceptual framework for involving patients in treatment decisions. They suggest that patients' experience of involvement may vary in these different contexts. The consequences of involving patients in treatment decisions appeared to suggest some different motivations of the Australian cancer doctors. Some doctors expressed a view of deflecting responsibility, some saw involvement as reassurance that they had selected or recommended the treatment with the best fit for their patients, while a third motivation was the benefit from the subsequent improved relationship involvement engenders. It is perhaps in understanding the motivation of doctors that answers the question of whether involvement increases patients' responsibility.

Does encouraging patients to be more autonomous affect decisional responsibility and absolve doctors of ultimate responsibility? Edwards et al (2006) propose that clinicians should pay attention to the decisional responsibility preferences of patients as well as involve patients in the process. Their data suggest that when responsibility preferences are not matched patients are less satisfied. The opinions of the patients interviewed qualitatively in their study reflect the views expressed by the doctors in our study, that the process and the decision are separate entities. These findings support the notion that a shared decision-making consultation can result in a doctor-led, shared or patient-led decision, while the process itself reflects the components of shared decision-making models (Elwyn, Edwards et al. 1999). However the term decision responsibility in this study refers to the decision maker and does not appear

to imply responsibility beyond this. The motivation of doctors to involve patients, particularly those doctors who seek to deflect responsibility perhaps suggest that in the context of treatment decision-making responsibility may well imply that the decision-maker is responsible for the decision and the subsequent outcome?

Does it make a difference if the treatment decision is in a preference-sensitive or grey context as opposed to choosing between a standard or alternative treatment, or if patients are choosing not to have treatment when an option with documented effectiveness exists? And does this issue of responsibility only matter when things do not go according to plan? Little is known about patient views on this issue, and this would be a fruitful area for future research.

Involvement to help patients choose or to disclose uncertainty?

Some doctors expressed concern that discussing options and asking patients to be more involved was sometimes interpreted by patients as a sign that doctors did not know the 'right' answer and were therefore incompetent. This interpretation may reflect more about doctors own discomfort in discussing uncertainty with patients than patients' responses (Katz 1984). Alternatively this concern may stem from poor communication between doctors and patients about the role patients can have in treatment decisions. In the first stage of this thesis we asked doctors how often they had discussions with patients about the role they wished to play in decisions and 37% reported that they have this discussion with half or less of their patients. We also asked the breast and urological doctors whether they felt patients receiving a booklet

explaining their role in treatment decisions would be useful, but only 28% agreed with this approach.

Disclosing uncertainty

Admitting to patients that the outcome of their diagnosis or treatment is uncertain is an uncomfortable scenario. Ideally doctors wish to cure the sick; not being able to do this challenges that ethos. It might be expected that doctors who choose a career in oncology would accept the notion of uncertainty early in their careers. Further it might seem reasonable to believe that communicating uncertainty would be a skill honed in cancer specialists. Equally, despite patients rationally knowing that their disease may not be curable, they expect to hear from doctors that they will be cured or that if they have treatment 'x' it will result in outcome 'y'. More importantly that outcome 'y' is a certainty. Modern medicine however is not that simple, and today's cancer care has many treatment options which offer varying degrees of effectiveness, risks, benefits and a variety of side effects. For patients, their families and doctors survival is the number one priority, if that is guaranteed then that is the option that patients will take. When treatment options offer no guarantees the value which people place on other issues of body image, sexual function, and components which affect quality of life become more influential, and the importance of the doctor and patients sharing this information is paramount.

Communication of risk and benefits to patients is fundamental in involving patients in decisions. How to communicate uncertainty as suggested by Griffiths et al (2005)

should be highlighted in existing risk communication training modules. Disclosing uncertainty and subsequent discussion of all possible options and side effects does not imply that patients will make bad decisions; rather it prepares patients and their families for the road ahead. Concern about overburdening cancer patients with difficult decisions prompted consideration of when shared decision-making is appropriate. Some feel it is appropriate only in chronic illness, where different treatment options with equivalent outcomes exist, and where outcomes are uncertain (Whitney 2003), while others disagree. Discussing options does not preclude the giving of a recommendation, indeed most patients want their doctors to recommend the treatment and most patients follow their doctor's recommendation, but this does not suggest that discussing other options is a waste of time.

Patient involvement or patient-led decision-making

This issue raises the definition of shared decision-making and its interpretation by clinicians. Is shared decision-making about who makes the decisions or about how the decision is made; is asking patients to make difficult decisions a problem or do doctors think simply informing them of the options adds too much burden? It has been suggested that distinguishing between the decision and the process needs more exploration (Edwards and Elwyn 2006) and this was supported by the confusion evident in some answers in the current data set. A recent qualitative study of diabetic patients' interpretation of the meaning of involvement by Entwistle et al (2008) reported that the majority wanted to hear and accept a doctors' recommendation, even

those who spoke of making decision themselves appreciated guidance from their doctor towards the best decision.

Increased consultation time was the most common negative effect conveyed in this study, supporting our findings from the larger survey and mirroring findings in other studies on barriers to or problems with shared decision-making (Charles, Gafni et al. 2004; Gravel, Legare et al. 2006; Thistlethwaite, Heal et al. 2007; Shepherd, Tattersall et al. 2008). A number of studies have reported that collaborative decision-making does not increase consultation time and may save time in the long run as thorough initial discussion enables subsequent consultations to be more succinct (Edwards, Elwyn et al. 2002). Views that involving patients in decisions may save time down the track were proposed, however there is no evidence to confirm or deny this assertion. Data on consultation time over the long term would assist this controversy.

Positive effects reported in our interviews included better patients outcomes including requiring doctors to keep abreast of latest treatment advances, and the development of therapeutic trusting relationships where the doctor is reassured that the patients is informed and understands why a treatment is being given or not. This is in line with quantitative findings showing that the majority of doctors are in fact comfortable with, and regularly use shared decision-making (Charles, Gafni et al. 2004; Shepherd, Tattersall et al. 2007).

7.8 CONCLUSION

Cancer patients' preferences for information and involvement in treatment decisions require cancer doctors to shift toward using shared decision-making. This shift requires some changes in the way doctors manage their consultations and raises some questions about decision responsibility. Strategies which may assist doctors to manage the negative effects they experience and to enhance consultation skills to foster patient involvement in the process need to be developed and evaluated.

CHAPTER EIGHT

SYNTHESIS OF RESULTS

The focus of this thesis was to elicit information from practicing Australian cancer doctors concerning their attitudes towards involving patients in treatment decision-making. Data to support discussion were gained using a mixed methods approach, namely surveying a nationwide sample of cancer specialists, followed by in depth qualitative interviewing of a purposeful subset of the larger participant sample. This thesis gives empirical data on the reported practice of Australian cancer doctors and raises issues which impinge on doctors' support and practice in relation to involving cancer patients in treatment decisions.

Are doctors comfortable with shared decision-making and do they report using shared decision-making as their usual approach?

The primary outcome of stage one of this thesis is the reported usual approach of Australian cancer doctors treating one of five cancers (breast, colorectal, gynaecological, haematological and urological) to making treatment decisions with cancer patients.

The data show that the majority report high levels of comfort with a shared decision-making approach, irrespective of their cancer speciality or their discipline. Differences were noted in the reported use of a shared decision-making approach, with breast and urological cancer doctors being significantly more likely to report using shared decision-making than the other specialists. This finding supported the

hypothesis that there *will be a difference between breast cancer doctors and other cancer doctors in their attitudes to shared decision-making*. Breast cancer doctors are more likely to use a shared decision-making approach, yet it identified that urological cancer doctors are equally as supportive of this approach. In the discussion of Chapter Three these findings were supported by other commentators on the appropriateness of patient involvement in treatment decisions as being aligned to the existence of more than one treatment option considered clinically reasonable for a given clinical situation (McNutt 2004; Whitney, McGuire et al. 2004). The surgical options in early stage breast cancer and the options in prostate cancer suggest that cancer doctors practicing in these contexts have embraced shared decision-making because there are treatment options with similar outcomes. Additionally the data elicited from the telephone interviews completed in stage two of this thesis and reported in Chapter 5 suggest that the existence of treatment options, where one treatment is not considered superior to another, is a strong motivator for doctors to encourage patient involvement.

The impact of treatment is a further issue which arose from the qualitative findings, as doctors voiced their unwillingness to impose treatments with consequences affecting sexual function or gender specific body image, without the full support and understanding of patients. These concerns are especially relevant in the treatment of breast and prostate cancer, but include gynaecological cancer.

The qualitative findings also endorsed the original thoughts guiding the hypothesis above in the support breast and prostate cancer patients gain from high profile consumer groups. This raised profile and raised expectation of cancer patients encourages and empowers them to participate in decisions about their care as well as increasing general knowledge of the treatment options available.

The remaining hypotheses of *younger age and practice setting influencing doctors' attitudes towards use and comfort with shared decision-making* were not supported by the data, despite belief that doctors trained more recently in an era of patient-centred medicine would be more comfortable and therefore more likely to use this approach. Perhaps the confidence and communication skills which develop with age are also important contributors to the likelihood of practising shared decision-making.

Do doctors discuss involvement in treatment decisions with their patients and do they know which patients want to be involved and which don't?

To establish whether Australian cancer doctors discussed decisional participation with their patients in consultations, doctors were directly asked about their practice in stage one of this thesis. The results showed that most doctors reported discussing decision participation with their patients, yet a large minority (37%) did this with less than half of their patients. Similarly, most doctors were very comfortable with the notion of shared decision-making (84%) but far fewer reported that this was their standard approach (62%).

According to the findings in Stage Two, a number of issues feed into this decision to limit open invitations to participate in decision-making to only some patients. Doctors reported that certain patient attributes motivated them to seek their patients' involvement in reaching a treatment decision, namely younger age, female gender, perceived higher intelligence or education level, personality traits and certain occupations. Such patients were seen as capable of sharing decisions and likely to desire such involvement. Other patients were seen as less likely to want involvement in decision-making, and more likely to be harmed by such an approach. Whether doctors can make such judgements accurately in determining who to encourage and who not to encourage to share decisions is difficult to determine. Certainly there is a large literature reporting significant disparities between doctors' estimates of patients' preferences and patients' reports of the same preferences (Solomon, Pager et al. 2003).

Doctors practising medical oncology were more likely to predict that their patients wanted a more active role. These findings support the hypothesis stated in the introduction that *medical oncologists in Australia will have more positive attitudes to shared decision-making than their surgical counterpart*. However the stereotypical view of surgeons as being the most paternalistic and the worst communicators amongst the medical professions was challenged in these findings, since surgeons were more likely than many other disciplines to support shared decision-making.

The qualitative findings suggest that rather than being profession based, views on shared decision-making were rather influenced by the disease scenarios in which doctors worked. Doctors who treated diseases in which real treatment options with similar outcomes existed were more likely to support shared decision-making. The data also suggested that doctors in these clinical areas are responding to the increasing information and involvement expectations of their patients.

Where few treatment options existed and where the patients' prognoses were generally poor, doctors were less likely to embrace shared decision-making. Haematologists and paediatric oncologists for example, who were the least likely to report using shared decision-making as their usual approach talked about the lack of options for their patients and their hope that the next treatment might give a sustained response. In such a scenario, doctors and patients are more likely to collude to maintain hope by avoiding information exchange. Thus avoidance of share decision-making is motivated by 'caring too much' perhaps, rather than 'caring too little' and refusing to give up power.

In the qualitative interviews indentifying patients' preferences for information and involvement was noted as a key component of involvement. Doctors identified that making the right judgement was a skill which they developed with increasing consultation experience, but was one that was difficult to master as individual patients do not always fit within generalisations.

What stops doctors from involving patients in treatment decision-making?

System issues, particularly time, were the most frequently nominated barriers to involving patients in decision-making in the quantitative findings and were reiterated in the qualitative interviews, supporting findings elsewhere (Charles, Gafni et al. 2004; Gravel, Legare et al. 2006). Whether extra time at initial consultations is time well spent has not yet been proved or disproved. Views of doctors on this matter are conflicting despite some work concluding that collaborative decision-making may save time later (Edwards, Elwyn et al. 2002). Doctors voiced that addressing patients concerns and thereby reducing anxiety is beneficial to the doctor-patient relationship, and involvement fosters this. It may perhaps be worth investigating whether it is the time point in the consultation where a treatment decision is agreed that is delayed rather than the actual length of the consultation which is increased. Perhaps the energy doctors expend to negotiate or coerce is greater giving the impression of more time spent.

Patient anxiety and concerns about how to manage this featured in both stages of this study as obstacles to involving patients in treatment decisions. Patients being overly anxious during consultations and the possibility of increasing anxiety by discussing options pushed some doctors towards involving their patients less. Anxiety does hinder patients' understanding, however as some doctors noted, giving patients more information and taking the time to explain things more clearly and helping them to understand their situation can reduce anxiety and make the consultation and ensuing relationship more effective. Offering a treatment recommendation was a strategy

which was used by some to overcome the concern that by asking patients to become involved would overburden them with responsibility and imply that the doctor did not know what to do. The notion of decisional regret came up as a potential concern for doctors. Doctors are care-providers and their reluctance to overburden patients was communicated as protective, a caring rather than paternalistic standpoint.

Very few doctors expressed difficulty in framing options for patients in the quantitative data, suggesting that doctors did not find explaining complex information about risks and benefits, communicating evidence or explaining differences between treatment options, a barrier to involving patients in treatment decisions. However, the need to transfer information to patients and ensure understanding was considered vital to patient involvement and a challenge.

Inexperience featured as a predictor of greater difficulties with system issues explained in detail in Chapter Four and was somewhat supported in comments made during the in depth interviews. The ability to determine what information or involvement patients might want to play appears to increase with consultation experience, explained perhaps by learning from mistakes or reflecting on what worked and what didn't. Equally with experience some doctors talked about strategies they used to assist their patients to participate; offering handwritten summaries, dictating letters in front of the patients are some examples.

The data documented limited doctor support for interventions which aim to encourage patient participation. Changing established practice is difficult, yet doctors do respond to changing patient expectations, as illustrated in the differences noted between the breast and urological cancer doctors compared to other doctors in the sample. Responding to patient expectations not only triggers this difference, but also demonstrates where interventions should be aimed; it is perhaps easier to change doctors by changing patient expectations than attempting to change doctors directly.

What things encourage doctors to involve their patients in decisions?

As mentioned above and explained in more detail in Chapters Four and Five of this thesis, the most significant motivators and facilitators to doctors involving patients in treatment decisions found in this project are trust in the doctor, the impact of treatment on the patient and specifically issues of body image and sexual function, and the role that significant others play in the decision and consultation process.

Trust is pivotal; doctors clearly want their patients to believe them to be trustworthy, a quality they hope their communication, reputation and expertise conveys. Patients who trust their doctors are easier to guide to the best treatment and on occasions allow doctors to prescribe or to commence treatment prior to patients fully comprehending their situation. Elements of shared decision-making according to Australian cancer doctors assist development of a trusting relationship. Two-way communication permits both parties to know what motivates the other; whilst obviously survival is important, other values elicited during consultations where

doctors elicit preferences helps doctors to know which treatment might be preferred and to understand why a patient may refuse a particular treatment.

Many doctors saw the impact of treatment on lifestyle and a patient's self-image as an indicator for involving patients in decision-making, particularly when the treatment would affect gender defining qualities. These issues clearly prompted doctors to discuss the options and outcomes of treatment in more depth, ensuring that patients understood and that patients agreed to the doctor recommended treatment, that the doctors were not seen to be imposing mutilating surgery without informed consent.

Does involving patients in treatment decisions change doctors' and patients' behaviour?

Shared decision-making fosters patient involvement in treatment decisions. The tenets of shared decision-making demand that doctors pay heed to the preferences their patients have. Shared decision-making does not dictate that patients make decisions. In the interviews with doctors, interpretation of shared decision-making or patient involvement often pointed to the process of the consultations rather than to who made the decision. Indeed most doctors felt that patients wanted the doctor to make the decision or at the very least to make a clear recommendation and doctors felt comfortable with this. The notion that the patients could take on the doctor's expertise in one or two consultations was not supported.

Involving patients requires new skills from doctors and in this way affects the way doctors behave. Knowing how to elicit preferences was a skill which the doctors knew they needed to have, yet most of them did not have a clear strategy to achieve this end. Asking patients what treatment they prefer is an easy method, yet many doctors stated this question may cause anxiety or bring their own expertise into question. Communication skills training was rarely mentioned by our participants and when asked in stage one whether access to such training would be helpful, the vast majority answered in the negative. Patients' preferences to receive detailed information are high, preferences for involvement are high too, but lower for wanting to make any decisions alone (Vick and Scott 1998; Jenkins, Fallowfield et al. 2001; Levinson, Kao et al. 2005). However doctors are the ones with control, authority and familiarity in consultations and their endorsement or not of patient involvement is influential.

The rise of consumer involvement in healthcare has also had an effect on doctors. The results of this study show that patients from communities who expect to play an active role have forced the doctors to change their behaviour to accommodate this. This change is reflected in the higher reported use of shared decision-making and reflected in the interviews where doctors described how patients are given the information, given time to think about the options with their families and then return to the doctor with a decision. The comments concerning documentation of this event to make these discussions transparent in medical notes suggests that some doctors

consider it important, as a reminder and level of protection on a legal, moral and ethical level in case of poor outcomes.

Uncertainty also features in doctors attitudes to patient involvement. In the case of prostate cancer, the acknowledged uncertainty in the medical fraternity of the best treatment is transferred to the patients by their use of shared decision-making and their actively seeking the patient's input into their selected treatment.

Moves to promote patient involvement in treatment decision-making have emerged from patient-centred medicine, reflecting autonomy and patients rights. With this, other issues arise, as found in this thesis, such as the concept of decision responsibility. Doctors gave conflicting responses to this issue and conclusions drawn from the small amount of data gathered indicate that this idea deserves more thought and study. If patients are making decisions are they taking on the responsibility for the outcome? As doctors encourage patients to be more active due to pressure from consumer movements, do they retain ultimate responsibility or pass on some level of responsibility to the patients too?

CONCLUSIONS

Shared decision-making is considered to be the gold standard approach to reaching treatment decision with patients. Despite this, many Australian cancer clinicians have not adopted this approach as their usual practice. Context, particularly medical specialty matters as does clinician gender, higher caseload of new patients, and the existence of reasonable treatment options.

