



**Beyond Breast Cancer:
An exploration of the experiences of middle-
aged female breast cancer survivors in
Australia.**

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THESIS ABSTRACT

Background: Individuals who live with, through and beyond breast cancer are known as survivors, and their numbers are growing. Middle-aged women, the group most impacted by breast cancer survivorship, report ongoing psychological, emotional and physical challenges years after being cleared of the disease.

Aim: The present study aims to explore how the experiences of breast cancer survivorship impacts the lives of Australian middle-aged women (n = 644), and to inform future provision of care and support.

Overview of Thesis: This thesis is divided into two sections. Section I is a review of existing and relevant international literature relating to experiences of middle-aged women and breast cancer survivorship including challenges related to side effects of treatment. Current and proposed care for the survivorship phase is also identified, highlight areas requiring further research.

Section II is a research manuscript formatted for the journal *Psycho-Oncology*. This manuscript outlines the qualitative methodology and thematic analysis applied to explore breast cancer survivorship experiences in middle-aged Australian women.

Research Findings: Findings highlight that unique life experiences can occur during a middle-aged life stage, which can be exacerbated by a diagnosis of breast cancer. Study findings confirm that breast cancer survivors experience long-lasting sequelae following their cancer diagnosis and treatment. Greater involvement of rehabilitation multidisciplinary professionals, particular occupational therapists can improve outcomes of the ongoing challenges post-diagnosis. Further investigation and application of survivorship care plans in Australia, including referral and increased involvement from allied health professionals, particularly occupational therapy, is recommended to address ongoing survivorship challenges.

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SECTION I – LITERATURE REVIEW

INTRODUCTION

The incidence of breast cancer is rising, however so are survival rates (Australian Institute of Health and Welfare & Cancer Australia, 2012). Research has revealed that in Australia, individuals diagnosed with breast cancer have a 90% chance of surviving beyond 5 years, which has increased from 72% in 1987 (Australian Institute of Health and Welfare & Cancer Australia, 2012). With increased survival rates, considerable attention is being invested in exploring the long-lasting sequelae of breast cancer including fatigue, pain, sleep disturbances, body image issues, and fear of recurrence (Buckland & Mackenzie, 2017; Cappiello, Cunningham, Knobf, & Erdos, 2007). Despite recognition of the functional and psychosocial long-term impacts of breast cancer in the literature, the survivor population continues to report unmet needs and distress (Burg et al., 2015; Wade & Lee, 2005b). The largest group of these survivors is middle aged women (40-65 years) who in addition to their breast cancer related challenges, experience a myriad of age-related expectations, pressures and changes (Rich, Choienta, & Loxton, 2013). Existing health care approaches often overlook these age-specific experiences, as well as the long-term impacts of breast cancer that extend beyond the end of active treatment. Some clinicians still consider post-treatment survivors to be cured, and therefore requiring no further intervention (Vivar & McQueen, 2005).

Purpose of Review

The purpose of this review is to examine and critique existing literature surrounding breast cancer survivorship, with emphasis on the experiences of this for middle-aged women. Subjects include middle-aged life experiences, understanding the short and long-term impact of breast cancer, global practices of care, and the role of rehabilitation care in addressing needs of breast cancer survivors.

Search Strategy

Rigorous searching of the following databases was conducted to ensure all accessible and relevant literature was considered for review: Medline, CINAHL, PsychINFO, and Scopus. Search terms included 'breast cancer', 'neoplasm', 'middle aged', 'women', 'survivor*', and 'experience*'. Results were refined through limits

including English language, peer reviewed articles, and a time restraint of the last 10 years. Abstracts of articles were screened for relevance and reference lists of significant articles were inspected for other relevant sources to further broaden the scope of the review.

