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# **The Perceptions of Australian Oncologists Regarding Cognitive Changes in Cancer Survivors**

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Thesis presented in partial fulfilment of the degree of  
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## STATEMENT OF AUTHENTICATION

I, Kate Smidt, hereby declare that this submission is my own work and that it contains no material previously published or written by another person except where acknowledged in the text. Nor does it contain material which has been accepted for the award of another degree.

Ethical approval from the University of Sydney Human Ethics Committee was granted for the study presented in this thesis. Informed consent was gained prior to data collection.

Name Kate Smidt

Signed \_\_\_\_\_

Date 28/11/2014

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## THESIS ABSTRACT

**Background:** With survivorship increasingly recognised as a distinct phase of cancer care, uncertainty has emerged within the oncology community regarding the roles and responsibilities of those caring for cancer survivors. Consequently, many cancer survivors are ill-informed of the potential challenges associated with the survivorship phase. Cognitive changes experienced by cancer survivors have received growing attention as a survivorship issue. Though often subtle in nature, cancer related cognitive changes (CRCC) can have a profound impact on a cancer survivor's quality of life (QOL). Nonetheless, cancer survivors report receiving limited information by treating oncologists regarding this phenomenon.

**Aim:** To explore the perceptions of oncology specialists regarding CRCC, and how their views may influence decisions about patient care.

**Overview of the Thesis:** The thesis is divided into two sections. Section I is a review of the existing and relevant literature relating to CRCC and their effects on cancer survivors' QOL, with a particular focus on the survivorship phase. A description of the search strategies used to locate literature is also included.

Section II is a manuscript formatted for submission to the journal *Psycho-Oncology*. This manuscript outlines the findings of a qualitative study exploring oncologists' understandings of CRCC, and their perceived role in the management of cancer survivors' cognitive concerns across the continuum of cancer care.

Findings from the project as a whole demonstrate the uncertainty of oncology specialists regarding the appropriate management of CRCC, and the need for specific interventions and clinical practice guidelines to address the effects of CRCC on cancer survivors' daily functioning and QOL.

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## **SECTION 1**

### **REVIEW OF THE LITERATURE**

#### **Exploring Cancer-Related Cognitive Changes and Their Effects on Cancer Survivors**

Kate Smidt

**Word Count:** 4,958 words

## **Literature Search Strategy**

A search of the literature was conducted using the electronic databases CINAHL, Medline and Web of Science. For each database, the search terms used were “cancer” OR “neoplasms” AND “cognition” OR “memory” OR “function” AND “oncologist” AND “perception” OR “belief” OR “opinion” AND “qualitative”. “Qualitative” was included in the search in order to identify gaps in this particular area of research, and thus inform the study’s design. Results were limited to English language publications from 1994 to present. To ensure a thorough review was performed, the reference lists of each article relating to the topic were screened to identify further studies not located in the initial database search.

The International Cancer and Cognition Taskforce (ICCT) website also contains a list of articles relating to cancer and cognitive changes. The library was searched for research not previously identified in this search strategy.

## **Introduction**

The purpose of this literature review is to inform and provide direction for the subsequent study *The Perceptions of Australian Oncologists Regarding Cognitive Changes*. Four key areas of research are reviewed including cancer survivorship, patient-centred cancer care, cancer-related cognitive changes (CRCC) and the management of cancer survivors' cognitive concerns. The review begins with a background of cancer prevalence and survival in Australia. This is followed by a brief history of cancer survivorship, including the redefining of the term 'cancer survivor'. Patient-centred cancer care is then discussed, with a particular focus on patient-clinician communication and the purpose of survivorship care plans. This is followed by an overview of the lasting effects of a cancer experience. The effects of CRCC on cancer survivors is critically examined, including potential causes and their long-term effects on quality of life (QOL). Cancer survivors' experiences with raising cognitive concerns to oncology specialists are explored. Finally, the evidence surrounding the awareness of oncology specialists regarding CRCC are critiqued, and limitations of this literature are identified. This review highlights the need for further research exploring the perceptions of oncologists regarding CRCC, and how their views may influence decisions about patient care. Although cancer survivors report the profound, long-term impacts of cognitive changes on daily functioning and QOL, reasons why the discussion around CRCC is more commonly initiated by cancer survivors or not addressed at all remains unclear in the current body of research. It is this question that the subsequent study aims to address.

### **The Prevalence of Cancer and Survival in Australia**

The term 'cancer' refers to a group of diseases characterised by the uncontrollable multiplication of cells in the body. These abnormal cells damage tissues in the surrounding region and, if unsuccessfully treated, can metastasise to other regions of the body and potentially cause mortality (AIHW & AACR, 2012).

The Australian Institute of Health and Welfare (AIHW) in collaboration with the Australasian Association of Cancer Registries (AACR) (2012) reported that one in two Australians will be diagnosed with cancer during their lifetime, and one in five of these Australians will die from the disease before the age of 85 years. The report estimated that over 120,000 Australians would be diagnosed with cancer in 2012 (excluding certain skin carcinomas), a figure that has almost doubled since 1991 (AIHW & AACR, 2012). The

increase in diagnoses for prostate cancer, breast cancer in females, bowel cancer and lung cancer is the primary reason for this rising figure (AIHW & AACR, 2012). Approximately 56% of males will account for all cancer diagnoses. Prostate cancer was the most commonly diagnosed cancer in males (18,560 cases), followed by bowel cancer (8,760), melanoma of the skin (7,440), lung cancer (6,620) and non-Hodgkin lymphoma (2,620). In females, breast cancer (14,560 cases) was the most commonly diagnosed, followed by bowel cancer (7,080), melanoma of the skin (5,070), lung cancer (4,650) and uterine cancer (2,270) (AIHW & AACR, 2012).

While cancer prevalence in Australia has increased, so have survival rates for people diagnosed with cancer. Five-year survival rates overall have increased from 47% between 1982 and 1987, to 66% between 2006 and 2010 (AIHW & AACR, 2012). According to the latest report on cancer prevalence in Australia, survival rates were highest for people diagnosed with thyroid cancer, lip cancer and melanoma of the skin (AIHW & AACR, 2012). Increasing survival rates can be attributed to improvements in early detection, diagnostic methods and treatment (Dickman & Adami, 2006).

Despite increasing survival rates, for many, a cancer diagnosis is life changing (Hewitt, Greenfield and Stovall, 2005). As the prevalence of cancer and survival continues to rise in Australia, it raises questions about the management of any lasting effects on a cancer survivor's health and well-being.

### **Redefining 'Cancer Survivor'**

Historically, the term 'cancer survivor' described someone who lived disease-free for at least five years after treatment (Rowland, Hewitt & Ganz, 2006). Today, five-year survival rates are commonly referenced for the purpose of research and national health statistics (Leigh, 2007). However, missing from current national datasets are means to capture the experiences of those living with a cancer diagnosis, and the unique needs of these individuals as a result of cancer survivorship (Leigh, 2007).

Before the mid-1970s, less than half of those diagnosed with cancer were expected to live past five years from the time of diagnosis (Rowland, Mariotto, Aziz & Tesauro, 2004). As five-year survival rates increased, a cancer survivorship advocacy community arose

throughout the 1970s and 1980s and attention was drawn to the long-term psychosocial, economic and legal ramifications of a cancer experience (Hewitt et al., 2005).

In an attempt to unify the expanding efforts of this community, the National Coalition for Cancer Survivorship (NCCS) was formed in the United States in 1986; representing an international milestone for cancer survivorship. The NCCS advocated for the right of an individual to identify as a cancer survivor across the continuum of cancer care. Thus, the NCCS redefined cancer survivorship to incorporate the individual, their family, caregivers and friends “from the time of diagnosis and for the balance of life” (National Coalition for Cancer Survivorship, n.d., “Our history”, para. 1). For the purpose of this review, the NCCS working definition of cancer survivor will be used to incorporate individuals and populations living with a cancer diagnosis at any phase across the continuum of cancer care.