Doctors support patient involvement but interpret involvement as participation in the decision process, not necessarily the decision. According to doctors, patients want their doctor to recommend a treatment and doctors want to do this. Involving patients in the decision process assists doctors to steer their patients towards that 'right' decision, and ensures that information is given explaining treatment, risks and benefits and likely outcome.

Involving patients is not always easy; doctors need excellent communication skills to draw out preferences from patients who are not familiar with this type of consultation. Our survey demonstrated that doctors are unfamiliar or reluctant to use interventions which assist patients to be more active.

Lack of time to involve patients fully, particularly by less experienced physicians, influences doctors to avoid this approach.

Involving patients in reaching decisions has both negative and positive consequences for doctors and patients. Extra time is required for patients to absorb increasing amounts of information but strategies, such as use of clinic nurses and individualised take home information to manage this can and are being used by some. Patients making decisions may affect the understanding of who is responsible for the outcome. How this plays out legally, ethically and morally is unclear.

LIMITATIONS

The studies in this thesis have a number of limitations. First the self-report nature of the survey means that it is impossible to verify whether participating clinicians actually practice as they reported. There is the potential for social desirability bias to have influenced the responses given by participants, with participants reporting their usual practice to be aligned with shared decision-making approach knowing the patient-centred ethos of modern healthcare. Further we asked doctors about their usual or general approach to treatment decision-making with their newly diagnosed or newly referred patients, without specifying a clinical scenario and did not allow them to indicate how they would respond in different situations, although many commented that they would vary their approach. Identification of participants was undertaken through professional societies and some eligible clinicians may not have received an invitation to participate if they were not registered members of the professional societies approached.

The data concerning the barriers and facilitators to treatment decision-making represent cancer physicians' perceptions; the data do not necessarily represent the importance physicians place on these barriers and facilitators.

The 59% response rate to the postal survey presents some limitation to the generalisability of the data. A further potential bias may be that the responders may be more interested in treatment decision-making approaches used with patients than non-responders. Consequently the reported experience of difficulties to involving patients in decision-making may be underreported and support for shared decision-making may be over representative of the situation in practice.

The data collected from the qualitative interviews also offer a potential for bias in the results as responders may be more interested in patient involvement in treatment decision-making than non-responders. Participants may have acceded to a social desirability bias and been reluctant to express negative views concerning involving patients in decision-making. Effort was made to assure participants that we were interested in their own views to gain insight into how patient involvement in decision-making works in practice and not an idealistic view on how it should work.

FUTURE RESEARCH

This thesis has raised more questions than it has answered and there are a number of issues which warrant future research.

Australian doctors report differences in involving patients in decision-making or shared decision-making and the context in which they encourage their patients to be involved appear to be dependent on a number of issues. Further work should seek to identify what these issues are and identify clinical scenarios where patients and doctors benefit from shared involvement in reaching a treatment decision.

In the data presented on barriers and facilitators to treatment decision-making with patients, trust was endorsed as vital to a shared process. As patients are encouraged to ask more questions of their doctors, doctors may feel that their patients trust them less. Identifying what trust means to patients and what doctor behaviours engender trust may provide a fruitful research ground, and assist in the development of a measure which reflects and assists doctors to gain their patients trust.

The role or impact of the presence of a third person in a consultation, a family member or other health professional, gave some food for thought. Is having a cancer nurse present in the consultation helpful to patients and/or a hindrance to doctors? In both the interviews and the postal survey a number of doctors supported the idea of patients being accompanied at the consultation, although support differed depending

on whom that person may be, a loved one or another healthcare professional such as cancer nurse. Many doctors endorse the value of cancer nurses to assist patients with understanding after their consultation yet the value of the nurse being present in the consultation may be a strategy which is helpful to both patients and doctors. Patient anxiety was frequently voiced as a barrier to patient involvement which is often reduced when patients understand what is going on. The role loved ones play in reducing anxiety by their presence in the consultation and the value of the presence of a patient advocate or nurse merit investigation.

The use of communication strategies and tools such as audio-recordings, question prompt lists and decision aids were not well supported by Australian doctors, indeed they were rarely mentioned in the interviews. Establishing why doctors are ignorant of or reluctant to use these methods is worth pursuing, as research developing and evaluating such tools, falls down if, despite positive results, doctors do not implement such strategies in their usual practice. Research investigating and targeting different implementation issues is therefore worthwhile.

Educating doctors about competences required to involve patients in reaching treatment decisions has been advocated. Once again developing strategies which doctors support is difficult. A number of training programs have been developed, however combining general communication skills and these competences merit exploration. Training programs need to identify and produce outcomes which doctors value.

The data from this thesis show that doctors find establishing and identifying patient involvement preferences difficult, yet did not have clear ideas as to how they could better predict or establish patients preferences. Further work might examine how doctors identify patient preferences or how patients can be encouraged to voice preferences in cancer consultations.

The consequences of involving patients in treatment decisions also raised the issue of who then takes responsibility for the treatment outcome. Further work with patients and doctors could explore this issue morally, ethically and legally.

Finally this thesis has highlighted some issues where doctors' interpretation of shared decision-making and its reality in consultations differed from the ideals put forward in models. Further work should focus on the idea of shared decision-making being a process rather than evaluation concentrating on the decision. Studies which report what patients' experience should evaluate the elements of the process, instead of reporting who made the decision. The OPTION scale developed by Elwyn et al (2003) goes some way to target the competences put forward by the models; using these methods to evaluate consultation practice may be more accurate in reporting whether patients experience a shared decision-making consultation.

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APPENDICES

Appendix 1. Information sheet for survey participants.

MPRU

Medical Psychology Research Unit



The University of Sydney

RESEARCH STUDY INTO SHARED TREATMENT DECISION MAKING: A SURVEY OF CANCER DOCTORS' VIEWS AND ATTITUDES ACROSS AUSTRALIA.

Specialising in research into psycho-oncology and health communication

PARTICIPANT INFORMATION STATEMENT

You are invited to take part in a research study entitled Shared Treatment Decision Making: A survey of cancer doctors' views and attitudes across Australia. A recent study in Canada has shown that oncologists and surgeons working with early stage breast cancer patients expressed high levels of comfort with shared decision-making whilst reporting a significantly lower proportion of shared decision-making in their actual practice. This survey is intended to replicate the study conducted in Ontario, Canada to gain greater insight into perceived difficulties in implementing shared decision-making. It is hoped that the results will guide the development of training materials to facilitate practice in this area.

The survey is endorsed by John Collins, Chair of the Breast Section of The Royal Australasian College of Surgeons and by Owen Ung, Chair of the Breast Group of COSA.

The study is being conducted by Heather Shepherd, and will form the basis for the degree of Masters of Psychological Medicine at the University of Sydney under the supervision of Phyllis Butow and Martin Tattersall.

If you agree to participate in this study you will be asked to complete the enclosed questionnaire. Included is a stamped self-addressed envelope for its return. All information you provide will be strictly confidential and only the investigators named above will have access to the data. All questionnaire and computer data will be identified only by an ID number. A report of the study may be submitted for publication, but individual participants will not be identifiable.

Participation in this study is entirely voluntary: you are not obliged to participate and - if you do participate - you can withdraw at any time. The questionnaire will take approximately fifteen minutes to complete.

If you would like to know more at any stage, please contact:
Heather Shepherd, Research Assistant, 02 9036 5419
Phyllis Butow, 02 9515 7097
Martin Tattersall, 02 9351 3675.

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics Administration, University of Sydney on (02) 9351 4811.

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E: mtatt@med.usyd.edu.au

Thank you for considering this information. This information sheet is yours to keep.

Appendix 2. Consent form for postal survey

MPRU**Medical Psychology Research Unit**

The University of Sydney

**RESEARCH STUDY INTO SHARED TREATMENT DECISION MAKING: A
SURVEY OF CANCER DOCTORS' VIEWS AND ATTITUDES ACROSS
AUSTRALIA.**

**Specialising in
research into
psycho-oncology
and health
communication**

PARTICIPANT CONSENT FORM

I,[name]
have read and understood the information for participants on the above
named research study.

I freely choose to participate in this study and understand that I can
withdraw without compromise at any time.

I understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

Medical Psychology Research
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NSW 2006
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E: mtatt@med.usyd.edu.au

Signature:

Name:

Date:

Appendix 3. Survey sent to breast cancer specialists

Medical Psychology Research Unit

ID No. _____
Date __ / __ / __

Treatment Decision-Making Study

A Research Project Of The Medical Psychology Research Unit And The
Department Of Cancer Medicine, University Of Sydney

CONFIDENTIALITY:

We would like to ask you to complete the following questionnaire. All the information will be treated as *strictly confidential* and your identity will never be revealed in any reports. The completed questionnaires will be kept separately from any information that could identify you and will be kept securely under lock and key. There is no need for you to write your name on this questionnaire.

INSTRUCTIONS:

There are no right or wrong answers. Just tick (✓) those answers that most apply to you.

When you have completed the questionnaire, please return it in the enclosed reply paid envelope and post it within the next seven days if possible.

Thank you very much for your help in this study

Case load of women with newly diagnosed early stage breast cancer

1) How many newly diagnosed early stage breast cancer patients (stage 1 or 2) do you see on average in a one-month period?

(✓ one box only)

- 2 or less
- 3 to 6
- 7 to 10
- 11 to 15
- 16 to 20
- 21 +

Your approach to providing information to women with newly diagnosed early stage breast cancer.

2) Using a rating scale of 1 to 5, where 1= No information, 5= A great deal of information, to what extent do you give information to cancer patients about:

For each item circle one number only

A	Extent of the disease	1	2	3	4	5
B	Details of treatment procedures	1	2	3	4	5
C	Benefits of treatment	1	2	3	4	5
D	Risks (side effects) of treatment	1	2	3	4	5
E	Impact of treatment on sexuality	1	2	3	4	5
F	Changes in appearance due to treatment	1	2	3	4	5
G	Effects of treatment on mood	1	2	3	4	5
H	Effects of treatment on family	1	2	3	4	5
I	Effects of treatment on social activities	1	2	3	4	5
J	Effects of treatment on patients' ability to care for themselves at home	1	2	3	4	5

Your approach to treatment decision making with women with newly diagnosed early stage breast cancer.

To answer the following questions please look at examples below. Each example shows a different way in which a decision about treatment can be made with a patient. Now think about your approach to decision-making with cancer patients over the last 6 months:

- Example 1
 After reviewing the medical records and examining the patient the doctor decides on a suitable treatment and presents this to the patient. The doctor gives information about the treatment including risks and benefits. The patient accepts the treatment that the doctor recommends.
- Example 2
 After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor then recommends a treatment that the patient accepts.
- Example 3
 After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor asks the patient to decide on a treatment and states that s/he is the best person to make the decision. The patient decides and informs the doctor of the treatment s/he prefers.
- Example 4
 After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor invites the patient to ask any questions. The doctor asks what his/her preferences for treatment are given his/her lifestyle and the issues that are important to him/her. Together they decide on a suitable treatment to implement.

3) My approach is usually more like: (✓ one box only)

- Example 1
- Example 2
- Example 3
- Example 4
- None of these
- Other, please specify _____

- 4) On a scale of 1 to 5, indicate your level of comfort in using each of four approaches to treatment decision-making described in the examples above.
(For each example, circle one number only)

		Not comfortable	←—————→			Extremely comfortable
A	Example 1	1	2	3	4	5
B	Example 2	1	2	3	4	5
C	Example 3	1	2	3	4	5
D	Example 4	1	2	3	4	5

Comment:

- 5) In the last 6 months have **you** initiated a discussion with any of your newly diagnosed breast cancer patients about how much they wish to participate in deciding on their treatment?

(✓ Yes or No)

Yes

If yes, with what percentage of patients did you have this discussion?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

No

6)

- a) What percentage of patients preferred that you take full responsibility for making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

- b) What percentage preferred that you and the patient share making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

- c) What percentage preferred that the patient take full responsibility for making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

7) When treatment options are available for your newly diagnosed breast cancer patients do you usually give them a choice of treatment options?

(✓ one box only)

Yes

No

8) When treatment options are available for your newly diagnosed breast cancer patients do you usually give them a specific treatment recommendation?

(✓ one box only)

Yes

No

9) How important are the following to a process of "shared" treatment decision-making between clinician and patient?

(For **each** statement circle **one number** only.)

	Not important	←————→			Extremely important
	1	2	3	4	5
A The doctor gives information (about the disease, the risks and benefits of treatment options) to the patient.	1	2	3	4	5
B The patient gives information to the doctor about what is important to him/her.	1	2	3	4	5
C The doctor shows care and understanding.	1	2	3	4	5
D The doctor gives a treatment recommendation to the patient.	1	2	3	4	5
E The patient alone decides on the treatment.	1	2	3	4	5
F The doctor insists that the patient accept the recommended treatment.	1	2	3	4	5
G The patient and the doctor discuss the pros and cons of the treatment options.	1	2	3	4	5
H The doctor and patient together agree on the treatment to be given.	1	2	3	4	5
I Only the doctor and the patient are involved when deciding on treatment.	1	2	3	4	5
J The doctor, patient and others (such as family or spouse) are involved when deciding on treatment.	1	2	3	4	5
K Other, <i>please specify</i> :	1	2	3	4	5

There are many factors that influence how treatment decisions are made. Some factors make decision-making difficult and can be a barrier to the process. Other factors are helpful and enable decision making to happen more easily.

10) To what extent do you experience the following as difficulties during the treatment decision-making process?

(For **each** statement circle **one number** only.)

	Never	Sometimes	Often	Almost always
A Insufficient time to spend with the patient.	1	2	3	4
B The patient does not understand the information I have given.	1	2	3	4
C I have insufficient information to make a decision about treatment at the first consultation.	1	2	3	4
D The patient does not want to participate in treatment decision making as much as I would like her to.	1	2	3	4
E The patient wants to participate more in deciding on her treatment than I would like her to.	1	2	3	4
F The patient is indecisive.	1	2	3	4
G There are cultural differences between the patient and me.	1	2	3	4
H The patient has received conflicting recommendations from various specialists.	1	2	3	4
I The patient requests a treatment not known to be beneficial.	1	2	3	4
J The patient refuses a treatment that may benefit her.	1	2	3	4
K The patient has difficulty accepting she has breast cancer.	1	2	3	4
L The patient is too anxious to listen to what I have to say.	1	2	3	4
M The patient brings too much information to discuss.	1	2	3	4
N The patient has other health problems. (Eg. heart disease)	1	2	3	4
O The patient wants to make a decision before receiving the information from me.	1	2	3	4
P The patient's family overrides the decision making process.	1	2	3	4
Q The patient has misconceptions about the disease or treatment.	1	2	3	4
R I experience difficulty knowing how to frame the treatment options for the patient.	1	2	3	4
S The patient comes expecting a certain treatment rather than a consultation.	1	2	3	4
T Other, please specify _____	1	2	3	4

11) To what extent do you experience the following as helpful during the treatment decision-making process?

(For **each** statement circle **one number** only.)

	Never	Sometimes	Often	Almost always
A Providing written information to the patient.	1	2	3	4
B The patient wants to participate in making the treatment decision.	1	2	3	4
C The patient is prepared (knowledgeable about disease and treatment) for the consultation.	1	2	3	4
D The patient has someone with them at the consultation.	1	2	3	4
E The patient is emotionally ready for decision-making.	1	2	3	4
F The patient trusts me.	1	2	3	4

Communication skills

12) If the patient wants less involvement than you think is optimal, how can this be addressed?

(Please ✓ any of the following suggestions that you would support)

- Preparing patient for a greater role in decision-making, by offering question prompt lists prior to the consultation.
- Booklet explaining clinical decision-making.
- Booklet about patient roles explaining shared decision-making.
- Access for medical practitioners to training to enhance skills in meeting patients' preferences for Shared decision making
- Having a third person in the room
- Explicitly negotiating shared decision making
- Input from breast care nurse/CNC prior to consultation
- Offering the patient written information about the treatment options available to her
- Other, _____

13) When you believe that there is no medical reason why a treatment decision needs to be made on the first consultation, how do you think pts should be encouraged to reflect on the treatment options before making a decision?

(Please ✓ any of the following suggestions that you think would be valuable)

- Follow up appointment to make a decision
- Giving written information highlighting treatment options
- Audio-taping consultation
- Encourage pt to talk to treatment team and general practitioner
- Telephone follow up to discuss treatment decision
- Worksheets for the patient to help her articulate what is important for her.
- Other, _____

Demographic information

14) Are you:

- Male
 Female

15) In what year were you born?

16) In what year did you qualify as a doctor?

17) At which university did you complete your medical school training?

18) In what setting do you perform most of your clinical activity?

(✓ all that apply: if several please indicate most activity with an asterisk)

- Private practice
 Public Hospital
 Cancer Centre
 University affiliated practice
 Other setting, please specify _____

19) On average how many hours a week do you devote to direct patient care in oncology?

(✓ one box only)

- Less than 20 hours per week
 20 hours or more per week

20) What is the size of the community where you perform most of your clinical duties?

(✓ one box only)

- Less than 100,000
 100,000 to 500,000
 More than 500,000

Thank you very much for completing this questionnaire. Your contribution to this research is greatly appreciated.
To ensure you do not receive a reminder please return the questionnaire in the postage paid envelope provided.

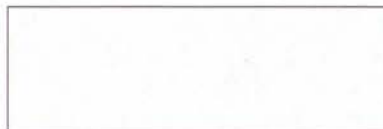
Appendix 4. Survey sent to urological cancer specialists

MPRU

Medical Psychology Research Unit



The University of Sydney

**Treatment Decision-Making Study**

A Research Project Of The Medical Psychology Research Unit And The Department
Of Cancer Medicine, University Of Sydney

CONFIDENTIALITY:

We would like to ask you to complete the following questionnaire. The completed questionnaires will be kept separately from any information that could identify you and will be kept securely under lock and key. There is no need for you to write your name on this questionnaire.

INSTRUCTIONS:

There are no right or wrong answers. Just tick (✓) those answers that most apply to you.

When you have completed the questionnaire, please return it in the enclosed reply paid envelope and post it within the next seven days if possible.