Theoretical Framework

The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2002) was used to inform the process of this study including reviewing the literature, analysis, and interpretation of data (see Figure 1). The author approaches the study from an occupational therapy lens. Like occupational therapy theory and practice, the ICF is based on a *biopsychosocial model* in which the medical and social models are seen to be inadequate to understand disability on their own. Integration of these models allows recognition that both body functions and structures, as well as factors of a complex environment may hinder or promote participation and well-being (Cooney, Galvin, Connolly, & Stokes, 2013; World Health Organisation, 2002) 'Well-being' in the context of this paper, relates to life satisfaction, and a sense of purpose and meaning (Steptoe, Deaton, & Stone, 2015). The ICF was also chosen due to the praise it has received for applicability to guide health research (Imms, 2006; World Health Organisation, 2002) and recognition that it permits a "more comprehensive picture of the aspects of health that are altered by breast cancer and its related treatment" (Cooney et al., 2013, p. 741). The term *disability* in the ICF, includes impairments, activity limitations and participation restrictions. The current research adopted this terminology to consider participant's breast cancer, or *disability* to have wide spreading impacts. Through this framework, researchers explored how breast cancer and related treatment can lead to physical and hormonal changes (body functions and structures), influenced by factors in the personal and environmental context (contextual factors), which limit engagement in desired occupations (activities) as well as social demands and requirements (participation) (Campbell et al., 2012).

Understanding these factors through the ICF framework allowed researchers to examine the diverse experiences of breast cancer survivors, and propose recommendations to improve survivorship care (World Health Organisation, 2002).

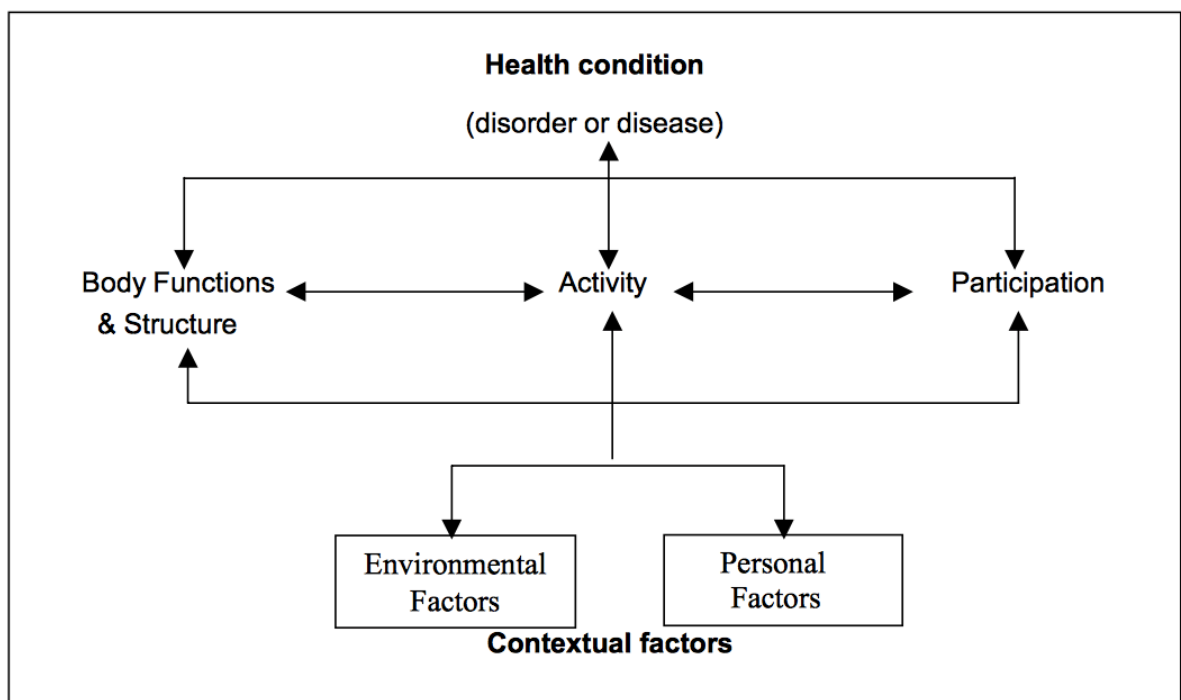


Figure 1. The International Classification of Functioning, Disability and Health (ICF) Framework. (<http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1>, p. 9)

MIDDLE- AGE RELATED EXPERIENCES IMPACTING BREAST CANCER SURVIVORSHIP.