### **The Survivorship Phase**

In 2005, the Institute of Medicine (IOM) in the United States released the report *From Cancer Patient to Cancer Survivor: Lost in Transition*. Though survivorship is not a new concept in cancer care, the report identified three major trends occurring within the area of cancer survivorship. Firstly, healthcare systems are acknowledging the chronic nature of the disease as more cancer survivors are living longer. Secondly, there has been an emergence of care models addressing the complex needs of individuals with chronic conditions. Thirdly, consumer advocacy for the provision of patient-centred care across the cancer trajectory continues to strengthen (Hewitt et al., 2005). Thus, the report aimed to raise awareness within the oncology community regarding the long-term implications of cancer and its treatment on survivors’ QOL, and identify strategies to improve the quality of survivorship care (Hewitt, et al., 2005).

Previously, the focus of cancer care has reflected a curative approach in the areas of clinical practice and research, and as a result, less attention has been given to the survivorship phase (Cheung, Neville, Cameron, Cook & Earle, 2009; Hewitt et al., 2005). The report highlighted the importance of a distinct survivorship phase in cancer care for the ongoing provision of quality services, information and support post-treatment (Hewitt et al., 2005). The main components of the survivorship phase include: prevention and surveillance of cancer recurrence and the potential late effects of a cancer diagnosis and treatment, interventions for the physical and psychological implications of a cancer experience, and

collaboration between oncology specialists and general practitioners (GPs) for the coordination of cancer survivors' long-term care needs (Ganz, 2006; Hewitt et al., 2005).

As survivorship becomes increasingly recognised as a distinct phase of cancer care, uncertainty has emerged within the oncology community regarding the roles and responsibilities of those caring for cancer survivors (Cheung et al., 2009; Mao et al., 2009; Nissen et al., 2007). In a quantitative study, cancer survivors, GPs and oncologists were surveyed to compare perceived responsibilities in the provision of survivorship care (Cheung et al., 2009). Although the study found similarities in the expectations of cancer survivors and oncologists regarding the responsibility of oncologists in screening for primary cancer recurrence, cancer survivors had higher expectations than oncologists regarding the role of oncologists in survivorship care (Cheung et al., 2009). Additionally, the Cheung et al. (2009) study identified an overlap in the expectations of oncologists and GPs for survivorship care, particularly in regards to follow-up, screening for other cancers and general preventive healthcare.

While this study highlighted the discrepancies between the expectations of cancer survivors, GPs and oncologists for survivorship care, the survey primarily concentrated on the areas of follow-up, screening for others cancer, preventive healthcare and management of comorbidities as a result of cancer diagnosis and treatment. Thus, future research should explore the expectations of cancer survivors, GPs and oncologists for survivorship care, particularly in the areas of advocacy, support and psychosocial care (Cheung et al., 2009). Furthermore, the majority of research on cancer survivorship has occurred in the United States to date, and future exploration in the Australian context is needed to explore the challenges faced by Australian cancer survivors in the survivorship phase (Jefford et al., 2008).

Ambiguity regarding the roles of the varying health professions involved in survivorship care has previously led to cancer survivors being ill-informed of the potential challenges associated with the survivorship phase, and subsequently ill-equipped to proactively manage their own survivorship care (Hewitt et al., 2005). Thus, it has been suggested that greater communication between cancer survivors, oncology specialists and other treating health professionals is critical for the provision of comprehensive survivorship care (Cheung et al., 2009; Mao et al., 2009).



## **Empowering Cancer Survivors Through Communication**

Throughout the continuum of cancer care, patient-clinician communication serves as a means for fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions and enabling patient self-management (Epstein & Street, 2007). Findings of a systematic review demonstrated the effectiveness of open and timely communication on the part of treating health professionals, particularly for decision making, compliance and overall satisfaction with cancer care (Rodin et al., 2009). The review also highlighted the benefits of honest, empathetic communication in assisting cancer survivors and their families to cope with the distress of a diagnosis and the burden of treatment (Rodin et al., 2009).

In addition to enhancing health outcomes for cancer survivors, effective communication elicited by treating health professionals is essential for the delivery of true patient-centred care (Levinson, Lesser & Epstein, 2010). The Institute of Medicine (IOM) describes patient-centred care as “a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patient’s wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care” (IOM, 2001b, p.7).

In a qualitative study exploring the perceptions of cancer survivors on patient-centred care, participants felt that empowerment through respect, honest information sharing and open communication, and shared decision making about treatment plans with oncology specialists were important features of patient-centred cancer care (Kvåle & Bondevik, 2008). Notably, while participants expressed a desire to be involved in decision making, it was felt that oncology specialists should make the final decisions regarding treatment. This study highlights the importance of patient-clinician communication in order to determine patients’ desires to be involved in their care, and to what extent, for the provision of patient-centred cancer care across the entire cancer trajectory (Kvåle & Bondevik, 2008).

### ***Survivorship Care Plans***

Communication is critical for the ongoing coordination of cancer survivors’ long-term care (Hewitt et al., 2005). In the report *From Cancer Patient to Cancer Survivor: Lost in Transition*, Hewitt et al. (2005) strongly recommended that cancer survivors and their GPs receive a survivorship care plan (SCP) by the primary treating oncologist at the completion of

treatment. The SCP should include a treatment summary (including the potential long-term sequelae as a result of treatment), plan for follow-up (including frequency and recommended content to be addressed during follow-up appointments), and information regarding health promotion strategies and psychosocial support services available in the community (Hewitt et al., 2005).

SCPs can empower cancer survivors to assume an active role in their long-term care, and thus promote patient-centred cancer care (Ganz & Hahn, 2008; Hewitt et al., 2005). Additionally, these plans can enhance communication between oncology specialists, GPs and cancer survivors, and ultimately foster a shared understanding of the specific roles and responsibilities of treating health professionals for the effective coordination of cancer survivors' long-term care (Dulko et al., 2013). In doing so, SCPs can alleviate the concerns of cancer survivors when transitioning from active treatment to the survivorship phase of the cancer care continuum (Haq et al., 2013).

Despite the recognised benefits of SCPs in the coordination of cancer survivors' ongoing care post-treatment, recent studies indicate a number of barriers in the effective implementation of SCPs in everyday practice. Establishing SCPs for cancer survivors and their GPs is time consuming, and as a result, oncologists may be reluctant in completing this lengthy document (Haq et al., 2013; Hewitt, Bamundo, Day & Harvey, 2007).

A cross-sectional survey was conducted to explore the attitudes of health professionals practising in Australia regarding the use of SCPs for breast cancer follow-up care (Brennan, Butow, Spillane & Boyle, 2010). 51% of oncology specialists, 83% of breast physicians and 92% of breast care nurses felt that SCPs would improve survivorship care for breast cancer survivors (Brennan et al., 2010). Time required to complete SCPs was a concern for some participants (Brennan et al., 2010). While this study demonstrates health professionals' support of SCPs in Australian cancer care, the lower percentage of oncologists in favour of this follow-up plan may support previous research findings that demonstrate oncologists' perceived barriers to completing SCPs (Haq et al., 2013; Hewitt, Bamundo, Day & Harvey, 2007). Ongoing education regarding the benefits of SCPs and the adoption of electronic medical record systems may assist oncologists in carrying out this important task for the provision of high quality survivorship care (Hewitt et al., 2007). Additionally, it is recommended that this service be reimbursed by third-party payers to health care, such as

Medicare Australia and private health insurance funds, given the time oncologists would need to delegate to completing SCPs (Hewitt et al., 2007).