Thank you very much for your help in this study

Caseload of patients with newly diagnosed cancer

1)

- a) Which of the following types of cancer does the majority of your caseload represent? (✓ one box only)

- Colorectal/Gastrointestinal
 Leukaemia/lymphoma
 Head and Neck
 Lung
 Gynaecological
 Prostate/urological
 Other, please specify _____

- b) How many newly diagnosed cancer patients of the type indicated in Q1 above do you see on average in a one-month period? (✓ one box only)

- 2 or less
 3 to 6
 7 to 10
 11 to 15
 16 to 20
 21 +

- 2) Your approach to providing information to patients with newly diagnosed cancer.

Using a rating scale of 1 to 5, where 1= No information, 5= A great deal of information, to what extent do you give information to cancer patients about: **For each item circle one number only**

A	Extent of the disease	1	2	3	4	5
B	Details of treatment procedures	1	2	3	4	5
C	Benefits of treatment	1	2	3	4	5
D	Risks (side effects) of treatment	1	2	3	4	5
E	Impact of treatment on sexuality	1	2	3	4	5
F	Changes in appearance due to treatment	1	2	3	4	5
G	Effects of treatment on mood	1	2	3	4	5
H	Effects of treatment on family	1	2	3	4	5
I	Effects of treatment on social activities	1	2	3	4	5
J	Effects of treatment on patients' ability to care for themselves at home	1	2	3	4	5

Your approach to treatment decision making with patients with newly diagnosed cancer.

To answer the following questions please look at examples below. Each example shows a different way in which a decision about treatment can be made with a patient. Now think about your approach to decision-making with cancer patients over the last 6 months:

- Example 1
After reviewing the medical records and examining the patient the doctor decides on a suitable treatment and presents this to the patient. The doctor gives information about the treatment including risks and benefits. The patient accepts the treatment that the doctor recommends.
- Example 2
After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor then recommends a treatment that the patient accepts.
- Example 3
After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor asks the patient to decide on a treatment and states that s/he is the best person to make the decision. The patient decides and informs the doctor of the treatment s/he prefers.
- Example 4
After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor invites the patient to ask any questions. The doctor asks what his/her preferences for treatment are given his/her lifestyle and the issues that are important to him/her. Together they decide on a suitable treatment to implement.

3) My approach is usually more like: (✓ one box only)

- Example 1
 Example 2
 Example 3
 Example 4
 None of these
 Other, please specify _____

4) On a scale of 1 to 5, indicate your level of comfort in using each of four approaches to treatment decision-making described in the examples above. (For each example, circle one number only)

		Not comfortable	←—————→			Extremely comfortable
A	Example 1	1	2	3	4	5
B	Example 2	1	2	3	4	5
C	Example 3	1	2	3	4	5
D	Example 4	1	2	3	4	5

5) In the last 6 months, have you initiated a discussion with any of your cancer patients about how much they wish to participate in deciding on their treatment?

(✓ Yes or No)

Yes

If yes, with what percentage of patients did you have this discussion?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

No

8)

a) What percentage of patients preferred that you take full responsibility for making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

b) What percentage preferred that you and the patient share making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

c) What percentage preferred that the patient take full responsibility for making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

7) When treatment options are available for your cancer patients, do you usually give them a choice of treatment options? (✓ one box only)

Yes

No

8) When treatment options are available for your cancer patients, do you usually give them a specific treatment recommendation? (✓ one box only)

Yes

No

9) How important are the following to a process of "shared" treatment decision-making between clinician and patient?

(For each statement, circle one number only.)

	Not important	←————→			Extremely important	
A	The doctor gives information (about the disease, the risks and benefits of treatment options) to the patient.	1	2	3	4	5
B	The patient gives information to the doctor about what is important to him/her.	1	2	3	4	5
C	The doctor shows care and understanding.	1	2	3	4	5
D	The doctor gives a treatment recommendation to the patient.	1	2	3	4	5
E	The patient alone decides on the treatment.	1	2	3	4	5
F	The doctor insists that the patient accept the recommended treatment.	1	2	3	4	5
G	The patient and the doctor discuss the pros and cons of the treatment options.	1	2	3	4	5
H	The doctor and patient together agree on the treatment to be given.	1	2	3	4	5
I	Only the doctor and the patient are involved when deciding on treatment.	1	2	3	4	5
J	The doctor, patient and others (such as family or spouse) are involved when deciding on treatment.	1	2	3	4	5
K	Other, <i>please specify</i> .	1	2	3	4	5

10) To what extent do you experience the following as helpful during the treatment decision-making process?

(For each statement, circle one number only.)

	Never	Sometimes	Often	Almost always	
A	Providing written information to the patient.	1	2	3	4
B	The patient wants to participate in making the treatment decision.	1	2	3	4
C	The patient is prepared (knowledgeable about disease and treatment) for the consultation.	1	2	3	4
D	The patient has someone with them at the consultation.	1	2	3	4
E	The patient is emotionally ready for decision-making.	1	2	3	4
F	The patient trusts me.	1	2	3	4

There are many factors that influence how treatment decisions are made. Some factors make decision-making difficult and can be a barrier to the process. Other factors are helpful and enable decision making to happen more easily.

11) To what extent do you experience the following as difficulties during the treatment decision-making process?

(For each statement, circle one number only.)

	Never	Sometimes	Often	Almost always
A Insufficient time to spend with the patient.	1	2	3	4
B The patient does not understand the information I have given.	1	2	3	4
C I have insufficient information to make a decision about treatment at the first consultation.	1	2	3	4
D The patient does not want to participate in treatment decision making as much as I would like him/her to.	1	2	3	4
E The patient wants to participate more in deciding on his/her treatment than I would like him/her to.	1	2	3	4
F The patient is indecisive.	1	2	3	4
G There are cultural differences between the patient and me.	1	2	3	4
H The patient has received conflicting recommendations from various specialists.	1	2	3	4
I The patient requests a treatment not known to be beneficial.	1	2	3	4
J The patient refuses a treatment that may benefit her.	1	2	3	4
K The patient has difficulty accepting s/he has cancer.	1	2	3	4
L The patient is too anxious to listen to what I have to say.	1	2	3	4
M The patient brings too much information to discuss.	1	2	3	4
N The patient has other health problems. (Eg. heart disease)	1	2	3	4
O The patient wants to make a decision before receiving the information from me.	1	2	3	4
P The patient's family overrides the decision making process.	1	2	3	4
Q The patient has misconceptions about the disease or treatment.	1	2	3	4
R I experience difficulty knowing how to frame the treatment options for the patient.	1	2	3	4
S The patient comes expecting a certain treatment rather than a consultation.	1	2	3	4
T Other, <i>please specify</i> _____	1	2	3	4

Communication skills

12) If the patient wants less involvement than you think is optimal, how can this be addressed?
(Please ✓ any of the following suggestions that you would support)

- Preparing patient for a greater role in decision-making, by offering question prompt lists prior to the consultation.
- Booklet explaining clinical decision-making.
- Booklet about patient roles explaining shared decision-making.
- Access for medical practitioners to training to enhance skills in meeting patients' preferences for Shared decision making
- Having a third person in the room
- Explicitly negotiating shared decision making
- Input from Cancer Nurse Coordinator/CNC prior to consultation
- Offering the patient written information about the treatment options available to her
- Other, _____

13) When you believe that there is no medical reason why a treatment decision needs to be made on the first consultation, how do you think pts should be encouraged to reflect on the treatment options before making a decision?
(Please ✓ any of the following suggestions that you think would be valuable)

- Follow up appointment to make a decision
- Giving written information highlighting treatment options
- Audio-taping consultation
- Encourage pt to talk to treatment team and general practitioner
- Telephone follow up to discuss treatment decision
- Worksheets for the patient to help her articulate what is important for him/her.
- Other, _____

Demographic information

14) Are you:

- Male
 Female

15) In what year were you born? _____

16) In what year did you qualify as a doctor? _____

17) At which university did you complete your medical school training? _____

18) Are you a: (✓ one box only)

- Medical Oncologist
 Radiation Oncologist
 Surgeon
 Other, please specify _____

19) In what setting do you perform most of your clinical activity?

(✓ all that apply: if several please indicate most activity with an asterisk)

- Private practice
 Public Hospital
 Cancer Centre
 University affiliated practice
 Other setting, please specify _____

20) On average how many hours a week do you devote to direct patient care in oncology?

(✓ one box only)

- Less than 20 hours per week
 20 hours or more per week

21) What is the size of the community where you perform most of your clinical duties?

(✓ one box only)

- Less than 100,000
 100,000 to 500,000
 More than 500,000

Thank you very much for completing this questionnaire. Your contribution to this research is greatly appreciated.
To ensure you do not receive a reminder please return the questionnaire in the postage paid envelope provided.

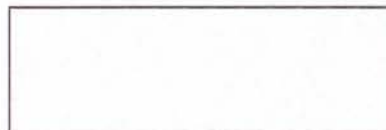
Appendix 5. Survey sent to colorectal, haematologists, gynaecological specialists

MPRU

Medical Psychology Research Unit



The University of Sydney

**Treatment Decision-Making Study**

A Research Project Of The Medical Psychology Research Unit And The Department
Of Cancer Medicine, University Of Sydney

CONFIDENTIALITY:

We would like to ask you to complete the following questionnaire. The completed questionnaires will be kept separately from any information that could identify you and will be kept securely under lock and key. There is no need for you to write your name on this questionnaire.

INSTRUCTIONS:

There are no right or wrong answers. Just tick (✓) those answers that most apply to you.

When you have completed the questionnaire, please return it in the enclosed reply paid envelope and post it within the next seven days if possible.

Thank you very much for your help in this study

Caseload of patients with newly diagnosed cancer

1)

a) Which of the following types of cancer does the majority of your caseload represent? (✓ one box only)

- Colorectal/Gastrointestinal
- Leukaemia/lymphoma
- Head and Neck
- Lung
- Gynaecological
- Prostate
- Other, please specify _____

b) How many newly diagnosed cancer patients of the type indicated in Q1 above do you see on average in a one-month period? (✓ one box only)

- 2 or less
- 3 to 6
- 7 to 10
- 11 to 15
- 16 to 20
- 21 +

2) Your approach to providing information to patients with newly diagnosed cancer.

Using a rating scale of 1 to 5, where 1= No information, 5= A great deal of information, to what extent do you give information to cancer patients about: *For each item circle one number only*

A	Extent of the disease	1	2	3	4	5
B	Details of treatment procedures	1	2	3	4	5
C	Benefits of treatment	1	2	3	4	5
D	Risks (side effects) of treatment	1	2	3	4	5
E	Impact of treatment on sexuality	1	2	3	4	5
F	Changes in appearance due to treatment	1	2	3	4	5
G	Effects of treatment on mood	1	2	3	4	5
H	Effects of treatment on family	1	2	3	4	5
I	Effects of treatment on social activities	1	2	3	4	5
J	Effects of treatment on patients' ability to care for themselves at home	1	2	3	4	5

Your approach to treatment decision making with patients with newly diagnosed cancer.

To answer the following questions please look at examples below. Each example shows a different way in which a decision about treatment can be made with a patient. Now think about your approach to decision-making with cancer patients over the last 6 months:

- =====
 ||| **Example 1** |||
 ||| After reviewing the medical records and examining the patient the doctor |||
 ||| decides on a suitable treatment and presents this to the patient. The doctor |||
 ||| gives information about the treatment including risks and benefits. The patient |||
 ||| accepts the treatment that the doctor recommends. |||
 ||| **Example 2** |||
 ||| After reviewing the medical records and examining the patient the doctor |||
 ||| presents the available treatment options. Information about the risks and |||
 ||| benefits of each option are given and discussed with the patient. The doctor |||
 ||| then recommends a treatment that the patient accepts. |||
 ||| **Example 3** |||
 ||| After reviewing the medical records and examining the patient the doctor |||
 ||| presents the available treatment options. Information about the risks and |||
 ||| benefits of each option are given and discussed with the patient. The doctor |||
 ||| asks the patient to decide on a treatment and states that s/he is the best |||
 ||| person to make the decision. The patient decides and informs the doctor of |||
 ||| the treatment s/he prefers. |||
 ||| **Example 4** |||
 ||| After reviewing the medical records and examining the patient the doctor |||
 ||| presents the available treatment options. Information about the risks and |||
 ||| benefits of each option are given and discussed with the patient. The doctor |||
 ||| invites the patient to ask any questions. The doctor asks what his/her |||
 ||| preferences for treatment are given his/her lifestyle and the issues that are |||
 ||| important to him/her. Together they decide on a suitable treatment to |||
 ||| implement. |||
 =====

3) My approach is usually more like: (✓ one box only)

- Example 1
 Example 2
 Example 3
 Example 4
 None of these
 Other, please specify _____

- 4) On a scale of 1 to 5, indicate your level of comfort in using each of four approaches to treatment decision-making described in the examples above.
(For each example, circle one number only)

		Not comfortable	←—————→			Extremely comfortable
A	Example 1	1	2	3	4	5
B	Example 2	1	2	3	4	5
C	Example 3	1	2	3	4	5
D	Example 4	1	2	3	4	5

Comment:

- 5) In the last 6 months have you initiated a discussion with any of your cancer patients about how much they wish to participate in deciding on their treatment?

(✓ Yes or No)

Yes

If yes, with what percentage of patients did you have this discussion?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

No

6)

- a) What percentage of patients preferred that you take full responsibility for making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

- b) What percentage preferred that you and the patient share making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

- c) What percentage preferred that the patient take full responsibility for making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

7) When treatment options are available for your cancer patients do you usually give them a choice of treatment options?

(✓ one box only)

Yes

No

8) When treatment options are available for your cancer patients do you usually give them a specific treatment recommendation?

(✓ one box only)

Yes

No

9) How important are the following to a process of "shared" treatment decision-making between clinician and patient?

(For each statement circle one number only.)

		Not important	←————→			Extremely important
		1	2	3	4	5
A	The doctor gives information (about the disease, the risks and benefits of treatment options) to the patient.	1	2	3	4	5
B	The patient gives information to the doctor about what is important to him/her.	1	2	3	4	5
C	The doctor shows care and understanding.	1	2	3	4	5
D	The doctor gives a treatment recommendation to the patient.	1	2	3	4	5
E	The patient alone decides on the treatment.	1	2	3	4	5
F	The doctor insists that the patient accept the recommended treatment.	1	2	3	4	5
G	The patient and the doctor discuss the pros and cons of the treatment options.	1	2	3	4	5
H	The doctor and patient together agree on the treatment to be given.	1	2	3	4	5
I	Only the doctor and the patient are involved when deciding on treatment.	1	2	3	4	5
J	The doctor, patient and others (such as family or spouse) are involved when deciding on treatment.	1	2	3	4	5
K	Other, <i>please specify</i> .	1	2	3	4	5

There are many factors that influence how treatment decisions are made. Some factors make decision-making difficult and can be a barrier to the process. Other factors are helpful and enable decision making to happen more easily.

10) To what extent do you experience the following as difficulties during the treatment decision-making process?

(For each statement circle one number only.)

	Never	Sometimes	Often	Almost always
A Insufficient time to spend with the patient.	1	2	3	4
B The patient does not understand the information I have given.	1	2	3	4
C I have insufficient information to make a decision about treatment at the first consultation.	1	2	3	4
D The patient does not want to participate in treatment decision making as much as I would like him/her to.	1	2	3	4
E The patient wants to participate more in deciding on his/her treatment than I would like him/her to.	1	2	3	4
F The patient is indecisive.	1	2	3	4
G There are cultural differences between the patient and me.	1	2	3	4
H The patient has received conflicting recommendations from various specialists.	1	2	3	4
I The patient requests a treatment not known to be beneficial.	1	2	3	4
J The patient refuses a treatment that may benefit her.	1	2	3	4
K The patient has difficulty accepting s/he has cancer.	1	2	3	4
L The patient is too anxious to listen to what I have to say.	1	2	3	4
M The patient brings too much information to discuss.	1	2	3	4
N The patient has other health problems. (Eg. heart disease)	1	2	3	4
O The patient wants to make a decision before receiving the information from me.	1	2	3	4
P The patient's family overrides the decision making process.	1	2	3	4
Q The patient has misconceptions about the disease or treatment.	1	2	3	4
R I experience difficulty knowing how to frame the treatment options for the patient.	1	2	3	4
S The patient comes expecting a certain treatment rather than a consultation.	1	2	3	4
T Other, <i>please specify</i> : _____	1	2	3	4

11) To what extent do you experience the following as helpful during the treatment decision-making process?

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	Never	Sometimes	Often	Almost always
A Providing written information to the patient.	1	2	3	4
B The patient wants to participate in making the treatment decision.	1	2	3	4
C The patient is prepared (knowledgeable about disease and treatment) for the consultation.	1	2	3	4
D The patient has someone with them at the consultation.	1	2	3	4
E The patient is emotionally ready for decision-making.	1	2	3	4
F The patient trusts me.	1	2	3	4

Demographic information

12) Are you:

- Male
 Female

13) In what year were you born?

14) In what year did you qualify as a doctor?

15) At which university did you complete your medical school training?

16) Are you a:

(✓ one box only)

- Medical Oncologist
 Radiation Oncologist
 Surgeon
 Other, please specify _____

17) In what setting do you perform most of your clinical activity?

(✓ all that apply: if several please indicate most activity with an asterisk)

- Private practice
 Public Hospital
 Cancer Centre
 University affiliated practice
 Other setting, please specify _____

Please Turn Over

18) On average how many hours a week do you devote to direct patient care in oncology?

(✓ one box only)

- Less than 20 hours per week
- 20 hours or more per week

19) What is the size of the community where you perform most of your clinical duties?