‘Middle-aged’ has been referred to by several different titles including the ‘young old’ (Lazarus & Lazarus, 2006), ‘mature aged’ (Majeed, Forder, Mishra, Kendig, & Byles, 2015b), and those ‘entering later life’ (Majeed, Forder, Mishra, Kendig, & Byles, 2015a). All titles similarly depict a dynamic and often turbulent stage of life for women that can include menopause, changes to role requirements as a mother, and in the workforce, a need to adopt a caring role for elderly parents, or the loss of a parent and/or spouse (Wheeler, 1997).

Middle-aged women are also the group most impacted by a breast cancer diagnosis, which can exacerbate existing life challenges (Wade & Lee, 2005b). In the Australian Longitudinal Study of Women’s Health (ALSWH) data being examined, Wade and Lee (2005b) discussed that the middle-aged group (45-50 years) are seven times more likely to develop breast cancer than the younger group (18-23 years), yet compared to the older women (70-75 years), are expected to suffer greater adversity related to their physical, mental and social functioning due to being engaged in vocational, parental and social roles (Wade & Lee, 2005b). A study in the

UK found similar age-related differences in the experience of breast cancer survivorship. Analysis of questionnaire data (n = 483) found that the middle-aged group (46-53 years old) expressed statistically significantly more, and different needs in survivorship than other age groups (Vivar & McQueen, 2005).

Erikson's Theory on Middle-Age

Erik Erikson's 1959 'Theory of Psychosocial Stages' states that a middle-aged life stage typically involves the need to establish one's mark on the world. This need is defined by Erikson as '*generativity*' (Slater, 2003). Erikson's theory reflects the psychoanalyst's belief that well-being and identity stems from a resolution of psychosocial conflict during middle-adulthood. According to Erikson, women between 45 and 60 years achieve healthy identities through caring for others, raising children who will outlast them, contributing to a meaningful workforce or society, and maintaining relationships (Slater, 2003). A diagnosis of breast cancer can challenge a woman's ability to participate in these roles and activities, and consequently leave a sense of stagnation. According to the theory, '*Stagnation*' is the diametric opposite of '*generativity*', and elicits feelings of being disconnected or uninvolved with one's community and society, leading to dissatisfaction with one's identity (Slater, 2003). Clearly, middle-aged women have unique conflicts related to their life-stage that will shape their experience of breast cancer survivorship in a very different way than those of other life-stages.

Body Functions and Structures - Menopause

In addition to striving for a sense of generativity, middle-aged women also experience biological changes specific to their age. Menopause is a typical experience of middle-age, usually occurring between 45 and 55 years old (Cancer Australia, 2013). It refers to a woman's final menstrual cycle, signifying a change in the body's functioning, which for some includes a number of symptoms lasting on average one to five years with varying severity. Symptoms can include hot flashes, stress and mood changes, fatigue, weight gain, and impaired memory (Cancer Australia, 2013; National Breast and Ovarian Cancer Centre, 2010).

Treatment for breast cancer, can induce early onset menopause, meaning these symptoms are not only experienced sooner, but concurrently with the emotional and

psychosocial challenges of a new breast cancer diagnosis. Approximately two-thirds of women diagnosed with breast cancer before the age of 50, will go through menopause because of their treatment (Cancer Australia, 2013). Breast cancer treatments including chemotherapy and hormonal therapies may induce early temporary or permanent menopause (Cancer Australia, 2013). Many argue that menopause, whether triggered through breast cancer treatment or naturally occurring, is not well understood (Thomas-MacLean, 2005). Regardless of causation menopause adds to the burden of personal challenges for women with breast cancer. Further exploration of middle-aged women's lived experience of early onset menopause due to breast cancer treatment, will strengthen understanding, and effective management of it.