The survivorship phase represents an immensely personal and challenging time for cancer survivors, their families, caregivers and friends. The implementation of effective communication channels between health professionals and their patients can contribute to improved health outcomes, and ensure cancer care reflects a patient-centred approach (Hewitt et al., 2005; Venetis, Robinson, Turkiewicz & Allen, 2009). Thus, patient-centred communication and the use of SCPs can raise awareness of the long-term sequelae experienced by cancer survivors as a result of a cancer experience.

### **The Lasting Effects of a Cancer Experience**

The long-term and late effects of cancer and its treatment can have a lasting impact on a cancer survivor's QOL (Stein, Syrjala & Andrykowski, 2008; Zebrack, Yi, Petersen & Ganz, 2008). Long-term effects are usually defined as the physical and psychological implications that develop during the treatment phase and continue for at least five years post-treatment (Stein, et al., 2008). Alternatively, late effects are not present during treatment but develop in the survivorship phase as a delayed outcome of treatment (Stein, et al., 2008).

Physical long-term and late effects of treatment, such as reduced muscle strength, stamina and mobility can restrict cancer survivors' participation in meaningful everyday activities (Ness, Wall, Oakes, Robison & Gurney, 2006). Additionally, problems with sexual functioning, fatigue, osteoporosis and weight gain are lasting implications of cancer and its treatment, which can impact upon a cancer survivor's daily function and QOL (Frumovitz et al., 2005; Miller et al., 2005; Partridge & Winer, 2004; Potosky, 2004; Schultz, Klein, Beck, Stava, & Sellin, 2005).

Psychological long-term and late effects due to a cancer experience, such as anxiety and depression, can be difficult to determine given their prevalence within the general population (Stein, et al., 2008). Nonetheless, cancer survivors have expressed feelings of chronic unhappiness and distress well into the survivorship phase. This may be attributed to a cancer diagnosis and the burden of treatment, in addition to fear of a new primary cancer diagnosis or recurrence (Deimling, Bowman, Sterns, Wagner & Kahana, 2006; Hodgkinson et al., 2007; Schultz et al., 2005).

In contrast, some cancer survivors report positive outcomes of their cancer experience, such as personal growth and greater appreciation for life (Bower et al., 2005; Hodgkinson et al., 2007). Nonetheless, the long-term challenges faced by cancer survivors are significant and if not appropriately managed, can ultimately diminish a person's QOL; further emphasising the need for collaboration between treating health professionals and their patients for the coordination of survivorship care (Hewitt et al., 2005).

### **Cognitive Changes Associated With a Cancer Experience**

Subtle changes to cognition are widely acknowledged as an issue present during the survivorship phase (Vardy, Wefel, Ahles, Tannock & Schagen, 2008). Changes in the cognitive domains of information and processing speed, attention, memory retrieval and executive function are commonly reported by cancer survivors throughout the continuum of cancer care (Vardy et al., 2008; Wagner, Sweet, Butt, Lai & Cella, 2009). While this phenomenon has received growing attention in the literature, particularly with regards to cancer survivorship, the explicit cause of cognitive changes remains unknown (Selamat, Loh, Mackenzie & Vardy, 2014).

#### ***Cognitive Changes as a Result of Chemotherapy Treatment***

'Chemobrain' or 'chemofog' are common terms used by cancers survivors, health professionals and researchers to describe subtle cognitive changes as a result of chemotherapy treatment (Argyriou, Assimakopoulos, Iconomou, Giannakopoulou & Kalofonos, 2011). Cognitive changes may be due to hormonal imbalances and the toxic effects that chemotherapeutic agents can have on the brain (Christie et al., 2012; McAllister et al., 2004). Furthermore, cognitive changes as a result of chemotherapy may be further exacerbated by anxiety, depression and fatigue (McAllister et al., 2004)

Prospective longitudinal studies have found that standard-dose and high-dose chemotherapy treatment can cause subtle changes in cancer survivors' cognition during and after treatment (Schagen, Muller, Boogerd, Mellenbergh & van Dam, 2006; Wefel, Lenzi, Theriault, Davis & Meyers, 2004). Schagen et al. (2006) examined changes in cognitive function as a result of standard-dose and high-dose chemotherapy amongst breast cancer survivors. The study found that a greater number of participants who received high-dose

chemotherapy experienced a decline in cognitive performance compared to participants who received standard-dose chemotherapy (Schagen et al., 2006).

Alternatively, a prospective study evaluating the effects of standard-dose chemotherapy on breast cancer survivors' cognition found that only a small proportion of participants experienced a decline in concentration and memory, and the majority remained unaffected or improved over time (Jenkins et al., 2006). Participants who had experienced a decline in cognitive performance also experienced treatment-induced menopause, suggesting that a reduction in oestrogen may exacerbate cognitive changes or even effect cognition independently of chemotherapeutic agents (Jenkins et al., 2006).

Though research has mainly concentrated on breast cancer populations, preliminary evidence suggests that survivors diagnosed with other cancers such as ovarian cancer (Correa & Hess, 2012) and testicular cancer (Schagen et al., 2008) may also experience cognitive changes as a result of chemotherapy. Thus, a need exists for robust, longitudinal studies in tumour groups other than breast cancer to determine and compare prevalence and severity of cognitive changes between tumour groups as a result of treatment (Janelsins, Kesler, Ahles & Morrow, 2014).

### ***Cognitive Changes as a Result of a Cancer Diagnosis***

While research has largely focused on the effects of chemotherapy on cognition after treatment, a small number of prospective longitudinal studies have evaluated the cognitive functioning of cancer survivors pre-chemotherapy and post-chemotherapy (Hermelink et al., 2007; Jansen, Cooper, Dodd & Miaskowski, 2011; Wefel et al., 2004). Assessment of participants' cognition at the pre-chemotherapy stage found that a proportion of cancer survivors are experiencing subtle changes in cognitive performance prior to the commencement of chemotherapy, which are unrelated to anxiety or depression (Hermelink et al., 2007; Jansen et al., 2011; Wefel et al., 2004).

In one prospective randomised longitudinal trial, approximately 33% of breast cancer survivors demonstrated reduced cognitive function prior to receiving chemotherapy (Wefel et al., 2004). The study revealed pre-chemotherapy decline in cognition relating to attention, learning and processing speed (Wefel et al., 2004). While the study's sample size was relatively small ( $n = 18$ ), it was the first known published trial to examine cognitive changes at the pre-chemotherapy and post-chemotherapy stages using a longitudinal design. Pre-

treatment cognitive changes in cancer survivors may be due to factors relating to the disease itself such as the production of pro-inflammatory cytokine levels in the brain, which may subsequently lead to disruptions in cognitive function (Meyers, Albitar & Estey, 2005; Seruga, Zhang, Bernstein & Tannock, 2008; Vardy et al., 2007).

### ***Cognitive Changes as a Result of Other Confounding Factors***

Various personal factors may influence a cancer survivor's cognitive function throughout the cancer trajectory, including age, education, genetics and treatment-induced menopause (Ahles & Saykin, 2007; McAllister et al., 2004). Additionally, psychological and physical implications as a result of a cancer diagnosis and the burden of treatment, such as anxiety, depression and fatigue can influence a cancer survivor's perceived cognitive deficits (Ahles & Saykin, 2007; Biglia et al., 2012; Jansen et al., 2011; McAllister et al., 2004; Pullens, De Vries & Roukema, 2010).

In recent years, research has explored the association between self-perceived cognitive deficits and neuropsychological impairment in cancer survivors. While negative emotional functioning can impact how a survivor judges their cognitive performance, prospective studies have found that self-perceived cognitive deficits do not correlate with neuropsychological assessment outcomes (Biglia et al., 2012; Hermelink et al., 2010; Skaali et al., 2011). Nonetheless, a cancer survivor's perceived cognitive deficits can impact participation in meaningful, everyday activities and ultimately hinder their QOL beyond the survivorship phase (Burgess et al., 2005; Mehnert, 2007; Shilling & Jenkins, 2007).