(✓ one box only)

- Less than 100,000
- 100,000 to 500,000
- More than 500,000

Thank you very much for completing this questionnaire. Your contribution to this research is greatly appreciated.
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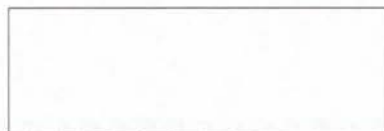
Appendix 6. Survey sent to paediatric oncologists

MPRU

Medical Psychology Research Unit



The University of Sydney

**Treatment Decision-Making Study**

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Thank you very much for your help in this study

Caseload of patients with newly diagnosed cancer

1)

a) Which of the following types of cancer does the majority of your caseload represent? (✓ one box only)

- Leukaemia/lymphoma
- Sarcoma
- Neurological
- Other, please specify _____

b) How many newly diagnosed cancer patients of the type indicated in Q1 above do you see on average in a one-month period? (✓ one box only)

- 2 or less
- 3 to 6
- 7 to 10
- 11 to 15
- 16 to 20
- 21 +

2) Your approach to providing information to patients, or their parent/guardian, with newly diagnosed cancer.

Using a rating scale of 1 to 5, where 1= No information, 5= A great deal of information, to what extent do you give information to cancer patients about: *For each item circle one number only*

A	Extent of the disease	1	2	3	4	5
B	Details of treatment procedures	1	2	3	4	5
C	Benefits of treatment	1	2	3	4	5
D	Risks (side effects) of treatment	1	2	3	4	5
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F	Changes in appearance due to treatment	1	2	3	4	5
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I	Effects of treatment on social activities	1	2	3	4	5
J	Effects of treatment on patients' ability to care for themselves at home	1	2	3	4	5

Your approach to treatment decision making with patients with newly diagnosed cancer.

To answer the following questions please look at examples below. Each example shows a different way in which a decision about treatment can be made with a patient. Now think about your approach to decision-making with cancer patients over the last 6 months:

- Example 1
 After reviewing the medical records and examining the patient the doctor decides on a suitable treatment and presents this to the patient. The doctor gives information about the treatment including risks and benefits. The patient accepts the treatment that the doctor recommends.
- Example 2
 After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor then recommends a treatment that the patient accepts.
- Example 3
 After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor asks the patient to decide on a treatment and states that s/he is the best person to make the decision. The patient decides and informs the doctor of the treatment s/he prefers.
- Example 4
 After reviewing the medical records and examining the patient the doctor presents the available treatment options. Information about the risks and benefits of each option are given and discussed with the patient. The doctor invites the patient to ask any questions. The doctor asks what his/her preferences for treatment are given his/her lifestyle and the issues that are important to him/her. Together they decide on a suitable treatment to implement.

3) My approach is usually more like: (✓ one box only)

- Example 1
- Example 2
- Example 3
- Example 4
- None of these
- Other, please specify _____

- 4) On a scale of 1 to 5, indicate your level of comfort in using each of four approaches to treatment decision-making described in the examples above.
(For each example, circle one number only)

	Not comfortable	←—————→			Extremely comfortable
A Example 1	1	2	3	4	5
B Example 2	1	2	3	4	5
C Example 3	1	2	3	4	5
D Example 4	1	2	3	4	5

Comment:

- 5) In the last 6 months have you initiated a discussion with any of your cancer patients, or their parent/guardian, about how much they wish to participate in deciding on their treatment?

(✓ Yes or No)

Yes

If yes, with what percentage of patients did you have this discussion?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

No

6)

- a) What percentage of patients, or their parent/guardian, preferred that you take full responsibility for making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

- b) What percentage preferred that you and the patient, or their parent/guardian, share making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

- c) What percentage preferred that the patient, or their parent/guardian, take full responsibility for making a decision about treatment?

(✓ one box only)

<10%

10-25%

26-50%

51-75%

>75%

7) When treatment options are available for your cancer patients do you usually give them, or their parent/guardian, a choice of treatment options?

(✓ one box only)

Yes

No

8) When treatment options are available for your cancer patients do you usually give them, or their parent/guardian, a specific treatment recommendation?

(✓ one box only)

Yes

No

9) How important are the following to a process of "shared" treatment decision-making between clinician and patient?

(For each statement circle one number only.)

		Not Important	←————→			Extremely important
A	The doctor gives information (about the disease, the risks and benefits of treatment options) to the patient.	1	2	3	4	5
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C	The doctor shows care and understanding.	1	2	3	4	5
D	The doctor gives a treatment recommendation to the patient and their parent/guardian.	1	2	3	4	5
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F	The doctor insists that the patient accept the recommended treatment.	1	2	3	4	5
G	The patient and the doctor discuss the pros and cons of the treatment options.	1	2	3	4	5
H	The doctor and patient, or their parent/guardian, together agree on the treatment to be given.	1	2	3	4	5
I	Only the doctor and the patient are involved when deciding on treatment.	1	2	3	4	5
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K	Other, <i>please specify</i> .	1	2	3	4	5

There are many factors that influence how treatment decisions are made. Some factors make decision-making difficult and can be a barrier to the process. Other factors are helpful and enable decision making to happen more easily.

10) To what extent do you experience the following as difficulties during the treatment decision-making process?

(For each statement circle one number only.)

	Never	Sometimes	Often	Almost always
A Insufficient time to spend with the patient and their parent/guardian.	1	2	3	4
B The patient, or their parent/guardian, does not understand the information I have given.	1	2	3	4
C I have insufficient information to make a decision about treatment at the first consultation.	1	2	3	4
D The patient does not want to participate in treatment decision making as much as I would like him/her to.	1	2	3	4
E The patient, or their parent/guardian, wants to participate more in deciding on his/her treatment than I would like him/her to.	1	2	3	4
F The patient, or their parent/guardian, is indecisive.	1	2	3	4
G There are cultural differences between the patient, or their parent/guardian, and me.	1	2	3	4
H The patient, or their parent/guardian, has received conflicting recommendations from various specialists.	1	2	3	4
I The patient, or their parent/guardian, requests a treatment not known to be beneficial.	1	2	3	4
J The patient, or their parent/guardian, refuses a treatment that may benefit him/her.	1	2	3	4
K The patient, or their parent/guardian has difficulty accepting s/he has cancer.	1	2	3	4
L The patient, or their parent/guardian, is too anxious to listen to what I have to say.	1	2	3	4
M The patient, or their parent/guardian brings too much information to discuss.	1	2	3	4
N The patient has other health problems. (Eg. heart disease)	1	2	3	4
O The patient, or their parent/guardian, wants to make a decision before receiving the information from me.	1	2	3	4
P The patient's family overrides the decision making process.	1	2	3	4
Q The patient, or their parent/guardian, has misconceptions about the disease or treatment.	1	2	3	4
R I experience difficulty knowing how to frame the treatment options for the patient, or their parent/guardian.	1	2	3	4
S The patient, or their parent/guardian, comes expecting a certain treatment rather than a consultation.	1	2	3	4
T Other, <i>please specify</i> : _____	1	2	3	4

11) To what extent do you experience the following as helpful during the treatment decision-making process?

(For each statement circle one number only.)

	Never	Sometimes	Often	Almost always
A Providing written information to the patient.	1	2	3	4
B The patient, or their parent/guardian, wants to participate in making the treatment decision.	1	2	3	4
C The patient, or their parent/guardian, is prepared (knowledgeable about disease and treatment) for the consultation.	1	2	3	4
D The patient, or their parent/guardian, has someone with them at the consultation.	1	2	3	4
E The patient, or their parent/guardian, is emotionally ready for decision-making.	1	2	3	4
F The patient, or their parent/guardian, trusts me.	1	2	3	4

Demographic information

12) Are you:

- Male
 Female

13) In what year were you born?

14) In what year did you qualify as a doctor?

15) At which university did you complete your medical school training?

16) Are you a:

(✓ one box only)

- Medical Oncologist
 Radiation Oncologist
 Surgeon
 Other, please specify _____

17) In what setting do you perform most of your clinical activity?

(✓ all that apply: if several please indicate most activity with an asterisk)

- Private practice
 Public Hospital
 Cancer Centre
 University affiliated practice
 Other setting, please specify _____

Please Turn Over

18) On average how many hours a week do you devote to direct patient care in oncology?

(✓ one box only)

- Less than 20 hours per week
- 20 hours or more per week

19) What is the size of the community where you perform most of your clinical duties?

(✓ one box only)

- Less than 100,000
- 100,000 to 500,000
- More than 500,000

Thank you very much for completing this questionnaire. Your contribution to this research is greatly appreciated.
To ensure you do not receive a reminder please return the questionnaire in the postage paid envelope provided.

Appendix 7. Information sheet for telephone interview participants.

MPRU

Medical Psychology Research Unit



The University of Sydney

Research in psycho-
oncology and health
communication

RESEARCH STUDY INTO SHARED TREATMENT DECISION MAKING: A SURVEY OF CANCER DOCTORS' VIEWS AND ATTITUDES ACROSS AUSTRALIA.

PARTICIPANT INFORMATION STATEMENT

Recently you participated and completed our survey identifying cancer doctors' views about and attitudes to shared treatment decision making across Australia. The results from this postal survey suggest that some doctors believe that shared decision-making is appropriate in some but not all clinical situations. We are now exploring further the characteristics of situations in which doctors feel shared decision making is appropriate or not. It is hoped that the results will guide the development of training materials and resources which target the clinical situations where shared decision making is most likely to be used.

In order to achieve this we are conducting telephone interviews with a number of respondents to our survey. If you agree to participate in this second stage of the study you will be contacted by telephone at a time convenient for you and asked to participate in a semi-structured interview exploring clinical situations where different decision-making approaches are acceptable to clinicians. The interview will last approximately 15 minutes and will be audio-taped so that no information is lost. Included is a consent form with a stamped self-addressed envelope for its return. If you are happy to participate, please indicate on the consent the best time(s) for the research co-ordinator to phone you. All information you provide will be strictly confidential and only the investigators named below will have access to the data. All audiotapes and computer data will be identified only by an ID number, and will be destroyed after 7 years, as required by NHMRC. A report of the study may be submitted for publication, but individual participants will not be identifiable.

Participation in this study is entirely voluntary: you are not obliged to participate and - if you do participate - you can withdraw at any time.

The study is being conducted by Heather Shepherd, and will form the basis for the degree of Doctor of Philosophy in the School of Psychological Medicine at the University of Sydney under the supervision of Professors Phyllis Butow and Martin Tattersall.

If you would like to know more at any stage, please contact:

Heather Shepherd, Research Assistant, 02 9036 5419

Phyllis Butow, 02 9351 2859

Martin Tattersall, 02 9351 3675.

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gabriody@mail.usyd.edu.au (Email).

This information sheet is for you to keep

Appendix 8. Consent form for telephone interviews

MPRU

Medical Psychology Research Unit



The University of Sydney

Research in psych-
oncology and health
communicationRESEARCH STUDY INTO SHARED TREATMENT DECISION MAKING: A SURVEY OF
CANCER DOCTORS' VIEWS AND ATTITUDES ACROSS AUSTRALIA.

PARTICIPANT CONSENT FORM (semi structured telephone interviews)

In giving my consent I acknowledge that:

I, give consent to my participation in the research project
Name (please print)

TITLE:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) now or in the future.
4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

Signed:

Name:

Date:

My contact telephone number is _____

Please suggest a time that would be convenient for us to contact you. Or circle a time below.

The most convenient time/s to reach me by telephone are: _____

Monday	Tuesday	Wednesday	Thursday	Friday
9am	9am	9am	9am	9am
11am	11am	11am	11am	11am
3pm	3pm	3pm	3pm	3pm
5pm	5pm	5pm	5pm	5pm

Appendix 9 Questions for telephone interviews

Project Title" Shared Treatment Decision Making: A survey of cancer doctors' views and attitudes across Australia. HREC Approval Number: 7575

Questions for semi-structured telephone interviews

- 1) Can you tell me what you think are the most important features of involving patients in decision making?

- 2) What do you think about involving patients in making treatment decisions?
 - a. What about it is good or bad for the patient?
 - b. What about it is good or bad for you?
 - c. What about it is good or bad for the health system as a whole?

- 3) GPs have said that SDM is useful in some situations (e.g. AF, menorrhagia, HRT,) but not in others. Do you think there are situations where SDM is more appropriate than others? If so, what are they? Which clinical scenarios?
 - a. (If respond with "where there is clear choice") How do you determine when there is clear choice?
 - b. How do you determine if the patient views this in the same way you do? E.g. patients may be interested in the no treatment option?
 - c. Do you think it is ever appropriate not to disclose a treatment option? For example, if it is expensive and you know the patient has a limited income?
 - d. Are there circumstances in which you either have not or might disclose a clinically relevant option to a particular patient? (or might not disclose an option that you would sometimes mention to other patients with the same diagnoses)
 - e. Can you describe how you would normally present treatment options to your patients? Do you list them in order of your preference/recommendation? Do you present equal amounts of information on each? Do you spend more time on the ones you think are more appropriate?

- 4) In our survey doctors who treated breast and urological cancers were more positive about SDM than others. Why do you think that might be?

- 5) Some patients don't want SDM. To what extent do you think patients vary in terms of their preferences for SDM? Do you establish if your patients want to participate in decision making? How do you establish whether your patient wants SDM?
 - a. In your experience what sorts of patients tend to like and dislike SDM?
 - b. In what senses do you think patients like/dislike SDM? Or are there particular aspects which patients like/dislike?

- c. Would you ever encourage passive patients to participate or do you simply accept their passivity? How do you decide which patients to push a little? How would you go about encouraging them to SDM?
- 6) In our survey, some doctors reported that some patients are incapable of SDM because they are too anxious, or lack understanding of their disease status and/or the information they receive— do you agree?
 - a. Can you give an example of a patient who could not share decision-making?
- 7) In your experience does SDM take up extra time? Does it ever save time down the track?
- 8) Do you routinely offer a patient a follow-up consultation so they have time to think about the treatment choices?
 - a. What might prohibit this approach?
- 9) How, if at all do you think SDM impacts on your own and the patient's responsibility for the decision? Does SDM shift the ultimate decision responsibility? How easy or difficult is this for you and for the patient?
- 10) SDM involves sharing responsibility for the decision as well as information about the options and consequences of these. Is this difficult?
 - a. For you? How?
 - b. For the patient? How?

Appendix 10. Published manuscript



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The context influences doctors' support of shared decision-making in cancer care

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Most cancer patients in westernised countries now want all information about their situation, good or bad, and many wish to be involved in decision-making. The attitudes to and use of shared decision-making (SDM) by cancer doctors is not well known. Australian cancer clinicians treating breast, colorectal, gynaecological, haematological, or urological cancer were surveyed to identify their usual approach to decision-making and their comfort with different decision-making styles when discussing treatment with patients. A response rate of 59% resulted in 624 complete surveys, which explored usual practice in discussing participation in decision-making, providing information, and perception of the role patients want to play. Univariate and multivariate analyses were performed to identify predictors of use of SDM. Most cancer doctors (62.4%) reported using SDM and being most comfortable with this approach. Differences were apparent between reported high comfort with SDM and less frequent usual practice. Multivariate analysis showed that specialisation in breast or urological cancers compared to other cancers (AOR 3.02), high caseload of new patients per month (AOR 2.81) and female gender (AOR 1.87) were each independently associated with increased likelihood of use of SDM. Barriers exist to the application of SDM by doctors according to clinical situation and clinician characteristics.

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Keywords: shared decision-making; doctor speciality; doctor discipline; treatment decisions

Shared decision-making (SDM) is perceived by many as the preferred way for health professionals and patients to approach treatment decisions. Public expectation to be fully informed about healthcare and available options has increased over recent years and there is decreasing acceptance of paternalism, highlighted in references to patients as consumers in the medical ethics and healthcare literature (Shotton, 1997). Meeting the involvement preferences of patients has positive effects on outcomes such as increased patient satisfaction and reduced decisional conflict and improved concordance with treatment regimens (Anderson *et al*, 1995; Jahng *et al*, 2005).

Shared decision-making lies between paternalism and informed decision-making and can be considered an important component of patient-centred care (Edwards *et al*, 2003). Shared decision-making involves two steps: presentation of facts about treatment options and discussion of preferences, with the doctor's and patient's values together determining the final decision (Eddy, 1990). The challenges for the clinician are to minimise patients' misunderstanding and misinterpretation of risks or benefits of treatment and to avoid imposing his or her own treatment preferences onto the patient.

From the clinician's perspective, SDM is a useful way of presenting to patients the reality that outcomes in medicine are not certain. Shared decision-making is particularly appropriate in instances where there is more than one clinically reasonable treatment option or where there is a reasonable degree of uncertainty in the outcome of a particular intervention (Whitney *et al*, 2003; Kaplan, 2004).

The literature suggests that SDM is not always achieved, although it is not clear whether patient or doctor barriers are more important. The preferences of cancer patients in this area have been widely studied (Say *et al*, 2006) but information is limited on the attitudes and practise of cancer clinicians when discussing treatments.

We surveyed cancer clinicians across Australia from August 2004 to May 2006 to document their views on SDM and discover whether their views differed systematically according to doctor characteristics. We aimed to gain an expansive understanding of use and support of the different approaches to decision-making when discussing treatment options and did not identify particular clinical situations in the survey instrument. We hypothesised that certain factors may influence the support and use of SDM such as doctor speciality, clinician practice, practice setting, and patient caseload. As younger doctors have been educated in evidence-based medicine and during the rise of medical consumerism, we also expected more positive attitudes to SDM in this age group. Other doctor characteristics might also influence attitudes and practise. Because of reduced access to some treatments and therefore reduced choice for patients in rural areas, we thought that doctors practising in rural communities might favour a SDM approach less than their colleagues in urban practices.

MATERIALS AND METHODS

Participants

Medical and radiation oncologists and surgeons practising mainly in oncology across Australia specialising in managing people with

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five tumour types (breast, colorectal, gynaecological, haematological, or urological cancers) were invited to participate in the study. Doctors were identified through the Australia and New Zealand Breast Cancer Trials Group, the Royal Australian College of Surgeons – Breast Section, the Medical Oncology Group of Australia, the Colorectal Surgical Society of Australasia, Australian Society of Gynaecologic Oncologists, the Australasian Leukaemia and Lymphoma Group, and the Urological Society of Australasia. The invitation letter clearly stated the intended participants as cancer doctors. Doctors who had retired from active practice were excluded from the study.