While the explicit cause of cognitive changes in cancer survivors remains unknown, Vardy et al. (2008) suggest these changes are likely multifactorial; brought about by the complex relationship between the disease, its treatments and an individual's unique personal factors. Regardless of aetiology, cognitive changes can have a serious effect on the health and well-being of cancer survivors.

### **Associations Between Cognitive Changes, Daily Function and Quality of Life**

Though largely subtle in nature, cognitive changes as a result of a cancer diagnosis and treatment can have a profound impact on a person's daily functioning and overall QOL (Lauver, Connolly-Nelson & Vang, 2007; Munir et al., 2011; Tannock, Ahles, Ganz & van Dam, 2004; Wefel et al., 2004). Diminished functional ability can impede a cancer survivor's

transition back to work (Bradley, Neumark, Bednarek & Schenk, 2005; Duijts, 2014), community engagement (Reid-Arndt, Yee, Perry & Hsieh, 2009) and participation in meaningful activities, such as driving and reading (Myers, 2012).

In a qualitative exploratory study that investigated the long-term side effects of chemotherapy for breast cancer survivors, cognitive changes were one of the most commonly documented chronic symptoms by participants (Boykoff, Moieni & Subramanian, 2009). Participants reported feeling fearful and saddened that they were no longer able to retain new information like they once could; leading to a sense of hopelessness and diminished self-efficacy. Furthermore, participants claimed they were unable to fulfil pre-existing roles within their personal, professional and social environments as a result of cognitive changes. Consequently, participants could not perform meaningful activities independently, which hindered their overall health and well-being (Boykoff et al., 2009).

In a recent qualitative descriptive study, breast cancer survivors expressed feeling frustrated by self-perceived cognitive deficits (Von Ah, Habermann, Carpenter & Schneider, 2013). Furthermore, participants reported a decline in self-confidence, social relationships and their ability to perform work duties to the same level that they were once use to as a result of perceived cognitive deficits (Von Ah et al., 2013). This study also highlighted the needs of cancer survivors to have their cognitive concerns validated and supported by family, friends and healthcare providers (Von Ah et al., 2013).

### **Rehabilitation and Management of Cancer-Related Cognitive Changes**

Despite the lasting impacts of cognitive changes, there appears to be a lack of information provided to cancer survivors regarding the potential for cognitive changes as a result of a cancer experience (Mitchell & Turton, 2011). In an exploratory study, breast cancer survivors and oncology health professionals were interviewed to identify the degree of information available to patients regarding the possible side effects of chemotherapy (Munir et al., 2011). While all participants reported to have received information about the physical side effects of treatment, discussions around cognitive changes were generally patient-led or not addressed at all (Munir et al., 2011). This was supported by the responses of health professionals, who acknowledged the lack of information provided to patients regarding the possibility of cognitive changes. This study highlighted the uncertainty of health professionals regarding the management of patients' cognitive concerns. Additionally, the

study emphasised the need for future research in order to identify evidence-based interventions for the treatment of subtle cognitive changes as a result of a cancer experience (Munir et al., 2011).

In the Boykoff et al. (2009) study, a large proportion of participants reported having their cognitive concerns dismissed by treating health professionals. According to the self-reports of participants, oncologists provided little to no warning prior to commencing chemotherapy, and would frequently blame confounding factors such as age when patients raised the issue of cognitive changes (Boykoff et al., 2009). This lack of validation left cancer survivors feeling frustrated and scared; ultimately impacting on their QOL (Boykoff et al., 2009). While a small subset of participants did receive validation when raising their cognitive concerns to health professionals, participants acknowledged the lack of management guidelines for the treatment of CRCC (Boykoff et al., 2009). Additionally, many participants expressed a desire to be informed about the possibility for CRCC pre-treatment, and felt that being forewarned by oncologists would assist in coping with this potential symptom of treatment (Boykoff et al., 2009).

A cross-sectional survey was conducted to better understand the perceptions of oncologists, nurses, and pharmacists practising in Asia regarding the significance, effects and potential causes of cognitive changes following cancer diagnosis or treatment. Of all participants ( $n = 193$ ), oncologists were less likely to identify chemotherapy as the leading cause for cognitive changes in patients (Cheung et al., 2013). Approximately half of the respondents claimed that patients seldom raised the issue of cognitive changes. Cheung et al. (2013) suggest that this inconsistency in the study's findings may support previous research, which indicates that oncologists do not specifically address this potential side effect of a cancer diagnosis or treatment with their patients (Boykoff et al., 2009; Munir et al., 2011). However, further exploration is needed into why oncologists do not generally inform patients of the possibility of CRCC.

Cheung et al.'s (2013) study is the first known published study to examine the perceptions of oncology health professionals regarding the phenomenon of subtle cognitive changes and its effects on cancer survivors. As this study collectively examined the perceptions of Asian oncology health professionals, future research using individual group sampling would assist in identifying similarities and differences in perceptions amongst the varying healthcare professions involved in survivorship care (Cheung et al., 2013).



Additionally, future research within a westernised context would account for the contrasting features of western and eastern cultures in a healthcare setting.

### **Conclusion**

The subtle cognitive changes experienced by cancer survivors following cancer diagnosis and treatment are becoming increasingly acknowledged within the oncology community as a survivorship issue. Self-reports of cancer survivors demonstrate the profound impact that changes in cognition can have on QOL. Nonetheless, research identifies a gap in oncology specialists' practice in providing consultation and support to cancer survivors regarding the possible changes to cognition following cancer diagnosis and treatment. As a result, cancer survivors report feeling disempowered, ill-informed of the potential, long-term implications of CRCC, and subsequently ill-equipped to assume a proactive role in their survivorship care. While previous research demonstrates oncology specialists' awareness of this phenomenon and the lack of information provided to cancer survivors regarding CRCC, factors influencing this limitation in oncology specialists' practice remains unexplored in the literature. Consequently, the cognitive concerns of cancer survivors are often dismissed, impeding the likelihood of multidisciplinary collaboration for the holistic management of CRCC and their effects on cancer survivors' daily functioning and QOL.

### **Recommendations for Future Research**

Understanding the reasons why discussions around CRCC are generally initiated by cancer survivors or not addressed at all remains unclear in the current body of research. What is known is that discussions between oncologists and patients regarding the potential effects of treatment on cognition are rare, particularly when compared with informing cancer survivors of the physical side effects of cancer diagnosis and treatment. Thus, there is a need to explore the perceptions of oncologists regarding their understandings and practice around CRCC, and how their views may influence decisions about patient care. In doing so, possible barriers to best practice can be identified and addressed in order to support the provision of patient-centred cancer care.

Accordingly, the subsequent study aims to employ qualitative methods to address the following research questions:

- How do oncologists perceive cognitive changes and the underlying cause(s) in cancer survivors following diagnosis and treatment?
- How do oncologists anticipate and address cognitive changes with their patients across the continuum of cancer care, including the survivorship phase?

### **Significance and Scope of the Study**

This study does not explicitly seek to prove or disprove existing research regarding the cause of cognitive changes in cancer survivors. Instead, the objective of the study is to explore Australian oncologists' understandings of the cognitive changes experienced by survivors as a result of a cancer diagnosis and treatment, and how their views may influence decisions about patient care. The findings of this study will contribute to an understanding of how to address the need for specific interventions and management guidelines addressing CRCC and their effects on cancer survivors to assist oncologists in their practice. It is also hoped that study findings will raise awareness of referral options for Australian oncologists to other health professionals who can provide rehabilitation services to help manage and overcome CRCC for cancer survivors. Shedding light on this under-addressed aspect of oncology practice places the needs of the cancer survivor as central to their care, and should foster a more holistic approach to the management of CRCC by involving all members of the multidisciplinary team.