Questionnaire

The survey instrument was based on a structured questionnaire developed by Charles *et al.* (2003, 2004) in Ontario, Canada in 1998 through a process of focus groups and pilot-testing. With permission, we used this questionnaire with some alterations. The survey presented unlabelled examples constructed from the conceptual framework presented by Charles *et al.* (1997, 1999) in earlier publications to reflect the following decision-making approaches: paternalistic, information-sharing only, informed, and shared (see Figure 1). Doctors were asked to select which of the examples best reflected their usual approach to treatment decision-making with their newly diagnosed or newly referred patients. Doctors were asked to rate their comfort levels with each of the decision-making approaches on a five-point Likert scale, from not comfortable to extremely comfortable. Doctors also indicated with what percentage of their patients they usually initiated a discussion concerning participation in decision-making, whether they routinely offered a treatment recommendation, and which role they felt their patients wanted to play: passive, shared, or active. Finally, doctors indicated the amount of detail they usually provide from 1 = no information to 5 = a great deal of information on 10 topics related to the benefits and costs of treatment options.

Design and procedures

This was a cross-sectional survey. Permission was sought to obtain contact details of all group members from each representative

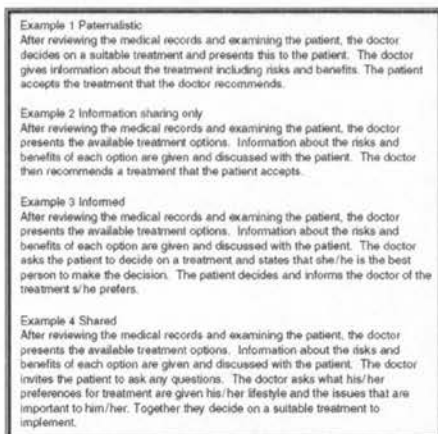


Figure 1 Treatment decision-making examples.

body. If this was granted, the research team sent each doctor a package through the mail which included a letter inviting their participation and outlining that the survey intended to compare views of cancer doctors, an information sheet, a consent form, a copy of the questionnaire, and postage-paid envelope. If contact details were not provided, the packages were distributed by the representative body. Written endorsement of the survey was sought and obtained from representative bodies. Reminders were dispatched at 6 and 12 weeks if no response had been received. A modified approach by Dillman (1978) was used to follow up invited participants. The second contact was by mail and comprised a letter reminding the participant of the questionnaire and the value their input would bring to the study. The third and final contact included a second copy of the questionnaire with a return envelope, a letter outlining the aims of the survey, and a further reminder of the importance of their contribution and the proportion of completed surveys that had been received so far. The returned surveys were anonymous.

Data analysis

Demographics and characteristics of the sample were analysed using descriptive statistics. Univariate analysis was completed to identify associations between variables and usual approach to decision-making and high comfort with SDM. Logistic regression analyses were completed with usual approach, recoded as shared or not, and with comfort, recoded as low or high, as the dependent variables in multivariate analysis to identify predictors of use of and comfort with SDM. Covariates for initial inclusion into the model were identified through univariate analysis ($P \leq 0.25$). To identify the final predictive factors for retention in the model, we applied multivariable logistic regression analysis. We used the likelihood ratio test in a backwards elimination process, with $P < 0.05$ for a covariate to be retained in the final model. Model fit was assessed with Hosmer–Lemeshow goodness of fit χ^2 tests. All analyses were performed using SPSS for Windows Version 14.

RESULTS

Participants

Of 1198 total surveys mailed, 136 were returned and regarded as being ineligible (doctor retired, deceased, not clinically active, overseas, and incorrect address). From the remaining 1062 eligible participants, 632 surveys were returned, a response rate of 59%. Eight respondents declined to participate. Twenty of the surveys were completed by clinicians who reported that they did not treat patients in the five targeted tumour groups; therefore, these data were excluded from statistical analysis. The response rate was higher in the groups where the researchers contacted the participants directly, perhaps because the mailing list being used by the professional society did not exclude retired or non-practising doctors. Within the non-respondents, tumour specialties were breast 30%, colorectal 10%, gynaecological 2%, haematological 9%, urological 42% and 7% unknown. The high non-responders in the urological cohort may reflect the mail out method in this group. Excluding the urological cohort on whom we had no information, 89% of the non-responders were male. Comparison of these characteristics with the study sample reveals no notable differences.

Table 1 shows the demographics of the 604 participating clinicians. Males (83.3%) made up the larger proportion of the sample. Mean age of the sample was 50 years and mean number of years medically qualified was 26 years. The majority (68.8%) worked >20h per week in direct patient care. The majority (58.7%) worked in community sizes of >500 000.

**Table 1** Demographics of sample

Variable	N (%) ^a
Cancer type	
Breast	308 (51.0)
Colorectal	79 (13.1)
Gynaecological	27 (4.5)
Leukaemia/lymphoma	83 (13.7)
Urological	107 (17.7)
Doctor type	
Medical oncologist	126 (20.9)
Radiation oncologist	51 (8.4)
Surgeon	354 (58.6)
Haematologist	61 (10.1)
Paediatric oncologist	12 (2.0)
Gender	
Male	544 (83.3)
Female	101 (16.7)
Medical training	
Australia	544 (90.4)
Other	58 (9.6)
Direct patient care per week	
<20 h	170 (31.2)
20 h or more	375 (68.8)
Main place of clinical work	
Private hospital	217 (39.8)
Public hospital	165 (30.3)
Cancer centre	43 (7.9)
University affiliated	8 (1.5)
Public/private 50/50	111 (20.4)
Other	1 (0.2)
Community size	
<100 000	41 (7.5)
100 000–500 000	184 (33.8)
>500 000	319 (58.7)
Caseload of new patients per month^b	
2 or less	81 (13.5)
3–6	232 (38.8)
7–10	147 (24.6)
11–15	69 (11.5)
16–20	37 (6.2)
21+	32 (5.4)
Median	3–6 new patients per month
Age (mean)	50 years (32–79 years)
Years qualified (mean)	26 years (4–56 years)

^aPercentages based on valid cases only. ^bWith specified cancer.

Usual approach to decision-making

The majority reported that their usual approach to decision-making with cancer patients was most like the SDM approach (see Table 2). The paternalistic approach and the informed decision-making approach were selected by fewer doctors.

Most doctors (82.1%) reported initiating a discussion about participating in decision-making with their patients; however, only 62.5% instigated this dialogue with more than half of their patients. Offering treatment options when available was almost unanimously supported (98.5%).

Comfort with different approaches to decision-making

Comfort levels with each of the four decision-making approaches are shown in Table 2. The model with which most doctors (59.7%)

reported being most comfortable was the SDM approach; 37.1% reported being least comfortable with the paternalistic model.

Information giving

The amount and type of information doctors routinely gave to newly diagnosed or newly referred patients varied according to specialty (Table 3). Items that doctors gave the most information about were extent of disease, treatment procedures, and benefits and risks. Items about which doctors gave the least information were effects of treatment on family, sexuality, and mood. The amount of information given was scored out of 50; the mean score was 37.38, s.d. 5.372.

Comparing the mean scores of amount of information given by clinicians according to their usual approach to decision-making revealed that doctors using SDM gave significantly more information (mean score 38.27) than doctors who reported not using SDM (mean 35.86), $P = 0.00$.

Clinician perception of patient role preference

Forty-five per cent of doctors reported that more than half of their patients preferred to share decision-making responsibility with their doctors (see Table 4). When this response was examined by specialty and doctor discipline, significantly more urological (55.1%) and breast (53.4%) cancer doctors reported that more than half of their patients wanted to share responsibility ($P = 0.00$, d.f. = 4, OR = 42.35). Significantly more medical oncologists ($P = 0.00$, d.f. = 4, OR = 32.94) than other disciplines reported that more than half of their patients wanted to share decision-making responsibility. The other disciplines stated that the majority of their patients wanted the doctor to take the decision-making responsibility. Very few clinicians (<10%) felt that the majority of their patients wanted to take the lead in this process.

Predictors of usual approach to decision-making

The original four category response to usual approach to decision-making was collapsed into two categories; SDM or not. This decision was taken as only example 4 describes SDM fully, incorporating sharing of decision-making responsibility, encouragement of patient involvement, and discussion of patient preferences and values relevant to the situation.

We analysed the data using crosstabs and χ^2 to identify significant predictors of usual approach to decision-making. Univariate analysis results are presented in Table 5.

More medical oncologists (66.1%) and surgeons (66.2%) reported using a shared approach than other doctors. The duration of direct patient care per week and the size of the community in which the doctors practised did not influence the approach to treatment decision-making. More doctors specialising in breast or urological cancer reported using a shared approach than doctors specialising in colorectal, gynaecological, or haematological cancer. To further explore these results, we grouped the clinicians into those treating cancers with well-known preference-sensitive decisions and those where there are not. Breast and urology cancer doctors (prostate cancer) were combined to form the preference sensitive group ($n = 415$) and colorectal, gynaecological, and leukaemia/lymphoma doctors were grouped as the non-preference sensitive group ($n = 189$). This variable was included in the multivariate analysis reported below.

We performed binary logistic regression of usual approach to decision-making (shared or non-shared) using independent variables with χ^2 of <0.25. Variables entered in the model were cancer type (breast and urological doctors vs colorectal, gynaecological, and haematological doctors, gender, age (three groups), new patient caseload per month (2 or less, 3–6, 7–10, or >11), and country of medical training (Australia vs elsewhere). We used

Table 2 Usual approach to decision-making and comfort levels with each approach

	Usual approach N (%)	Not comfortable N (%)	Somewhat comfortable N (%)	Neutral N (%)	Very comfortable N (%)	Extremely comfortable N (%)
Paternalistic (example 1)	6 (1.0)	198 (37.1)	144 (27.0)	85 (15.9)	60 (11.3)	46 (8.6)
Information sharing (example 2)	138 (23.2)	39 (7.3)	95 (17.8)	135 (25.3)	154 (28.9)	110 (20.6)
Informed (example 3)	49 (8.2)	73 (13.7)	118 (22.1)	115 (21.5)	145 (27.2)	83 (15.5)
Shared (example 4)	372 (62.4)	11 (2.1)	23 (4.3)	49 (9.1)	133 (24.8)	320 (59.7)
None of these	1 (0.2)					
Other	30 (5.0)					

Table 3 Amount of information given to new patients

	No information N (%)	A little information N (%)	Some information N (%)	Quite a bit of information N (%)	Great deal of information N (%)	Mean (s.d.)
Extent of the disease	1 (0.2)	4 (0.7)	37 (6.2)	233 (38.8)	326 (54.2)	4.46 (0.658)
Details of treatment procedures	1 (0.2)	0 (0)	22 (3.7)	193 (32.1)	385 (64.1)	4.60 (0.578)
Benefits of treatment	1 (0.2)	0 (0)	18 (3.0)	234 (39.1)	346 (57.8)	4.54 (0.573)
Risks (side effects) of treatment	1 (0.2)	2 (0.3)	36 (6.0)	237 (39.5)	324 (54.0)	4.47 (0.640)
Impact of treatment on sexuality	34 (5.7)	128 (21.4)	189 (31.6)	136 (22.7)	111 (18.6)	3.27 (1.158)
Changes in appearance due to treatment	22 (3.7)	63 (10.5)	197 (32.9)	218 (36.4)	99 (16.5)	3.52 (1.006)
Effects of treatment on mood	41 (6.8)	135 (22.5)	247 (41.1)	133 (22.1)	45 (7.5)	3.01 (1.010)
Effects of treatment on family	51 (8.5)	179 (29.8)	223 (37.1)	107 (17.8)	41 (6.8)	2.85 (1.033)
Effects of treatment on social activities	22 (3.7)	114 (19.0)	233 (38.8)	178 (29.7)	53 (8.8)	3.21 (0.972)
Effects of treatment on patients' ability to care for themselves at home	15 (2.5)	72 (12.0)	194 (32.4)	229 (38.2)	89 (14.9)	3.51 (0.969)
Total information giving score						37.38 (5.372)

Table 4 Perception of patient preferred role

	Doctor takes full responsibility N (%) ^a	Share responsibility N (%) ^a	Patient takes full responsibility N (%) ^a	χ^2 (d.f.)
Cancer specialty				$\chi^2(4) = 17.16^{**}$
Breast	80 (26.8)	159 (53.4)	4 (1.3)	
Colorectal	41 (52.6)	26 (33.3)	1 (1.3)	
Leukaemia/lymphoma	43 (53.8)	18 (22.5)	1 (1.3)	
Gynaecological	16 (61.5)	5 (19.2)	0 (0.0)	
Urological	22 (20.6)	59 (55.1)	2 (1.9)	
Doctor type				$\chi^2(4) = 31.13^{**}$
Medical oncologists	29 (24.2)	70 (58.3)	2 (1.7)	
Radiation oncologists	22 (44.0)	15 (30.0)	0 (0.0)	
Haematologists	31 (52.5)	11 (18.6)	0 (0.0)	
Paediatric oncologists	5 (45.5)	4 (36.4)	1 (9.1)	
Surgeons	115 (33.0)	167 (47.9)	5 (1.4)	

d.f. = degrees of freedom. ** $P < 0.01$. ^a% of doctors who reported the role > 50% of their patients preferred.

a backward stepwise likelihood ratio model; non-shared was the reference category of the dependent variable. The final model has a χ^2 of 51.31, d.f. = 5, $P = 0.00$. Goodness of fit is supported by the Hosmer-Lemeshow test; χ^2 4.62, d.f. = 7, $P = 0.71$.

Doctors practising in breast or urological cancer were three times as likely to use a shared approach compared to colorectal, gynaecological, or haematological doctors ($P < 0.001$, OR = 3.02, 95% CI 2.08-4.37). Doctors reporting the highest numbers of new patients per month had 2.8 times the odds of using a shared approach ($P < 0.005$, OR = 2.81, 95% CI 1.54-5.16). Female doctors had 1.9 times the odds of using shared approach compared to their male colleagues ($P < 0.001$, OR = 1.87, 95% CI 1.13-3.10). Variables not independently associated with usual approach to decision-making were country of medical training and age (see Table 6).

Predictors of comfort with SDM

Univariate analysis was undertaken for high comfort with the SDM (see Table 7). Shared decision-making was rated with the highest comfort levels by doctors treating breast or urological cancers (87.6%). Medical (89.0%) and radiation oncologists (78%) and surgeons (84.3%) reported being most comfortable with the shared approach.

We performed binary logistic regression of comfort with SDM (low comfort or high comfort) using independent variables with χ^2 of < 0.25 . Variables entered in the model were cancer type (breast and urological doctors vs colorectal, gynaecological, and haematological doctors), doctor gender, and new patient caseload per month. We used a backward stepwise likelihood ratio model: low comfort was the reference category of the dependent variable. The

Table 5 Univariate analyses of usual DM approach by doctor characteristics

	Non-shared N (%)	Shared N (%)	χ^2 (d.f.)
Doctor type			
Medical oncologists	42 (33.9)	82 (66.1)	$\chi^2(4) = 15.240^{**}$
Radiation oncologists	24 (48.0)	26 (52.0)	
Surgeons	118 (33.8)	231 (66.2)	
Haematologists	32 (52.5)	29 (47.5)	
Paediatric oncologists	8 (66.7)	4 (33.3)	
Tumour type			
Breast	99 (32.9)	202 (67.1)	$\chi^2(4) = 37.256^{**}$
Colorectal	42 (53.8)	36 (46.2)	
Leukaemia/lymphoma	44 (53.0)	39 (47.0)	
Gynaecological	16 (59.3)	11 (40.7)	
Urological	23 (21.5)	84 (78.5)	
Cancer speciality			
Breast and urological	122 (29.9)	286 (70.1)	$\chi^2(1) = 32.538^{**}$
Colorectal, gynaecology, and haematology	102 (54.3)	86 (45.7)	
Gender			
Male	198 (39.9)	298 (60.1)	$\chi^2(1) = 6.873^{**}$
Female	26 (26.0)	74 (74.0)	
Age			
Under 40 years	25 (29.4)	60 (70.6)	$\chi^2(2) = 2.802$
40–55 years	125 (39.2)	194 (60.8)	
Over 55 years	73 (38.2)	118 (61.8)	
Country of medical training			
Australia	195 (36.4)	341 (63.6)	$\chi^2(1) = 2.313$
Other	27 (46.6)	31 (53.4)	
New patient caseload per month			
2 or less	38 (47.5)	42 (52.5)	$\chi^2(3) = 10.345^{**}$
3–6	90 (39.6)	137 (60.4)	
7–10	56 (38.4)	90 (61.6)	
11+	37 (27.0)	100 (73.0)	
Direct patient care per week			
<20 hrs	63 (38.0)	103 (62.0)	$\chi^2(1) = 0.694$
20+ hrs	127 (34.2)	244 (65.8)	
Community size			
<100 000	12 (30.0)	28 (70.0)	$\chi^2(2) = 7.06$
100 000–500 000	63 (34.8)	118 (65.2)	
500 000+	115 (36.5)	200 (63.5)	

d.f. = degrees of freedom. * $P < 0.05$, ** $P < 0.01$.

final model has a χ^2 of 23.55, d.f. = 5, $P = 0.00$. Goodness of fit is supported by the Hosmer–Lemeshow test; χ^2 10.55, d.f. = 6, $P = 0.10$.

In multivariate regression analysis, doctors practising in breast or urological cancer were 2½ times as likely to be very comfortable with SDM compared to colorectal, gynaecological, or haematological doctors ($P < 0.001$, OR = 2.53, 95% CI 1.52–4.24). Female doctors had 2.3 times the odds of being very comfortable with SDM compared to their male counterparts ($P < 0.05$, OR = 2.31, 95% CI 1.01–5.27). Overall caseload did not produce a significant result; however, doctors reporting the highest numbers of new patients per month showed 2.3 times the odds of being very comfortable using SDM ($P = 0.05$, OR = 2.33, 95% CI 0.10–5.44) (see Table 8).

Our results show a discrepancy between reported usual practice of SDM and high comfort with that approach. This mismatch is highest in the gynaecological doctors (48.2%) (see Table 9).

Table 6 Multivariate Logistic Regression predicting usual approach to decision-making

Independent variables	β (s.e.)	Wald (χ^2) (d.f.)	AOR (95% CI)
Age	0.00 (0.14)	$\chi^2(1) = 0.00$	1.00 (0.75–1.33)
Country of training			
Australia	0.42 (0.30)	$\chi^2(1) = 1.98$	1.52 (0.85–2.74)
Other			
Caseload			
0–2		$\chi^2(3) = 11.33^{**}$	1.00
3–6	0.53 (0.27)	$\chi^2(1) = 3.78$	1.71 (1.00–2.92)
7–10	0.57 (0.29)	$\chi^2(1) = 3.74$	1.77 (0.99–3.14)
>11	1.03 (0.31)	$\chi^2(1) = 11.23^{**}$	2.81 (1.54–5.16)
Cancer speciality			
Colorectal, gynaecology, and haematological	1.10 (0.19)	$\chi^2(1) = 33.94^{**}$	3.02 (2.08–4.37)
Breast and urological			
Gender			
Male			1.00
Female	0.63 (0.26)	$\chi^2(1) = 5.99^{**}$	1.87 (1.13–3.10)

AOR = adjusted odds ratio; d.f. = degrees of freedom; 95% CI = 95% confidence interval. * $P < 0.05$, ** $P < 0.01$.

DISCUSSION

We investigated usual practice and comfort levels with treatment decision-making across cancer care in Australia. Our expectation that differences would exist between tumour specialties and between doctor disciplines was supported. Since a clear treatment choice is available in the management of early breast cancer and because of the breast cancer consumer movement, we expected more positive attitudes to SDM to be evident in surgeons treating this disease. Demographic differences were apparent in Australian clinicians' approach to decision-making, not only in their usual practice but also in their comfort with the styles presented in the survey.

Comfort with and use of SDM

Respondents reported high levels of comfort with SDM and discomfort with a paternalistic model. These results reflect the changes over recent years in the expectations and information preferences of patients and suggest that clinicians are responding to an increasingly consumerist model of healthcare. A UK study that used focus group interviews with general practitioners also reported positive attitudes to patient involvement (Elwyn *et al*, 2000). Doctor use of SDM in our survey was associated with reported greater information giving compared to colleagues who did not use a shared approach.

Our hypothesis that doctors treating breast cancer would involve patients in decision-making was supported. Breast cancer doctors in Australia strongly endorsed SDM as found in Canada (Charles *et al*, 2004). Indeed there were strong similarities between the decision-making practices of Australian and Canadian breast cancer doctors (Charles *et al*, 2004), suggesting a similar culture surrounding treatment decision-making in the two countries. Shared decision-making was also strongly supported by the urological specialists. Conversely, support for SDM was low in paediatric oncologists and haematologists. Paediatricians may feel that parents of seriously ill children need to be informed of options, but led to the preferred treatment because of the extremely emotional context. Other clinicians, however, may feel more able to share decision-making where a treatment decision is

Table 7 Univariate analyses of high comfort levels with SDM*

	High comfort with SDM N (%)	χ^2 (d.f.)
Doctor type		
Medical oncologists	105 (89.0)	$\chi^2(4) = 4.95$
Radiation oncologists	39 (78.0)	
Haematologists ^b	4 (66.7)	
Paediatric oncologists	9 (81.8)	
Surgeons	296 (84.3)	
Cancer specialty		
Breast and urological	360 (87.6)	$\chi^2(1) = 12.74^{**}$
Colorectal, gynaecology and haematology	93 (74.4)	
Gender		
Male	372 (83.0)	$\chi^2(2) = 4.56^*$
Female	81 (92.0)	
Age		
Under 40 years	65 (86.7)	$\chi^2(2) = 0.42$
40–55 years	241 (83.4)	
Over 55 years	146 (84.6)	
Country of medical training		
Australia	412 (84.4)	$\chi^2(1) = 0.00$
Other	39 (84.8)	
Caseload per month		
2 or less	62 (81.6)	$\chi^2(3) = 6.65$ $P = 0.084$
3–6	62 (80.6)	
7–10	111 (86.7)	
11+	113 (90.4)	
Direct patient care per week		
<20 hrs	137 (82.5)	$\chi^2(1) = 0.70$
20+ hrs	315 (85.4)	
Community size		
<100 000	34 (85.0)	$\chi^2(2) = 1.27$
100 000–500 000	158 (86.8)	
500 000+	259 (83.0)	

* $P < 0.05$ ** $P < 0.01$. Percentages here represent respondents who reported comfort levels of 4 or 5 on the 5-point Likert scale, 1 = not comfortable, 5 = very comfortable. ^bAn initial decision to shorten the survey for participants other than breast cancer specialists, excluding the question concerning comfort levels with each of the four decision making examples was reversed mid-way through sending the survey to second cohort (haematologists) and explains the small number of responses in this group for these questions.

a real choice between two options with similar survival outcomes (Whitney *et al.*, 2003), such as mastectomy vs breast conservation or radical prostatectomy vs hormone therapy and brachytherapy for prostate cancer. The surgical treatment options in breast cancer may explain the higher proportion of surgeons (who have a clear choice to offer) compared to medical oncologists (who may feel that systemic therapy is definitely indicated) who reported sharing decision-making with their patients. Similarly, colorectal, gynaecological oncologists, and haematologists may also feel that their patients need more direction due to lack of treatment options available. This interpretation is supported elsewhere with family physicians asserting that SDM is most appropriate when clinical equipoise exists (Elwyn *et al.*, 2000; Whitney *et al.*, 2003). Respondents were not asked to identify a particular decision, nor did the questionnaire stipulate that the questions should be answered in contexts where equitable treatment options existed; yet our results indicate that context and existence of equitable treatment options may play a part in doctors' comfort and readiness to use SDM.

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Table 8 Multivariate logistic regression predicting high comfort with SDM

Independent variables	β (s.e.)	Wald (χ^2) (d.f.)	AOR (95% CI)
Cancer specialty			
Colorectal, gynaecology and haematological	0.93 (0.26)	$\chi^2(1) = 12.58^{**}$	2.53 (1.52–4.24)
Breast and urological			
Caseload			
0–2		$\chi^2(1) = 0.80$	1.11 (0.55–2.22)
3–6	0.10 (0.35)		
7–10	0.56 (0.40)		
>11	0.84 (0.43)		
Gender			
Male		$\chi^2(1) = 3.97^*$	2.31 (1.01–5.27)
Female	0.84 (0.42)		

AOR = adjusted odds ratio; d.f. = degrees of freedom; 95% CI = 95% confidence interval. * $P < 0.05$, ** $P < 0.01$.

Table 9 Discrepancy between high comfort level and reported use of SDM

	Usual approach N (%)	High level of comfort N (%)	Mismatch
Tumour type			
Breast	202 (67.1)	266 (86.9)	198
Colorectal	36 (46.2)	51 (67.1)	209
Leukaemia/lymphoma	39 (47.0)	18 (81.8)	348
Gynaecological	11 (40.7)	24 (88.9)	482
Urological	84 (81.6)	94 (89.5)	79
Doctor type			
Medical oncologists	91 (65.0)	105 (89.0)	240
Radiation oncologists	26 (50.0)	39 (78.0)	280
Haematologists	29 (47.5)	4 (66.7)	192
Paediatric oncologists	4 (28.6)	9 (81.8)	532
Surgeons	231 (69.2)	296 (84.3)	151

The consumer movement and public awareness of surgical treatment options in breast and prostate cancer may also have contributed to these results. The doctors in these specialties may be responding to this shift, as their patients demand more information and a role in discussing and deciding about treatment. Breast and urological cancer doctors believe more of their patients wish to be involved in decision-making. Indeed, studies that have investigated the information and involvement preferences of patients demonstrate that breast cancer patients prefer a more active role than other cancer patients (Beaver *et al.*, 1996; Degner *et al.*, 1997; Bruera *et al.*, 2002).

Differences according to caseload in support of SDM may be related to practice setting and multi-disciplinary relationships. Doctors who treat fewer patients with a particular cancer may be less comfortable with involving patients in decision-making due to their reduced familiarity with treatment options. Those with a large caseload are perhaps more likely to be a multi-disciplinary team member where SDM is fostered, and more likely to feel confident in offering a number of options.

Discrepancy between reported comfort levels and usual practise

The discrepancy in the reporting of comfort with SDM and the use of this approach in practice mirrors the Canadian results. For all

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surveyed clinicians except those treating colorectal cancer, over 80% reported high levels of comfort with SDM; yet, with the exception of the breast and urological cohorts, less than 50% reported using this approach for the majority of their patients. Interpretation of this discrepancy affords varying standpoints. Some commentators may interpret this discrepancy as evidence that in certain oncology clinical situations choice does not exist and therefore doctors would not use an SDM approach. Whitney discusses the issue of no treatment as a non-viable option and cites the example of a life-threatening gunshot wound and the inappropriateness of SDM in this context. Yet in oncology, no treatment could be seen as medically reasonable in many instances where treatment reduces risk but does not eliminate it, and carries serious side effects. This interpretation opens up the debate on what constitutes a medically reasonable option and whether this always includes intervention. More generally, however, these criteria for SDM may be refuted by those who comment that SDM is always appropriate even in circumstances where a treatment choice is obvious, as patients need to be involved in the decision to understand the logic. There may also be other barriers to implementation of SDM, which we as yet do not understand.

Similar discrepancies have been reported internationally. General practitioners in the United Kingdom also professed support for SDM but when their own consultations were analysed the participating doctors agreed components of SDM did not occur (Stevenson *et al*, 2000). Braddock *et al* (1999) analysed 1057 consultations of primary care physicians and surgeons in 1993 and found that only 11.3% included discussion of alternative treatment options and just 7.8% included pros and cons. An Australian study in 2001 of consultations with advanced cancer patients showed that only 27% of patients were offered a choice, and 44% were given information on an alternative course of action to anticancer therapy (Gattellari *et al*, 2002). In a Dutch study of advanced cancer patient care, acknowledgement of the medical oncology options of palliative chemotherapy or watchful waiting occurred in half of the consultations, with just 27% receiving extensive explanation of the watchful waiting option (Koedoot *et al*, 2004). These results lead us to conclude that the discrepancy between reported high comfort and actual SDM practice may be greater than that our self-reported data shows. It is important to explore barriers to implementation that might explain this discrepancy.

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CONCLUSIONS

Despite SDM being lauded as the gold standard for treatment options discussion and reported high levels of comfort with SDM, Australian clinicians are not currently reporting that this is their usual practice. Cancer specialty, clinician gender, and higher caseload of new patients influence cancer doctors' use of SDM. Breast and urological cancer patients can expect a consultation where their involvement and information preferences are more likely to be explored. Clinician attitudes and use of SDM can be influenced by the clinical situation in which they practice. Further work is required to establish whether clinicians in cancers other than breast and urological cancers recognise clinical scenarios where they support and use SDM.

LIMITATIONS

A limitation of this study is the self-report nature of the survey; therefore, we cannot verify whether participating clinicians actually practise as they reported. There is the potential for social desirability bias to have influenced the responses given by participants, with participants reporting their usual practise to be SDM knowing the patient-centred ethos of modern healthcare. Finally, we asked doctors about their usual or general approach to treatment decision-making. This did not allow them to indicate how they would respond in different situations, although many commented that they would vary their approach. Identification of participants was undertaken through professional societies and some eligible clinicians may not have received an invitation to participate if they were not registered members of the professional societies approached.

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Appendix 10 Published manuscript

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ORIGINAL REPORT

Physician-Identified Factors Affecting Patient Participation in Reaching Treatment Decisions

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A B S T R A C T

Purpose

Cancer physicians report high comfort with shared decision making but a lower frequency of using this approach in practice. Information regarding physicians' perceptions of what helps and what hinders patient involvement in decision making may facilitate understanding of this discrepancy.

Methods

We surveyed 604 Australian cancer physicians treating breast, colorectal, gynecologic, hematologic, or urologic cancer to investigate barriers and facilitators to reaching treatment decisions with their patients and their support of strategies to encourage patient involvement and reflection on treatment options. Factor analysis and regression analyses were used to investigate relationships between variables and identify predictors of greater reporting of barriers to sharing treatment decisions with patients.

Results

Insufficient information at the first consultation (28.9%) and insufficient time (28.4%) were the most frequently reported barriers to reaching treatment decisions with patients. Multivariate analysis revealed that less experienced physicians more commonly reported system barriers ($P = .00$). Patients trusting their physician and being accompanied at the consultation were most helpful to reaching a treatment decision. Providing written information about treatment options, making a further appointment to reach a decision, encouraging the patient to speak with their family physician and treatment team, and the presence of a third person during the consultation were felt to encourage involvement and reflection on treatment decisions.

Conclusion

Cancer physicians experience difficulties when reaching treatment decisions with their patients. Interventions and strategies that physicians support are required to enhance patient involvement in reaching a treatment decision.

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INTRODUCTION

Involving patients in discussion about treatment options and reaching a treatment decision is increasingly common. Cancer patients report wanting to be involved in treatment decision making; however, this preference is often not achieved when consulting with their cancer physicians.¹⁻⁴ Public expectation to be fully informed about health care and available interventions has increased over recent years, alongside decreasing acceptance of medical paternalism.⁵ Patients who are involved in reaching a treatment decision report increased satisfaction, reduced decisional conflict, and improved compliance with treatment.^{6,7}

We surveyed cancer clinicians across Australia from August 2004 to May 2006 to document their comfort with and use of different decision-making approaches and their attitudes toward treatment de-

cision making with patients. We found cancer physicians in Australia are comfortable with shared treatment decision making (STDm), but their reported use of this approach is considerably less than their comfort with this concept.⁸ This article reports the perceived barriers and facilitators to treatment decision making identified by cancer physicians when consulting with newly referred or newly diagnosed cancer patients. We hypothesized that factors such as type of cancer treated; physician discipline, age, and experience; and patient caseload may influence experience of barriers to STDm. Interventions are proposed that may assist physicians to encourage patient involvement and reflection on treatment options.

METHODS

Participant recruitment and procedures are reported in full elsewhere.⁸ Medical and radiation oncologists, hematologists, pediatric oncologists, and cancer surgeons

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practicing in Australia, managing people with five cancer sites (breast, colorectal, gynecologic, hematologic, or urologic), were invited to participate. Professional representative bodies were contacted to gain permission to invite group members to participate in this study. If this was granted and the addresses were provided, the research team mailed each physician a package including an invitation to participate in the survey intended to compare views of cancer physicians, an information sheet, a consent form, the questionnaire, and postage paid envelope. In the urologic cohort contact details were not provided, but the representative body sent the package to their members. The survey instrument was based on a structured questionnaire developed by Charles et al.^{9,10} in Ontario, Canada, in 1998 through focus groups and pilot testing. The survey assessed the validity of the conceptual framework developed by Charles et al.,^{11,12} both in its' description of the meaning of STD and in the agreement of practicing physicians to the key components. With permission, we used this questionnaire with some alterations. The questionnaire presented four examples of a treatment decision-making scenario, each one representing one of the following approaches: paternalistic, information sharing only, informed, and shared. The survey did not define shared decision making (SDM). This was a cross-sectional survey. Participants were asked to rate on a four-point Likert scale to what extent they experienced selected items as barriers or facilitators to decision making. Physicians treating breast or urologic cancer were also asked to report their support for a range of listed interventions to encourage patient involvement and reflect on treatment options during the decision-making process.

Data Analysis

Demographics and characteristics of the sample were analyzed using descriptive statistics. To identify and explain relationships between variables, exploratory factor analysis was completed using the MS-DOS program COFA 87 (R.P. McDonald, News South Wales, Australia). Exploratory Factor Analysis allows conceptual thoughts to be tested and reveals loadings of items onto a number of factors, which can be more concretely classified conceptually and confirmed by Confirmatory Factor Analysis using the MS-DOS program CONFA. Given the preliminary stage of this field, it was felt appropriate to use this two-stage approach. Multiple linear regression analysis was used to assess predictors of greater reporting of barriers to treatment decision making where more than two variables emerged with $P < .2$. We used a backwards elimination process, with $P < .05$ for a covariate to be retained in the final model. Descriptive statistics and correlational and regression analyses were undertaken using SPSS for Windows Version 14 (SPSS Inc, Chicago, IL).

RESULTS

Participants

Of 1,062 eligible physicians approached, 624 completed surveys were returned, representing a response rate of 59%. This low response rate is comparable to the mean response rate of 54% for physician surveys.¹³ Twenty surveys completed by clinicians who reported they did not treat patients in the five targeted tumor groups were excluded from statistical analysis. Within the nonrespondents, tumor specialties were as follows: breast, 30%; colorectal, 10%; gynecologic, 2%; hematologic, 9%; urologic, 42%; and unknown, 7%. The high nonresponder rate in the urologic cohort may reflect the mailout method in this group. Excluding the urologic cohort on whom we had no sex information, 89% of the nonresponders were men. Comparison of this characteristic with the study sample reveals no notable differences.

Table 1 shows the demographics of the 604 participating clinicians. Male clinicians (83.3%) made up the larger proportion of the sample. Mean age was 50 years, and mean time since medical qualification was 26 years.

Table 1. Demographics of Sample

Variable	No.	%*
Cancer type treated		
Breast	308	51.0
Colorectal	79	13.1
Gynecologic	27	4.5
Leukemia/lymphoma	83	13.7
Urologic	107	17.7
Physician discipline		
Medical oncologist	128	20.9
Radiation oncologist	51	8.4
Surgeon	354	58.6
Hematologist	61	10.1
Pediatric oncologist	12	2.0
Sex		
Male	503	83.3
Female	101	16.7
Country of medical school attended		
Australasia	552	91.7
United Kingdom/Europe/Canada and South Africa	40	6.6
Asia/Southeast Asia/Middle East	10	1.7
Direct patient care per week, hours		
< 20	170	31.2
≥ 20	375	68.8
Community size		
< 100,000	41	7.5
100,000-500,000	184	33.8
> 500,000	319	58.7
Caseload of new patients per month†		
0 to 6	313	52.3
7+	285	47.7
Median		3-6
Age, years		
Mean		50
Range		32-79
Years since graduation		
Mean		26
Range		4-56

*Percentages are based on valid cases only.
†With specified cancer.