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## SECTION II

### JOURNAL MANUSCRIPT

**TARGET JOURNAL:** **Psycho-Oncology**  
(See Appendix A - Author Guidelines)

**TITLE:** **The Perceptions of Australian Oncologists Regarding  
Cognitive Changes in Cancer Survivors**

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**Abstract Length:** 219 words

**Word Count (including abstract and tables):** 4,994 words

**Number of Tables:** 2

**Number of References:** 40

### **Note to the Examiner**

- Tables have been inserted within the manuscript text rather than at the end to enhance readability.
- The study's sample size is sufficient for publication in this journal.

## Abstract

**Objective:** Cancer related cognitive changes (CRCC) can have a profound impact on a cancer survivor's quality of life. Nonetheless, cancer survivors report receiving limited information by oncology specialists regarding this phenomenon. This qualitative study aimed to explore the perceptions of oncology specialists regarding CRCC, and how their views may influence decisions about patient care.

**Methods:** Thirteen medical oncologists and five radiation oncologists currently practising in Australia participated in this study. Data collection involved individual, semi-structured interviews via telephone. Data were audio-recorded, transcribed verbatim and analysed using a thematic approach.

**Results:** Four key themes emerged: (1) Beliefs about the impact of priming on cancer survivors' perceived cognitive function (2) Perceptions of who is more likely to raise concerns of cognitive change (3) Uncertainty of how to best manage CRCC (4) Oncologists' perceived role in the management of CRCC

**Conclusions:** CRCC and its impact on the cancer survivor's journey has been under-addressed by oncology specialists, and they are uncertain of potential management strategies. With cancer survival rates increasing, there is a need for specific interventions and management guidelines addressing CRCC and their effects on cancer survivors. Future exploration should focus on the survivor as central to their care, and holistic approaches to CRCC management involving all members of the multidisciplinary team.

**Key words:** cancer, oncology, cognition, survivorship, clinical practice, qualitative

# **The Perceptions of Australian Oncologists Regarding Cognitive Changes in Cancer Survivors**

## **Introduction**

One in two Australians will be diagnosed with cancer during their lifetime [1]. While cancer prevalence in Australia has increased, so have five-year survival rates for people diagnosed with cancer [1]. As survivorship becomes increasingly recognised as a distinct phase of cancer care, uncertainty has emerged regarding the roles and responsibilities of those caring for cancer survivors [2-4]. In a study by Cheung et al. [2], cancer survivors were found to have higher expectations than oncologists regarding the role of oncologists in survivorship care. Additionally, the study identified an overlap in the expectations of oncologists and general practitioners (GPs) for survivorship care, particularly regarding follow-up, screening for other cancers and preventive healthcare [2]. The gaps in survivorship care have previously led to cancer survivors being ill-informed of the potential challenges associated with the survivorship phase [5].

Subtle changes to cognition are widely acknowledged as an issue present during the survivorship phase [6], and can impact daily functioning and quality of life (QOL) [7]. Changes in the cognitive domains of information and processing speed, attention, memory retrieval and executive function are commonly reported by cancer survivors along the continuum of cancer care [6]. While this phenomenon has received growing attention in the literature, the explicit cause of cognitive changes remains unknown [8].

‘Chemobrain’ or ‘chemofog’ are common terms used to describe subtle cognitive changes as a result of chemotherapy treatment [9]. Cognitive changes may be due to hormonal imbalances and the toxic effects that chemotherapeutic agents can have on the brain [10]. A small number of prospective longitudinal studies have evaluated the cognitive functioning of cancer survivors pre-chemotherapy and post-chemotherapy, and found that a proportion of cancer survivors are experiencing cognitive changes prior to commencing chemotherapy [11-13]. Pre-treatment cognitive changes may be due to factors relating to the disease itself such as the production of pro-inflammatory cytokine levels in the brain [14].

Various personal factors may also influence a cancer survivor’s cognitive function throughout the cancer trajectory, including age, education, genetics and treatment-induced menopause [10, 15]. Additionally, psychological and physical implications as a result of a

cancer diagnosis and the burden of treatment, such as anxiety, depression and fatigue can influence a cancer survivor's cognitive function [10, 12, 15, 16]. While negative emotional functioning can impact how a survivor judges their cognitive performance, prospective studies have found that self-perceived cognitive deficits do not correlate with neuropsychological assessment outcomes [11, 16, 17]. However, self-reports of cancer survivors highlight the impact of perceived cognitive deficits on overall health and well-being [18, 19].

Despite the lasting impacts of cancer-related cognitive changes (CRCC), there appears to be a lack of information provided to cancer survivors regarding the possibility of cognitive changes following cancer diagnosis and treatment [20]. In a study by Boykoff et al. [18], a large proportion of participants reported having their cognitive concerns dismissed by oncologists and were provided little to no warning prior to commencing chemotherapy. This lack of validation left cancer survivors feeling frustrated and scared; ultimately impacting on their QOL [18]. A recent study explored the perceptions of oncologists, nurses, and pharmacists practising in Asia regarding CRCC [21]. Approximately half of the oncologists in the study claimed that patients seldom raised the issue of cognitive changes. These findings may support previous research, which indicate that oncologists do not specifically address this potential side effect of a cancer diagnosis or treatment with their patients [18, 22].

Reasons why the discussion around CRCC is generally initiated by cancer survivors or not addressed at all remains unclear in the current body of research. What is known is that discussions between patients and oncologists regarding the potential effects of treatment on cognition are rare, leaving patients feeling isolated and disempowered. This research asks:

- How do oncologists perceive CRCC and the underlying cause(s) in cancer survivors?
- How do oncologists anticipate and address CRCC with their patients across the continuum of cancer care, including the survivorship phase?

The aim of this study was to explore the perceptions of Australian oncologists regarding CRCC, and how their views may influence decisions about patient care.

## **Methods**

### ***Study Approach***

This study adopted a qualitative approach using thematic analysis [23]. A thematic approach can foster insightful findings addressing research questions that seek to identify values, perceptions and experiences [23], such as exploring oncology specialists' perceptions of cognitive changes in cancer survivors.

Ethics approval was obtained from the Human Research Ethics Committee at the University of Sydney, Australia (Reference no. 2014/323).

### ***Sampling and Recruitment***

Medical and radiation oncologists currently practising in Australia were eligible to participate in the study. Participants were recruited through advertisements that were distributed via email by membership organisations within the oncology community. The advertisement invited members to complete an online Expression of Interest if willing to participate in the study. The purpose of the Expression of Interest was to collect participants' demographic information to enable stratification of the sample if possible, availability for interview, and gaining informed consent.

Snowballing was also used in recruitment in an attempt to maximise participation by a group with a known, low response rate due to existing priorities in everyday practice [24]

### ***Data Collection***

Data collection involved individual, telephone interviews. Interviewing via telephone rather than face-to-face was selected due to likely constraints regarding time and location for participants. A semi-structured interview schedule (see Appendix B) was used for all interviews to enable information sharing and knowledge building [25]. Prior to commencing interviews, participants provided verbal consent for interviews to be audio-recorded and transcribed verbatim. Interviews lasted between 15 and 30 minutes.

### ***Data Analysis***

In keeping with Braun and Clarke's guidelines for a rigorous thematic approach, six phases of analysis were applied: 1. Familiarisation with the data, 2. Generating initial codes, 3. Searching for themes, 4. Reviewing themes, 5. Defining and naming themes and 6. Writing the report [23]. An inductive approach to coding was performed during the data analysis

phase, where the data drove the coding process as opposed to coding data using a pre-existing framework [23].

In addition to transcribing thirteen of the eighteen interviews, the first author repeatedly read each of the transcripts. Initial codes were then generated from the data and organised into potential, broader themes that signified meaning and were relevant to the research questions.