Perceived Barriers to Treatment Decision Making

Experience of items perceived as barriers to treatment decision making is presented in Table 2. Response categories were on a four-point Likert scale: never, sometimes, often, and almost always. Items experienced by the most physicians as difficulties almost always were as follows: the physician having insufficient information to make a decision at the first consultation (6.6%) and insufficient time to spend with the patient (5.5%). Items perceived by the most physicians as never a hindrance to treatment decision making were as follows: the doctor experiencing difficulty in framing the treatment options for the patient (48.3%) and the patient's family overriding the decision-making process (43.7%). Most common difficulties reported often or almost always were as follows: the physician having insufficient information to make a decision at the first consultation (28.9%), insufficient time to spend with the patient (28.4%), patient having other health problems (27.9%), patient having misconceptions about their disease or treatment (27.1%), patient being indecisive (24.2%),

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Table 2. Items Experienced as Difficulties or as Helpful to the Treatment Decision-Making Process (N = 604)

Item	Never		Sometimes		Often		Always	
	No.	%	No.	%	No.	%	No.	%
Items experienced as difficulties during treatment decision making								
I have insufficient information to make a decision about treatment at the first consultation	58	9.6	371	61.5	134	22.2	40	6.6
Insufficient time to spend with the patient	87	14.4	345	57.2	138	22.9	33	5.5
The patient has other health problems (eg, heart disease)	28	4.7	406	67.4	157	26.1	11	1.8
The patient has misconceptions about the disease or treatment	11	1.8	428	71.1	154	25.6	9	1.5
The patient is indecisive	22	3.7	432	72.1	139	23.2	6	1.0
The patient is too anxious to listen to what I have to say	32	5.3	428	71.1	132	21.9	10	1.7
The patient does not understand the information I have given	12	2.0	467	77.4	116	19.2	8	1.3
The patient has difficulty accepting she/he has cancer	96	15.9	458	76.0	43	7.1	6	1.0
The patient comes expecting a certain treatment rather than a consultation	115	19.1	443	73.5	43	7.1	2	0.3
There are cultural differences between the patient and me	121	20.1	440	73.1	37	6.1	4	0.7
The patient has received conflicting recommendations from various specialists	59	9.8	505	83.7	34	5.6	5	0.8
The patient requests a treatment not known to be beneficial	65	10.8	500	83.3	31	5.2	4	0.7
The patient brings too much information to discuss	130	21.6	441	73.4	28	4.7	2	0.3
The patient wants to make a decision before receiving the information from me	243	40.3	343	56.9	14	2.3	3	0.5
The patient wants to participate more than I would like him/her to	231	38.4	357	59.3	10	1.7	4	0.7
I experience difficulty knowing how to frame the treatment options for the patient	291	48.3	304	50.5	7	1.2	0	0
The patient's family over-rides the decision-making process	263	43.7	332	55.1	5	0.8	2	0.3
The patient refuses a treatment that may benefit him/her	30	5.0	566	93.9	3	0.5	4	0.7
Items experienced as helpful to treatment decision making								
The patient trusts me	0	0	11	1.8	231	38.5	359	49.7
The patient has someone with them at the consultation	0	0	51	8.5	267	44.4	284	47.1
Providing written information to the patient	2	0.3	117	19.4	217	36.0	267	44.3
The patient wants to participate in making the treatment decision	1	0.2	107	17.8	300	49.9	193	32.1
The patient is emotionally ready for decision making	2	0.3	134	22.2	271	44.9	196	32.5
The patient is prepared (knowledgeable about disease and treatment) for the consultation	4	0.7	245	40.7	231	38.4	122	20.3

patient being too anxious (23.6%), and patient not understanding the information given (20.6%).

On the basis of conceptual analysis and the correlational findings, exploratory factor analyses were conducted. Two items, cultural differences and patient receiving conflicting recommendations, were removed because of statistical reasons. The items of insufficient information and patient comorbidity were removed because of their relatively low factor loadings and because they did not fit conceptually with the other items loaded onto the patient difficulties factor. Confirmatory factor analysis produced a four-factor model, conceptually defined as follows: patient difficulties, preference for a not recommended treatment, system difficulties, and agenda-setting patient. The patient difficulties factor included items that covered misunderstanding or lack of understanding, anxiety, denial, withdrawal, and indecision. The patient preference for a not recommended treatment factor included items that indicated the patient did not want to accept the physician-recommended treatment, through refusal or request for another treatment. System issues included lack of time, misunderstanding of the nature of the consultation and the decision-making process, and physician difficulties in framing options. The fourth factor included items that reflected an agenda-setting patient, either by bringing too much information or by wishing to be more involved than the doctor was comfortable with. The factor loadings for this

analysis confirmed the four-factor exploratory analysis. The analysis gave a χ^2 of 199.99 on 84 degrees of freedom, with a Steiger Lind root mean square error of approximation of 0.05, a root mean residual of 0.04, and a goodness of fit index of 0.98. These values indicate that the model provides a good approximation to the data. Factor loadings are presented in Table 3.

Predictors of Barriers to Treatment Decision Making

To further explore the reported barriers, the variables relating to each factor were summed and a score was computed for each of the four factors. A higher score represented greater reporting of the factor as a difficulty. Mean scores are presented in Table 3.

Results of univariate analysis are presented in Table 4. Urologic cancer physicians had the highest mean score for the patient difficulties factor. Breast cancer physicians had the lowest mean score for the preference for a not recommended treatment factor. Hematologists and gynecologic physicians had the highest mean score for system difficulties. Surgeons reported the highest mean score for patient difficulties, and hematologists reported the highest mean score for system difficulties. Mean scores for each of the factors were comparable, regardless of physicians' reported usual approach to decision making. Physicians whose initial medical training was completed in Asia, Southeast Asia, or the Middle East had higher mean scores for

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Table 3. Factor Analysis									
Item	1	2	3	4	Unique Variance	No.	Mean	SD	Range
Factor 1: Patient difficulties									
The patient does not understand the information I have given	0.48				0.77	596	12.9	1.8	8-24
The patient does not want to participate as much as I would like him/her to	0.42				0.82				
The patient is indecisive	0.50				0.49				
The patient has difficulty accepting she/he has cancer	0.59				0.66				
The patient is too anxious to listen to what I have to say	0.58				0.66				
The patient has misconceptions about the disease or treatment	0.42				0.82				
Factor 2: Patient prefers a not recommended treatment									
The patient requests a treatment not known to be beneficial		0.71			0.49	600	3.9	0.6	2-8
The patient refuses a treatment that may benefit her		0.62			0.62				
Factor 3: System difficulties									
Insufficient time to spend with the patient			0.32		0.90	601	8.8	1.7	5-17
The patient wants to make a decision before receiving the information from me			0.58		0.66				
The patient's family over-rides the decision-making process			0.58		0.67				
I experience difficulty knowing how to frame the treatment options for the patient			0.38		0.86				
The patient comes expecting a certain treatment rather than a consultation			0.50		0.75				
Factor 4: Agenda-setting patient									
The patient wants to participate more in deciding on his/her treatment than I would like him/her to				0.45	0.80	600	3.5	0.9	2-8
The patient brings too much information to discuss				0.78	0.66				

NOTE: All loadings for each item are provided with the salient loadings in bold. Abbreviation: SD, standard deviation.

three of the four factors: patient difficulties, system difficulties, and agenda-setting patient. Physicians reporting less direct patient contact per week and fewer new patients per month showed a higher mean score for the patient difficulties factor.

Our data showed a high correlation between the variables of age and years of experience ($P < .01$) and physician discipline and type of cancer treated ($P < .01$). We included only years of experience and type of cancer treated in regression analyses. Bivariate correlation of cancer, years of experience, doctor sex, and community size showed significant correlation with system difficulties (Table 4). New patients seen per month, cancer type treated, and hours of practice per week showed significant correlation for the patient preference for a not recommended option.

Predictors of greater reporting of system difficulties were identified using linear regression (Table 5). Three variables included had a significant association with a higher system limitation score. Variables included in the model were years of experience, cancer type treated, and community size. The final model ($R^2 = 0.035$) showed that physicians with less experience ($P = .000$) reported greater frequency of system difficulties as barriers to decision making with patients.

Facilitators to Treatment Decision Making

Six possible facilitators were listed and the frequencies with which physicians found these helpful obtained. As responses were skewed, the original four categories on a Likert scale were collapsed into a dichotomous score. Those reported by physicians as experienced as helpful never or sometimes were recoded as not helpful, and those reported as experienced often and almost always helpful were recoded as helpful. The majority of physicians (98.2%) re-

ported that the patient trusting them was helpful and that the patient being accompanied in the consultation (91.5%), the patient wanting to participate (82.0%), and providing written information were helpful (80.3%; Table 2).

Interventions to Encourage Patient Involvement and Reflection

Most (81%) of the breast and urologic cohort supported offering patients written information concerning available treatment options; 69% supported a third person being at the consultation, and 50% endorsed input from a senior cancer nurse before the consultation. There was less support for six other interventions to encourage involvement. Three of six possible interventions for encouraging patient reflection after the consultation were well supported. A follow-up appointment to make the decision was supported by 96.2%, as was written information highlighting treatment options (89.9%) and encouragement for the patient to speak with the treatment team and their general practitioner (72.7%). Worksheets to assist the patient to articulate their values and preferences were supported by one fifth (19.4%; Table 6).

DISCUSSION

We examined the reported barriers and facilitators to treatment decision making of a large sample of practicing cancer physicians across Australia. We hypothesized that physician characteristics, including discipline and the type of cancer treated, may influence experience and perception of factors as barriers to SDM.

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Table 4. Univariate Analysis of Factor Scores

Parameter	Factor 1: Patient Difficulties		Factor 2: Patient Prefers a Not Recommended Treatment		Factor 3: System Difficulties		Factor 4: Agenda-Setting Patient	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Cancer type treated								
Breast	12.85	1.78	3.82*	0.59	8.64†	1.69	3.41	0.82
Colorectal	13.05	1.64	3.96*	0.44	8.72†	1.58	3.42	0.86
Gynecologic	13.04	1.51	4.04*	0.96	9.11†	1.45	3.44	0.85
Hematologic	12.78	1.42	3.96*	0.42	9.40†	1.60	3.62	0.70
Urologic	13.26	2.48	4.14*	0.70	8.92†	2.12	3.66	1.06
Breast and urologic	12.96	1.99	3.90‡	0.64	8.71§	1.81	3.47	0.89
Colorectal, gynecologic, and hematologic	12.93	1.52	3.97‡	0.54	9.07§	1.59	3.51	0.79
Physician discipline								
Medical oncologist	12.59*	1.42	3.96	0.51	9.09*	1.44	3.50	0.81
Radiation oncologist	12.12*	1.18	3.94	0.31	9.27*	1.39	3.31	0.73
Surgeon	13.23*	2.07	3.90	0.70	8.55*	1.87	3.49	0.93
Hematologist	12.75*	1.42	3.95	0.47	9.51*	1.60	3.52	0.72
Pediatric oncologist	12.83*	1.59	4.00	0.00	8.73*	1.74	3.75	0.45
Physician sex								
Male	12.99	1.92	3.92	0.63	8.77‡	1.77	3.50	0.87
Female	12.74	1.50	3.95	0.48	9.08‡	1.68	3.41	0.81
Usual approach to decision making								
Doctor led	12.81	1.67	3.93	0.60	8.82	1.71	3.58	0.79
Shared	12.96	1.88	3.92	0.59	8.83	1.75	3.47	0.84
Patient led	12.85	1.43	3.88	0.56	8.78	1.82	3.44	0.97
Medical student training								
Australasia	12.97	1.90	3.92	0.59	8.81	1.76	3.48	0.86
United Kingdom/Europe/Canada and South Africa	12.62	1.21	4.00	0.78	8.85	1.63	3.45	0.85
Asia/Southeast Asia/Middle East	13.50	1.65	4.00	0.67	9.20	2.39	4.00	1.12
Years of postgraduate experience								
< 25	12.84	1.76	3.95	0.57	9.15*	1.63	3.42	0.88
≥ 25	13.04	1.93	3.90	0.64	8.53*	1.81	3.54	0.84
New patient caseload per month								
≤ 6	13.03	1.87	3.86§	0.62	8.75	1.80	3.48	0.84
≥ 7	12.86	1.83	3.99§	0.59	8.90	1.71	3.48	0.89
Direct patient care per week, hours								
< 20	13.14‡	2.09	3.85‡	0.75	8.63	1.96	3.40‡	0.94
≥ 20	12.89‡	1.80	3.96‡	0.55	8.84	1.67	3.52‡	0.84
Community size								
< 100,000	13.02	2.16	3.83	0.54	8.27‡	1.73	3.39	0.83
100,000-500,000	13.07	2.01	3.90	0.66	8.71‡	1.81	3.51	0.90
> 500,000	12.90	1.79	3.95	0.60	8.88‡	1.74	3.47	0.87

Abbreviation: SD, standard deviation.

*P < .001.

†P < .01.

‡P < .02.

§P < .05.

Lack of time was reported as one of the more frequently experienced barriers to treatment decision making by Australian cancer physicians. Physicians with less experience reported system issues as difficult more often. This may be because physicians with greater experience are more patient-centered in their approach to consultations or have become skilled at overcoming system issues. A number of studies have reported that collaborative decision making does not increase consultation time and may save time in the long run, because thorough initial discussion enables subsequent consultations to be more succinct.¹⁴⁻¹⁶ Moreover, addressing patient concerns may shorten initial consultations.

Patient misunderstanding was considered one of the key difficulties when reaching treatment decisions. Quirt et al¹⁷ explored the level of agreement between patients and their physicians about diagnosis, treatment aims, and risks and benefits. They reported that many lung cancer patients did not fully comprehend their situation and that this was underestimated by their physicians. If this discrepancy between the patient understanding and physician awareness of patient understanding is duplicated in Australia, this barrier may be higher than reported by our participants. Our data showed that physicians reported that patient anxiety and misconception of their disease or treatment were two of the most frequent barriers to sharing decision

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Table 5. Linear Regression							
Parameter	R ²	B	df	SE	F Statistic	β	P
Model							
Higher system difficulty score	0.035		3,536		7.536		.000
Individual predictor							
Constant		9.291		0.298			.000
No. of years qualified		-.053		0.008		-.174	.000
Breast and urologic v colorectal, gynecologic, and hematologic		0.154		0.178		0.037	.385
Community size: 100,000, 100,000-500,000, > 500,000		0.194		0.120		0.069	.105

making. This is not surprising, as emotion has a negative effect on many requirements for collaboration, making it more difficult for patients to take in information and consider their options. In the review of Gravel et al¹⁸ of barriers to implementing SDM in clinical practice, lack of applicability of the process owing to patient characteristics, such as anxiety, and characteristics of the clinical situation, such as lack of any real choice, also featured strongly.

Our data show cancer physicians' perceptions of what assists them when making treatment decisions. Patients' trust was regarded as the key facilitator. Patients also nominate trust in their physician as one of the most important factors when reaching a treatment decision.¹⁹ As patient involvement and the consumer role in healthcare grows,²⁰ the importance of physicians gaining their patients' trust may increase. Previous studies suggest that trust develops through excellent communication and by responding to patient preferences for information and involvement.²¹⁻²³ However, difficulties in defining and measuring trust complicate research into its' effect on doctor decision-making style.²⁴

Table 6. Interventions That Physicians Would Support to Encourage Patient Involvement and Reflection (n = 415)		
Intervention	No.	%
Offering the patient written information about the treatment options available	321	81.1
Having a third person in the room	273	68.9
Input from cancer nurse coordinator before consultation	196	49.5
Booklet explaining clinical decision making	135	34.1
Preparing patient for a greater role in decision making by offering question prompt lists before the consultation	124	31.3
Booklet about patient roles explaining shared decision making	111	28.0
Access for medical practitioners to training to enhance skills in meeting patients' preferences for SDM	99	25.0
Explicitly negotiating shared decision making	89	22.5
Input from cancer nurse coordinator post consultation	50	12.6
Follow-up appointment to make a decision	381	96.2
Giving written information highlighting treatment options	356	89.9
Encourage patient to talk to treatment team and general practitioner	288	72.7
Worksheets for the patient to help him/her articulate what is important for him/her	77	19.4
Audiotaping consultation	64	16.2
Telephone follow-up to discuss treatment decision	54	13.6

NOTE: Breast and urologic cancer physicians only. Abbreviation: SDM, shared decision making.

Patients' being accompanied at the consultation was viewed as helpful. This may reflect recognition of the two-fold benefit a companion brings for the patient (as a second pair of ears and as emotional support). However, the presence of a third person as a facilitator to patient involvement was supported less, implying that physicians are more comfortable with patients bringing a significant other to the consultation than having a third person present, perhaps a nurse or patient advocate. Perceived differences in the roles that a patient's family or significant other might play compared with that of a nurse practitioner are unclear.

Perceived patient willingness to participate in the decision-making process was viewed by the majority of physicians as a facilitator and reflects the notion that for a shared approach, both parties have to be willing to participate.^{11,12}

Some written information given to patients is not balanced or complete,^{25,26} yet our findings imply that patients and physicians may benefit from patients receiving written evidence-based information to reflect on the treatments being recommended.

We found little support for interventions designed to prepare patients to be involved in decision making, with less than one third of respondents embracing booklets explaining clinical decision making, patient roles in decision making, or use of question prompt lists. Audio recording of consultations was supported by only 16% of physicians. A review of the effectiveness of providing consultation audio recording or written summaries showed that the majority of patients found them to be useful and that recall and satisfaction with information received were improved. Anxiety or depression were not influenced by receipt of an audio recording or summary.²⁷ Our findings suggest this review's recommendation that physicians should consider offering patients audio recordings seems not to have been adopted in Australia.

Translating research evidence into practice remains a challenge for researchers keen to implement effective communication tools. An investigation of barriers to uptake of patient decision aids in clinical practice reported that physicians' lack of awareness and of the skills to use the tools effectively inhibited implementation.²⁸ Training programs targeted at health professionals are recommended to address the issue of lack of familiarity,^{11,12,18,28} yet our data reveal that Australian cancer physicians have minimal interest in access to training to meet patient preferences for SDM.

The difficulties identified in our survey and the limited support for strategies and interventions echo the views of Entwistle and Watt,²⁹ who state that the clinician's motivation to involve patients is influential and that success in facilitating involvement is inextricably linked to

this. The difficulties we report emphasize system and patient attributes that prove challenging for physicians. Insight into the difficulties that may be physician driven and reasons why physicians may be less supportive of patient involvement should be sought in further research. Changing established practice and successfully implementing evaluated communication interventions remains a challenge. Perhaps greater implementation success will be realized by aiming strategies at patients or at the system.³⁰

In conclusion, our survey sought to identify physician-perceived barriers and facilitators to the treatment decision-making process in cancer consultations and to explore support for interventions to increase patient involvement and reflection on treatment options presented to them.