### ***Rigour***

A number of strategies were employed to enhance the study's rigour. The first author used a journal to document their thoughts and interactions during and directly after interviews. This enabled reflexivity, and the ability to distinguish between personal values and assumptions and the true perspectives of participants [26]. Member checking was used to ensure accuracy of data [26]. Transcripts were sent to participants for the opportunity to edit responses. No participant requested any changes to be made. Throughout data analysis, consensus coding was conducted by three of the authors (Smidt, Mackenzie & Dhillon). Authors coded data separately then discussed similarities and differences between individual analyses and resolved any issues. Potential themes were then reviewed and refined before authors identified four key themes. Peer debriefing occurred throughout the research process. The second and third authors provided ongoing feedback to the first author, ensuring the reported interpretations and conclusions were true representations of the data set.

## **Results**

### **Participants**

Thirteen medical oncologists and five radiation oncologists participated in the study (Table 1). Most participants were aged 35-44, male and practised within the Australian public hospital system. Participants subspecialised in a range of cancer groups.

While participants had varying perceptions of CRCC, four key themes emerged from the interview data: (1) Beliefs about the impact of priming on cancer survivors' perceived cognitive function (2) Perceptions of who is more likely to raise concerns of cognitive change (3) Uncertainty of how to best manage CRCC (4) Oncology specialists' perceived role in the management of CRCC (Table 2).



**Table 1***Participant Demographics*

<b>Participant no.</b>	<b>State</b>	<b>Geographical Location</b>	<b>Gender</b>	<b>Age Range</b>	<b>Institution of Primary Practice</b>	<b>Oncology Discipline</b>	<b>Sub-Specialty</b>
1	QLD	Metropolitan	Male	65-74	Mixed	Medical	Breast
2	NSW	Regional	Female	35-44	Public	Radiation	Gastro-Intestinal, Head & Neck, Brain
3	VIC	Metropolitan	Male	45-54	Public	Medical	Breast, Genitourinary, Brain
4	NT	Rural	Male	35-44	Public	Radiation	Nil
5	VIC	Metropolitan	Male	35-44	Public	Medical	Breast, Gastro-Intestinal, Lung
6	QLD	Metropolitan	Female	35-44	Public	Medical	Lung, Brain
7	QLD	Metropolitan	Male	45-54	Private	Radiation	Genitourinary
8	VIC	Metropolitan	Female	45-54	Public	Medical	Breast, Genitourinary, Lung
9	WA	Metropolitan	Male	45-54	Public	Medical	Breast, Genitourinary
10	VIC	Regional	Male	35-44	Public	Medical	Nil
11	WA	Regional & Rural	Male	35-44	Public	Radiation	Nil
12	QLD	Metropolitan	Male	55-64	Mixed	Medical	Gastro-Intestinal, Melanoma
13	NSW	Regional	Male	25-34	Public	Medical	Breast
14	NSW	Metropolitan	Male	35-44	Public	Medical	Gastro-Intestinal, Lung, Melanoma
15	VIC	Metropolitan	Female	35-44	Public	Medical	Gastro-Intestinal, Lung
16	SA	Metropolitan	Male	35-44	Mixed	Medical	Genitourinary, Gynaecological, Brain, Sarcoma
17	NSW	Metropolitan	Female	45-54	Mixed	Medical	Breast, Gastro-Intestinal
18	ACT	Metropolitan	Female	45-54	Public	Radiation	Genitourinary, Head & Neck, Sarcoma, Melanoma

**Table 2***Themes and Sample Codes*

<b>Themes</b>	<b>Sample Codes</b>
<b>1. Beliefs about the impact of priming on cancer survivors' perceived cognitive function</b>	<ul style="list-style-type: none"> <li>- Higher rates of self-reports by breast cancer survivors (BCS)</li> <li>- Online forums, support groups influence perceived cognitive deficits (PCD)</li> <li>- Informing patients of CRCC pre-treatment may contribute to increased self-reports</li> <li>- Hesitant to initiate discussion due to priming effect</li> <li>- More likely to initiate discussion with BCS due to priming effect</li> <li>- Dissociation between PCD and measurable cognitive impairment</li> </ul>
<b>2. Perceptions of who is more likely to raise concerns of cognitive change</b>	<ul style="list-style-type: none"> <li>- Younger females</li> <li>- Older Adults</li> <li>- Cognitively demanding work roles</li> <li>- Cancer survivors receiving chemotherapy, radiotherapy to brain</li> <li>- Brain tumour, brain metastases</li> <li>- Fatigue</li> <li>- Anxiety</li> <li>- Depression</li> </ul>
<b>3. Uncertainty of how to best manage CRCC</b>	<ul style="list-style-type: none"> <li>- No management guidelines</li> <li>- Lack of screening assessments</li> <li>- Hesitant to initiate discussion due to uncertainty</li> </ul>
<b>4. Oncology specialists' perceived role in the management of CRCC</b>	<ul style="list-style-type: none"> <li>- Management of physical side effects</li> <li>- Screening for cancer recurrence</li> <li>- Health promotion</li> <li>- Normalise CRCC</li> <li>- Recommend informal tips/coping strategies</li> <li>- Referral to GPs, psychologists, other Allied Health</li> <li>- Referral for neuropsychological assessment</li> <li>- Perceived barriers: lack of post-treatment clinics, financial constraints, limited time for follow-up appointments</li> </ul>

## **Theme 1: Beliefs about the impact of priming on cancer survivors' perceived cognitive function**

Many oncology specialists perceived a difference in the frequency of reporting cognitive changes between survivors of breast cancer and other cancer groups. This difference was believed to be associated with the higher degree of supportive care provided to breast cancer survivors across the continuum of cancer care. Online forums, local support groups and information provided by not for profit organisations were believed to facilitate information sharing and raise awareness regarding the potential for cognitive changes as a result of a cancer experience.

Participant 3: *"...there's so much more literature about it [cognitive change] for women out there with breast cancer and support groups... I think the women are more aware of this whole chemo fog thing and the effects of chemotherapy in general."*  
[Medical oncologist]

Participant 14: *"I think in, in the breast cancer population this [cognitive change] is much more often discussed and you know, I think there are more services that are tuned in to help people with breast cancer when they have this problem. But certainly in the other tumour streams it [cognitive changes] doesn't seem to be the same degree of interest or reporting or, or recognition that this is a problem."* [Medical oncologist]

The previous experiences and perceptions of participants influenced how they anticipated and addressed cognitive changes with their patients. Some participants were hesitant to initiate discussions about possible cognitive changes, believing that patients were more likely to raise cognitive concerns if their oncologist informed them of this potential side effect.

Participant 1: *"I feel that priming is a key issue in all of this. You go into a room and give a talk to women then say, 'who's got some cognitive changes after chemotherapy?' and everybody puts up their hands. I don't believe the problem is that common... maybe I'm creating the problem... their problem is we've got to get them back into life again of which cognitive functioning is one of the aspects."* [Medical oncologist]

In contrast, some participants felt it was important to lead a discussion with breast cancer survivors regarding the potential for cognitive changes as a result of chemotherapy. Oncologist-led discussions that focussed specifically on cognitive issues aimed to ease the concerns of breast cancer survivors due to the heightened awareness within the breast cancer community.

Participant 12: *“So [for] the breast cancer population I would tend to talk about it more than I do in other groups up front, because I think it’s to try and prevent some of the issues. Some of the other groups I don’t think it’s such as issue... I’d talk more generally about the effects of treatment, how it might affect your life and how to manage that.”* [Medical oncologist]

## **Theme 2: Perceptions of who is more likely to raise concerns of cognitive change**

Most participants perceived the underlying cause of cognitive changes as multifactorial, rather than linked to a single treatment modality. Factors thought to contribute to changes in cancer survivors’ cognition included method(s) of treatment, associated medications, emotional functioning and the level of support available to survivors across the continuum of cancer care.

Participant 4: *“...the factors that go in to neurocognitive decline are psychological, spiritual, physical, disease-related, treatment-related, environmental. So it’s not something that we can say it’s one particular thing. It’s a number of things.”*

[Radiation oncologist]

Participants distinguished between objective cognitive deficits and patients’ self-perceived cognitive changes. The measureable effects on cognition as a result of primary brain tumours, brain metastases or radiotherapy to the brain were discussed. However, cancer survivors’ self-reports of subtle cognitive changes were often thought to be strongly linked to other confounding factors, such as fatigue, anxiety and/or depression.

Participant 10: *“But if a patient who has got a background history of psychological issues like depression and anxiety, and particularly those patients who have less psychosocial support, I feel that these patients... their cancer significantly impacts their cognition.”* [Medical oncologist]

Participant 9: *“It [cognitive change] tends to go hand in hand with fatigue, so people who get tiredness also get cognitive impairment. People who report no tiredness seem to be relatively unimpaired... with fatigue settling, some people come right literally within a small number of weeks.”* [Medical oncologist]

Age and gender of cancer survivors were believed to influence reporting of cognitive changes. Of the participants who felt these demographics contributed to perceived changes in cognition, the majority believed that younger women were more likely to report cognitive changes.

Participant 8: *...I have had very little complaint about it [cognitive change] from men. It's been largely women... I think that those patients under fifty and around that age, I would say, notice it [cognitive change] more.”* [Medical oncologist]

Additionally, participants discussed employment as a contributing factor to self-perceived cognitive changes.

Participant 9: *“So people in higher end jobs are more likely to notice it. If you're not doing a job that requires a high degree of cognitive function, then you're less likely to notice it.”* [Medical oncologist]

As cognitive changes were perceived by some oncologists as downstream effects of the cancer experience, they recommended screening for anxiety, depression and fatigue to ensure treatable symptoms were not missed.

### **Theme 3: Uncertainty of how to best manage cancer-related cognitive changes**

While participants felt cognitive changes had received growing attention as a survivorship issue, many expressed uncertainty regarding the management of CRCC, largely because they believed there were few options available to intervene. This uncertainty impeded the likelihood of oncologist-led discussions regarding CRCC.

Participant 13: *“But the difficulty is, is that I don't really know what to do about it, and it's hard to ask a question that you don't know the answer to or you don't know the solution to.”* [Medical oncologist]

Participant 14: “... you can't really fix it [cognitive changes] for them, and you don't even know how bad it is and you don't know where to go or anything, so most of the time you just end up just watching it and then just sitting on it and maybe even forgetting to ask about it the next time anyway. So it's like one of those things that aren't in my practice first and foremost.” [Medical oncologist]

Participants attributed their uncertainty to the absence of management guidelines. Additionally, participants discussed the challenge of accurately assessing the cognitive concerns of patients due to the lack of screening tools designed to measure subtle cognitive changes. In the absence of evidence-based guidelines, the management of patients' cognitive concerns differed amongst participants. Many acknowledged the need for ongoing research for the development and provision of specific interventions and management guidelines addressing CRCC and their effects on cancer survivors.

Participant 5: “...guidelines for clinicians would be useful as well, to sort of base what I'm doing on best practice and what evidence is out there...” [Medical oncologist]

#### **Theme 4: Oncologists' perceived role in the management of CRCC**

Participants emphasised their curative role across the continuum of cancer care, in addition to the management of physical side effects as a result of cancer and its treatments. Screening for cancer recurrence was perceived as an important aspect of an oncologist's role within the survivorship phase. Additionally, some participants discussed health promotion as a key responsibility of oncologists during the survivorship phase.

While discussions were often patient-led, some participants raised the potential for cognitive changes with their patients as part of the consenting process to treatment.

Participant 9: “It's part of consenting a patient to treatment. If you're going to give chemo you need to know everything it may do, all the things that may happen, commonly at least. So we tell people before they make a decision about whether to have chemo or not.” [Medical oncologist]

The management of patients' perceived cognitive changes varied amongst participants. When addressing cognitive concerns, many participants normalised this phenomenon and provided informal strategies to cope with the daily impact of cognitive changes.

Participant 2: *"... if you keep doing crosswords and puzzles and things like that in the long term because that keeps your brain ticking over and stops this [cognitive changes], or slows down the effects that may come on as a result of treatment."*  
[Radiation oncologist]

Participant 3: *"It usually boils down to just practical stuff like, make sure you get plenty of rest, don't drink too much coffee, write lists all that sort of stuff."* [Medical oncologist]

Referral to GPs and clinical psychologists was another common approach employed by participants in managing the cognitive concerns of patients, particularly if these changes were felt to be associated with anxiety or depression. A smaller number of participants referred patients to other members of the multidisciplinary team for supportive care, including nursing, occupational therapy and social work. Few participants informed patients of formal cognitive rehabilitation programs, such as memory clinics. Participants often discussed the role of clinical neuropsychologists in assessing measurable cognitive impairments. However, the time and resources required to administer neuropsychological assessments was perceived as a barrier to referring patients.

Participants spoke of the barriers to delivering holistic care across the cancer trajectory, including the survivorship phase. For example, one participant discussed the potential effectiveness of nurse-led post treatment clinics for the continuing provision of support to cancer survivors in the survivorship phase. However, the reason such clinics were uncommon within the Australian public hospital system was attributed to financial constraints. Additionally, participants discussed the limited time dedicated to follow-up appointments, particularly in public hospitals. As a result, participants felt restricted in their ability to delve deeper into the challenges faced by cancer survivors during the survivorship phase.

Participant 15: “... *We get them [cancer survivors] back usually every three months. Our job then is to get their scans done and we say to them, look that's good. Did you have any side-effects from the chemotherapy? No? Okay fine. Bye, see you in another three months. So we leave a lot of those things up to the general practitioner... I think we delegate some of that responsibility of that holistic aspect of their care to the community setting.*” [Medical oncologist]

## **Discussion**

Findings from this study confirm that oncology specialists are faced with cancer survivors who experience long-lasting sequelae as a result of their cancer diagnosis and treatment. While the Australian healthcare system now classifies many cancers as a chronic disease, cancer care offered by oncology specialists often reflects a medical approach and may not support patients in taking responsibility for and control of their own care [27]. Across the continuum of cancer care, one challenge for oncology specialists is patient-clinician communication, which enables patient self-management and is fundamental for the provision of patient-centred cancer care [28].

However, findings indicate that this does not appear to be translated into everyday oncology practice. Particularly for CRCC, cancer survivors report receiving little to no information from treating oncologists about this potential side effect of a cancer experience [20, 22], and results from this study suggest that discussions regarding CRCC are generally patient-initiated or not addressed at all. A number of factors may contribute to these findings, such as uncertainty regarding the appropriate management of CRCC. The lack of clinical practice guidelines for the treatment of CRCC is a perceived barrier to best practice, and consequently, some participants of this study were hesitant to discuss this potential side effect with patients. Additionally, uncertainty of participants have resulted in the inconsistent management of patients' cognitive concerns in the past.

Notably, only a small number of participants in this study discussed the potential for CRCC with patients when obtaining informed consent for treatment. As cancer survivors have previously expressed their desire to be informed and involved in treatment decision making [29], the provision of accurate and transparent information is essential for achieving true patient-centred cancer care. Moreover, as cancer survival rates continue to increase, patient education can foster health literacy and ultimately enable cancer survivors to assume a



proactive role in their long-term cancer care. In keeping with the principles of patient-centred cancer care and the ethical requirements of informed consent, cancer survivors need timely, balanced information regarding CRCC, its potential duration, cause(s) and recommendations for management.