What hinders? System issues, particularly time, are a barrier to shared treatment decision making, particularly for less experienced physicians. Patients who refuse the recommended treatment or wish to pursue a treatment not considered optimal are also seen as a barrier to STDM.

What helps? A patient trusting their doctor is important, although how to create and build trust is not clear. The value of the patient being accompanied during a consultation and being provided with quality written information is strongly endorsed by surveyed physicians.

Successful implementation of interventions to encourage patient involvement in decision making is a challenge. Interventions that physicians support need to be developed, as well as increasing physician access to and awareness of interventions already available.

This study presents self-reported survey data on cancer physicians' perceived barriers and facilitators to treatment decision making with their patients; the data does not necessarily represent

the importance physicians place on these barriers and facilitators. The 59% response rate presents some limitation to the generalizability of the data. There is potential for bias to have influenced the results, because responders may be more interested in treatment decision-making approaches used with patients than are nonresponders. Consequently, the reported experience of difficulties to SDM may be under-reported, and support for SDM may be over-representative of the situation in practice. The survey did not detail specific decisions contexts, and physicians were asked to consider their approach to decision making with their newly referred or newly diagnosed cancer patients.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: Heather L. Shepherd, Martin H.N. Tattersall, Phyllis N. Butow

Financial support: Martin H.N. Tattersall, Phyllis N. Butow

Administrative support: Heather L. Shepherd

Provision of study materials or patients: Heather L. Shepherd

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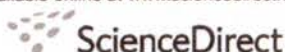
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Appendix 11. Published manuscript

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Schwerpunkt

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Abstract

This paper describes the current position of shared decision-making (SDM) within the Australian health care system. Australian health care includes a mixture of public and private practice governed by both regional and national policy. Support for SDM exists through guidelines and support for interventions to increase participation. However, there is no clear overall policy framework for SDM in Australia. The result is recognition that consumer involvement is important yet there are limited resources and

infrastructure, and no clear strategy to support implementation. Barriers to SDM at the macro, meso and micro levels of health care are described. Efforts to support consumer involvement to date have been targeted to the supply side of health care. There is now awareness of the need to target the demand side by educating consumers to ask for information and involvement in their health care.

Key words: Patient participation, patient information, shared decision-making, health care system, Australia

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Partizipative Entscheidungsfindung in Australien

Zusammenfassung

Diese Arbeit beschreibt den derzeitigen Stand der Partizipativen Entscheidungsfindung (PEF) im australischen Gesundheitssystem. Das australische Gesundheitssystem besteht aus einer Mischung von öffentlichen und privaten Gesundheitseinrichtungen, die von regionaler und nationaler Politik geführt werden. Unterstützung für PEF existiert durch Leitlinien und durch Interventionen, die Patientenbeteiligung erhöhen. Jedoch gibt es keinen klaren politischen Rahmen für PEF in Australien. Daraus folgt die Erkenntnis, dass die Einbeziehung von Patienten zwar wichtig ist,

allerdings sind die Ressourcen und die Infrastruktur begrenzt und es gibt keine klare Strategie die Umsetzung der PEF zu unterstützen. Es werden die Hürden für PEF auf Makro-, Meso- und Mikroebene beschrieben. Die derzeitigen Anstrengungen, die Patientenbeteiligung zu unterstützen, beziehen sich auf die Angebotsseite der Gesundheitsversorgung. Mittlerweile wurde erkannt, dass die Seite der Nachfrage durch Patientenschulungen zur Inanspruchnahme von Information und Einbeziehung in die Gesundheitsversorgung angezielt werden sollte.

Schlüsselwörter: Patientenbeteiligung, Patienteninformation, Partizipative Entscheidungsfindung, Gesundheitssystem, Australien

Wie vom Gastherausgeber eingereicht

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Australia has a population of approximately 20 million people, living in eight States and Territories (regions) in an area approximately the size of Western Europe. The Australian health care system is directed and funded at both a national and regional level, and includes a mixture of public and private health service delivery. The State and Territory governments fund a broad range of regional health services. The Commonwealth (or Federal) government fund most medical services out of hospital and most health research nationally. The Commonwealth provides non-directed funds to the State and Territories to administer public hospitals. Both the Commonwealth and the State and Territory governments variously fund community care for aged and disabled persons. General practice (GP) services are provided on a fee-for-service basis with an 85% rebate provided through Medicare. Medicare is the Commonwealth funded Australian health insurance system that provides universal access to health services. Private health insurance covers fees for private hospitals and selected doctors in public hospitals, in addition to allied health services, optical and dental care. This paper describes the current position of shared decision making (SDM) within Australian health care system.

1. Level of patient participation in macro, meso and micro levels

The Australian Government Department of Health & Ageing receives advice and recommendations from the National Health & Medical Research Council (NHMRC) which involves consumers via appointment of consumer representatives to committees and conducting public consultations before making regulatory recommendations or issuing guidelines. In 2002, the NHMRC together with the Consumers' Health Forum of Australia (see further details below) published the *Statement on Consumer and Community Participation in Health and Medical Research*; guidelines for consumer participation

at all levels and across all types of health and medical research in Australia [1]. The statement includes some principles of partnership of consumers and researchers in order to shape decisions about research priorities, specific research questions and design of research projects in a way that recognises and responds to the rights of all voices to be heard.

Australia has seven national health priorities receiving targeted funding; asthma, cardiovascular disease, diabetes, cancer control, injury prevention, arthritis and mental health. Several of these have programs for patient self-management. The Australian Government also has an extensive consumer health information website called "Health Insite" [www.healthinsite.gov.au] whose strategic plan specifically aims to involve consumers in the development and evaluation of the site. State Health Departments also have policies supporting consumer and community involvement in decision-making, planning, development and evaluation of services. The Western Australia (WA) Department of Health and the Health Consumers' Council of WA [http://www.hccwa.global.net.au/pages/policy_comment.html] have recently signed a state Consumer Participation Policy that require all levels of healthcare administration, from local public hospitals to Clinical Networks and decision-making committees to include at least one consumer representative.

The Consumer's Health Forum of Australia [http://www.chf.org.au] is an independent member-based non-government organisation which is funded by the Australian Government. It nominates and supports consumer representation with government, industry and professional organisations. A number of condition-specific non-government organizations (NGOs) also have key advocacy roles and these also involve consumers. NGOs include the National Breast Cancer Centre, Diabetes Australia, Cancer Australia and Cancer Councils in each state, Beyond Blue (mental health), Arthritis Foundation, and National Heart Foundation. Australia hosts the Cochrane Collaboration's Consumer and Communication Group.

2. Present state of SDM implementation in the Australian Health Care System

Shared decision-making is espoused in many policy and strategic direction documents, such as the NHMRC series of booklets on doctor-patient communication. *Making decisions about tests and treatments: Principles for better communication between healthcare consumers and healthcare professionals* [http://www.nhmrc.gov.au/publications] is a new toolkit intended to assist health professionals with optimising communication when discussing treatment options with consumers. On p. 1, it states:

"Whenever possible, people seeking health advice should have opportunities to explain and discuss their values and preferences, so that the decisions reached can take these into account".

The Australian Council for Safety and Quality in Health Care have also produced a document, *10 Tips for Safer Health Care*, [http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/10-tips] available in 15 languages, which aims to help people be more actively involved in their own healthcare [2]. A draft Cancer Services Standards Framework has also been developed stating that [3]

"all cancer patients are involved in decisions concerning their care to the extent that they wish" p.172.

While there is apparent support for SDM in Australia, implementation is limited. A survey of Australian oncologists found that 80% were comfortable with SDM but only 53% reported it as their usual approach, and many stated that they used it only with some patients [4] (Fig. 1).

Brown et al. [5] audited SDM in 59 consultation audio-recordings of 10 oncologists seeking consent to clinical trials. Doctors only introduced the concept of joint decision-making about treatment in 24% of consultations and, where it was discussed, it was rated as poor in 75% of cases. Information



Fig. 1. Australian Mammography Decision Aid Trial. http://www.health.usyd.edu.au/shdg/resources/decision_aids.php

preferences were checked in 40% of the consultations with 66% of these receiving a poor rating. The doctors invited patient questions and comments in 61% of the consultations; however, 70% of these were rated as poor. Uncertainty of treatment benefit was acknowledged in 54% of consultations. Patients were, however, commonly offered the option of delaying their decision about trial participation (78% of consultations). Thus, many aspects of SDM were rarely observed in this sample of oncology consultations. Focus group interviews and participant observation methods explored nurses' approaches to working with patients to support patients' participation in health care [6]. The authors noted a sharp contrast between the ideas nurses expressed and their actions observed in practice. Nurses said they supported consumer participation, yet observational data revealed nursing practices that excluded active participation by consumers. In conclusion, evidence for the implementation of SDM is sparse, and the few studies that have been conducted do not support optimism about the uptake of these ideas.

3. Mechanisms and institutions which support SDM in practice

Support for shared decision-making in Australia exists through guidelines and

support of interventions which aim to increase participation. Three NHMRC publications specifically promote patient involvement in decision making as part of optimal care [7–9] <http://www.nhmrc.gov.au/publications>.

The Royal Australian College of General Practitioners (RACGP) document *Sharing Health Care: Chronic Condition Self-Management Guidelines* also asserts that,

"When treatment is jointly planned and negotiated, and information is shared between doctor and patient, the patient is assisted to exercise autonomy and follow an agreed plan" [10]

<http://www.racgp.org.au/guidelines/sharinghealthcare>

These publications are complemented by a number of other consumer-led initiatives. The Patient Charter produced by the Victorian State Government states that,

"You should be fully involved in decisions about your care and be given the opportunity to ask questions and discuss treatments so you understand what is happening."

<http://www.health.vic.gov.au/patient-charter/patient.htm>

Tip One of The Australian Council for Quality and Safety in Health Care

document states, "Be actively involved in your own healthcare". [2]

Pamphlets produced by consumer groups, particularly in the oncology setting, promote patients' active participation in their healthcare. (e.g. *My Journey Kit*, developed by Breast Cancer Network Australia <http://www.bcna.org.au/>). Cancer Voices Australia also links advocacy groups across the country and aims to ensure cancer consumers are involved in decision making regarding treatment, research, support and care throughout their cancer journey.

Implementation of tools and interventions to increase patient participation

Decision Aids: In Australia decision aids (DAs) have been developed for a number of different settings.

- Health screening
- Genetic counselling
- Disease prevention
- Cancer early and advanced stage treatment decisions
- Clinical trial participation

Only one DA has been implemented nationally. The NHMRC commissioned the Sydney Health Decision Group (SHDG) to produce a DA for women considering hormone replacement therapy. Copies were distributed to GPs across Australia and can be downloaded from the internet [<http://www.nhmrc.gov.au/publications>] [11] (Fig. 2).

Question Prompt Lists (QPL): Question prompt lists aim to aid the patient in obtaining the information s/he may want by listing questions pertinent to their situation [12–16]. The Cancer Institute New South Wales is funding a project to evaluate the implementation of QPL for cancer patients consulting a surgeon, radiation or medical oncologist or a palliative care doctor in New South Wales. Palliative Care Australia has disseminated a QPL for patients consulting a palliative care doctor [<http://www.pallcare.org.au>].

graduating medical students should possess. The Australian Medical Council's Accreditation Standards for Medical Schools (2002) advise that all medical graduates should involve patients in formulating a management plan, and should be good listeners and able to provide information in a manner that allows patients and families to be fully informed.

Culturally diverse communities have varying perceptions of information exchange and decision making which may pose an important barrier to SDM [28–30]. Goldstein et al. [28] found that a Greek community in Australia preferred a greater involvement of the family in decision-making and a more paternalistic style in their doctor. A study of Aboriginal consumers reported they wanted GPs to spend more time in consultations to get to know them and to foster a relationship with the Aboriginal community outside of the GP-patient encounter [31]. In general, communication is facilitated when the health professional is aware of, respectful of, and sensitive to, the background, emotional and cultural needs of each individual patient. Most doctors lack skills in this area [32].

Consumer/patient related barriers

A number of barriers have been identified; anxiety, embarrassment or denial about the medical condition; being inexperienced in identifying and describing symptoms; being intimidated by healthcare settings; being overawed by the doctor's perceived status; being disadvantaged by differences in language and culture; being confused by the use of medical jargon; being reluctant to ask questions; or being concerned about taking up too much time [8].

Low literacy skills are another important barrier. Data from 1996 by the Australian Bureau of Statistics indicate that almost half the Australian population is likely to have some, or considerable, difficulty with written information materials [33]. There have been no attempts to develop tools or materials to facilitate SDM with low literacy groups in Australia.

5. Influence of patient rights on SDM implementation

There is no national patient charter or patient rights statement in Australia such as exists in the UK (NHS Patients Charter <http://www.pfc.org.uk/node/633>) and elsewhere. In 1993 the NHMRC issued *general guidelines for medical practitioners on providing information to patients (updated in 2004)* [7]. The guidelines hold no legislative power, rather they are seen to reflect the Australian common law right of legally competent patients to make their own decisions about medical treatment and their right to grant, withhold or withdraw consent before or during and examination or treatment (NHMRC 2004 p7).

Mental health policy and legislation has demonstrated a rights-based approach to patient participation which has been explicitly incorporated into the Mental Health Act (1990) and the Mental Health Legislation Amendment Act (1997). Individual state and area based health services (e.g. Victorian and WA State Governments (see weblinks previously listed), North Coast Area Health Service NSW; <http://www.ncahs.nsw.gov.au/support/>), and some hospitals (Royal Children's Hospital, Queensland; <http://www.health.qld.gov.au/qhppc/documents/QHPPCbooklet.pdf>) have voluntarily established their own individual patient charters. *Health Care Agreements* between the federal and state governments have meant that states must develop and implement systems to ensure that patients give informed consent. However patient participation in decision-making is limited by a serious deficiency in the understanding of healthcare practitioners and administrators as to what information constitutes informed consent, how and when it should be provided, and what decision-making support patients (and clinicians) require [34].

Consumer activism has played an important role in campaigning for change in Australia [35]. Groups formed by patients of failed healthcare

treatments or those with specific health conditions have raised the profile of patient rights [36]. Identity based consumer groups such as Aboriginal groups and women's groups also play an important role [37,38], as have large NGOs and national consumer organisations described in Section 1.

6. Present SDM-research and research funding

Researchers and Research groups

A small number of research groups and individuals are working in the area of SDM or patient choice. Nevertheless Australian research has made some important contributions, for example in patient-doctor communication [5,15,26,39,40], risk communication [41,42], consumer and patient preferences [43,44] and evidence based patient choice [43–46].

Research goals and priorities

The Australian government has articulated four National Research Priorities, one of which pertains to health. Within health the specific research priorities are described as follows:

- A healthy start to life
- Ageing well, ageing productively
- Preventive healthcare
- Strengthening Australia's social and economic fabric

[http://www.dest.gov.au/sectors/research_sector/policies_issues_reviews/key_issues/national_research_priorities/priority_goals/promoting_and_maintaining_good_health.htm#4#4]

However, none of these include provision for a research priority relating to SDM or patient choice.

Research funding

The NHMRC funded 853 grants amounting to \$500 million to commence in 2007. Only two specifically addressed patient choice: Gattellari et al., DESPATCH Delivering Stroke

Prevention in Atrial Fibrillation: assisting evidence based choice in primary care (\$524,653), and McCaffery et al., a randomized controlled trial of a bowel cancer screening decision aid for adults with low education and literacy (\$229,500), demonstrating a comparatively low commitment to funding SDM research in Australia.

7. Future perspectives of SDM in Australia

The legal system and consumer advocacy groups have influenced development of various policies for the sharing of information and decision-making between doctors and patients. The result is an unsystematic approach across Australia to the patients to being informed and involved in decision-making. Many doctors are still unaware of the minimum legal obligation to inform patients [34]. Consequently, there is a long way to go to ensure patients are both informed and involved in decisions about their health. To date all efforts at advancing the issues of patient rights and information have been targeted towards the supply side of health care, encouraging clinicians to adopt best-practice models in informing patients and shared decision-making, with mixed results. In the future consumer groups will need to target the demand side by educating consumers as to the questions to ask their clinicians to ensure that they get sufficient information to participate in decision-making and make decisions that will maximize their individual health outcome.

In 2005, the Australian government established a new health policy initiative called Strengthening Cancer Care. Increased research funding for cancer was announced as well as the establishment of a new health agency called Cancer Australia. Although none of their current research priorities explicitly include SDM, cancer patients have been a very powerful advocacy group in recent years and it is possible that they will influence the research priorities of this new initiative embracing

shared decision making and patient choice.

Statement on conflict of interest

We hereby declare there is no conflict of interest according to the Uniform Requirement for Manuscripts Submitted to Biomedical Journals.

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Zertifizierter Patientenratgeber „Umgang mit Psychopharmaka“

In psychischen Krisen sind Medikamente manchmal unverzichtbar. Das Ratgeberbuch „Umgang mit Psychopharmaka“ stellt alle Psychopharmaka auf dem deutschsprachigen Markt vor, erklärt die Funktionsweisen samt Wirkung und Nebenwirkung und gibt Hinweise zum Reduzieren und Absetzen. Die Stiftung Gesundheit hat das Buch zertifiziert. Die Gutachter bewerten das Werk „als einen sehr informativen, leicht verständlichen und optimal aufgeteilten Ratgeber, welcher einen umfassenden Überblick der medika-

mentösen und nicht-medikamentösen Behandlungsmöglichkeiten psychischer Erkrankungen liefert.“ Das Autorenteam möchte Patienten dazu ermutigen, sich eine eigene Meinung zu bilden sowie ihre Wünsche und Ziele in das Gespräch mit dem Arzt einzubringen und mit ihm gemeinsam zu „verhandeln“, welche Behandlung der beste Weg ist. „Umgang mit Psychopharmaka“, Nils Geva, Margret Osterfeld, Barbara Diekmann, BÄ-LANC Ratgeber, Psychiatrie Verlag, ISBN 978-

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