Previous research suggests that the effects of priming and pre-existing knowledge may contribute to an increased reporting of cognitive concerns by cancer survivors [30]. This notion was supported by the perceptions of some participants in this study. These perceptions and previous experiences of oncologists may further explain why oncologists are hesitant to disclose information to patients regarding this phenomenon as a result of a cancer diagnosis or treatment. While priming or informing patients of the possibility of CRCC has been shown to elicit a high rate of self-report cognitive changes after chemotherapy, it is unclear if this is due to a priming effect or whether it reflects cancer survivors feeling more able to report symptoms that are troubling them. Thus, if oncologists do not inform patients of this potential side effect, cancer survivors may feel less inclined to raise cognitive concerns [21].

Oncology specialists in this study felt that information provided by cancer-related online forums, support groups and societies contributed to reports of cognitive changes amongst cancer survivors. Yet if patients are not receiving information from their oncologists, this will be inevitable. The provision of balanced information may diminish the significance and likelihood of the priming effect however, future studies in this area of CRCC are warranted [30]. Additionally, further research into CRCC is necessary so the diverse group of people caring for cancer survivors can deliver accurate, evidence-based information to their patients.

Findings from this study support the belief that CRCC are caused by a multitude of factors [6], including treatment modality, the side effects of associated medications and the psychological impact of a cancer experience. Consistent with previous studies [11, 17], participants perceived a dissociation between cancer survivors' perceived cognitive changes and measurable cognitive impairment. Participants believed that perceived changes in cognitive functioning were strongly linked with fatigue, anxiety and/or depression. Previous research has demonstrated a correlation between perceived CRCC and negative emotional functioning [16], but causal relationship remains unclear. Regardless of the causes of CRCC, cancer survivors want their cognitive concerns to be acknowledged and validated by treating oncologists in a timely and open manner [18].

Interestingly, a number of participants perceived a greater likelihood in the reporting of cognitive concerns amongst cancer survivors in work roles requiring a high level of cognitive functioning. While previous studies demonstrate the challenges faced by cancer survivors returning to work due to CRCC [31, 32], there is limited evidence to suggest that cancer survivors are more likely to notice changes in cognition and subsequently report concerns to oncologists if they are in cognitively demanding positions. While cancer survivors experiencing CRCC may be unable to maintain productivity at work, the functional implications of CRCC are commonly reported by survivors of varying backgrounds and experienced across a range of settings [33]. As a result, some cancer survivors are unable to satisfactorily participate in a range of everyday activities, including driving [34] and community engagement [35].

Findings from this study highlight the barriers to delivering survivorship care from the perspective of Australian oncologists. Participants commonly discussed the minimal time assigned to follow-up appointments, particularly within the public healthcare system. This underlines the perceived role of oncologists in the survivorship phase, focussed mainly on screening for cancer recurrence and the management of physical side effects. In order to build the capacity of cancer survivors to take control of their own long-term care, the survivorship phase should also include avenues for health promotion, education and for the long-term health concerns of patients, including CRCC to be heard and addressed [5]. While participants in this study referred patients to GPs and psychologists for the management of CRCC, particularly if thought to be linked with anxiety and depression, very few discussed the role of other multidisciplinary team members in managing the cognitive concerns of cancer survivors. As suggested in previous research [36], the limited understanding of specialist roles in cancer care may prevent oncologists referring patients; ultimately limiting the provision of high quality survivorship care.

Cognitive rehabilitation is a growing area of interest in cancer care and there is research to suggest that group-based programs may improve cognitive function and overall quality of life [37]. Allied health professionals have much to offer in cognitive rehabilitation and management of long-term functional and psychological implications of a cancer experience [38]. Particularly for CRCC, occupational therapists can apply a holistic approach and foster participation in everyday activities through a range of coping skills and compensatory strategies [39]. However, oncology specialists tend not to refer for these

services. Further research is needed to determine effective interventions in managing the cognitive concerns of cancer survivors across the continuum of cancer care.

### **Scope and Limitations**

This study highlights Australian oncologists' understandings of CRCC, and how their beliefs extend to everyday practice. However, this study has several limitations that must be considered when interpreting the study's findings. The sample size is relatively small. The majority of participants were male, aged 35-44 and practised medical oncology within the Australian public hospital system in a metropolitan area. Thus, the results of this study may not be generalisable to other oncology disciplines, including radiation and surgical, to the Australian private hospital system, or to regional and rural areas of Australia. As participants were required to volunteer their participation in the study, it can be assumed that participants already demonstrated an awareness of CRCC and had a particular interest in this area of cancer care. Therefore, volunteer bias may impede the generalisability of the study's findings to the broader community of oncology specialists practising in Australia.

Additionally, a large subset of participants currently or previously subspecialise(d) in breast cancer. The perceptions of participants may reflect a bias towards this cancer group as research into CRCC has mainly focussed on breast cancer populations. Future studies could benefit from recruiting a larger number of oncology specialists from a range of disciplines within the public and private hospital systems. Furthermore, qualitative studies would enhance awareness of the barriers to delivering patient-centred cancer care, and ultimately call for quality improvement within the Australian healthcare system.

### **Conclusion**

As cancer survival rates increase, CRCC has received growing attention as a survivorship issue. CRCC can have a profound impact on a person's daily functioning and QOL [7]. Despite the long-term effects of cognitive changes on a cancer survivor's well-being, research indicates a gap in information sharing on the part of oncologists [18, 20]. The results of this study and other international studies highlight the uncertainty of oncologists regarding the appropriate management of CRCC. As a result, this aspect of a cancer survivor's journey is often under-addressed by oncology specialists [22]. Future research is

needed to determine evidence-based interventions and clinical practice guidelines for the treatment of cancer survivors' cognitive concerns across the continuum of cancer care.

In addition to primary cancer follow-up and screening for cancer recurrence, the survivorship phase should include avenues for health promotion and management of long-term sequelae as a result of a cancer experience [5]. The provision of timely and open information across the cancer trajectory can lead to improved health outcomes for cancer survivors, and ultimately promote a patient-centred approach to cancer care [40]. Future exploration should focus on the needs of the cancer survivor as central to their care, and should foster a more holistic approach to CRCC management by involving all members of the multidisciplinary team.

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### **Conflict of Interest**

The Authors have no conflicts of interest to disclose.

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## APPENDICES

### APPENDIX A: PSYCHO-ONCOLOGY – AUTHOR GUIDELINES FOR MANUSCRIPT SUBMISSION

#### Author Guidelines

#### Manuscript Submission

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## APPENDIX B: INTERVIEW SCHEDULE

### Interview Schedule

#### Question 1:

Please describe your perception of cognitive changes in your patients from diagnosis right through to the survivorship phase?

*Follow up questions if required:*

- Do you talk with your patients about cognitive changes?
  - If yes, what are the kinds of cognitive changes that patients describe to you?
  - If no, have you heard about possible cognitive changes in cancer patients?
- What is the general pattern and time frame of any cognitive changes in your patients throughout the cancer trajectory?

#### Question 2 (if not already answered in question 1):

What do you believe are the underlying causes of these changes?

- Do you think anti-cancer treatments such as chemotherapy, radiotherapy and hormonal therapy contribute to cognitive changes?
- If yes, how much do you think each treatment modality is responsible?

#### Question 3:

Are there specific characteristics that you can identify about the people who report cognitive changes?

*Follow up questions if required:*

- How do you perceive differences in cognitive changes amongst patients of different tumour groups?
- Are there some patients who consistently report cognitive changes more than others?

#### Question 4:

How do you approach the possibility of cognitive changes with your patients?

*Follow up questions if required:*

- Do you routinely ask your patients whether they are experiencing cognitive changes?
- At what stage would you ask your patient whether they are experiencing cognitive changes?
- If your patient reports changes in cognition, what action do you take?

**Question 5:**

To improve future practice and maximise quality of life for patients, what do you believe are some ways to address cognitive changes with patients from cancer diagnosis right through to the survivorship phase?

**APPENDIX C: UNIVERSITY OF SYDNEY HUMAN RESEARCH ETHICS  
COMMITTEE – STUDY APPROVAL**