Activity and Participation – Caring and Work.

With an ageing population, middle-aged women increasingly tend to have parents who are still alive and require their care. Pierret (2006), refers to the phenomenon of the middle-aged caring for both their elderly parents and dependent children, the 'sandwich generation'. Women of the 'sandwich generation', have been identified as volunteering their finances, time and energy to their neighbouring generations, meaning they concentrate less on their own well-being (Pierret, 2006). An experience of breast cancer co-occurring with these generational demands will therefore present unique challenges for women in this age group. Accustomed to being the carer, they find themselves being the ones in need, with physical and psychological barriers impeding their caring abilities.

As discussed in Erikson's 'Theory of Psychosocial Stages', participation in meaningful work contributes to a healthy identity for middle-aged women. Work has been recognised as "one of the central organising structures of adult life" (Maytal & Peteet, 2011, p. 105). Confidence, belonging, self-concept and identity are some examples of the advantageous outcomes of working (Australian Centre for Health Research, 2017; Tamminga, de Boer, Verbeek, & Frings-Dresen, 2010; Wells et al., 2013). Forty percent of breast cancer survivors either change their work, reduce work hours or demands, or do not return to work at all, which can result in lower self-esteem and quality of life, as well as financial losses (de Boer et al., 2015; Tamminga et al., 2010). Return to, or maintenance of work however, is seen as an important

part of recovery for breast cancer survivors as it can provide a sense of normalcy and distraction (Tamminga et al., 2010).

Sun et al. (2016) recently studied the barriers and facilitators for breast cancer survivors during their active treatment. Semi-structured interviews with 35 women undergoing breast cancer treatment, found that during this phase of survivorship, symptoms, emotional distress, appearance change, time-constraints, and inadequate support limited work participation. In contrast, factors facilitating workplace engagement and job retention included support from supervisors and co-workers as well as support found outside of the workplace (Sun et al., 2016).

Lazarus and Lazarus (2006) discuss that the end of paid employment can be satisfying as long as you have something meaningful to take the place of work. In the case of breast cancer however, cessation of employment is often unwanted and unplanned. Change of activities with breast cancer may result in psychological issues such as depression and a loss of identity (Breast Cancer Network Australia, 2017). Breast cancer survivors who retire early due to their cancer have been found to have a lower quality of life than those who remain in the workforce (Lindbohm et al., 2014). Services to support women in work post-breast cancer is required if they wish to remain in the workforce. Furthermore, investigation of the uptake of leisure activities or voluntary work compared to those who do not seek these activities after cancer related retirement, is recommended to explore post-work quality of life in breast cancer survivors.

BREAST CANCER SURVIVORSHIP

Improvements in breast cancer survival rates may be due to better early detection through screening, and advancing treatments (National Health Service, 2007). Good news of survivorship statistics however, may at times mask the reality of a longer illness trajectory with unpredictable health outcomes and challenges for the individual (Corner, 2008). Immediate, long term or delayed effects resulting from breast cancer and associated treatments can significantly impact an individual's functional capacity and quality of life (Vivar & McQueen, 2005). Recognition of this has generated interest in classifying survivorship as a distinct phase of breast cancer (Buckland, 2017; Cappiello et al., 2007). Traditional dichotomies of health and illness are evidently insufficient to describe the ongoing needs of breast cancer survivors

beyond active treatment (Buckland & Mackenzie, 2017; Cappiello et al., 2007; Thomas-MacLean, 2005).

Current literature lacks a standardised definition of *survivorship*. Meanings range from a time beginning at diagnosis and lasting until the end of life (Da Silva & Dos Santos, 2010), to a period that commences at the end of active treatment (Richardson et al., 2011). For the purpose of this review, a breast cancer survivor includes:

- i) Someone who has completed initial treatment and has no evidence of active breast cancer;
- ii) Someone who has the progressive disease and may be receiving treatment however, are not in the terminal phase of illness; or
- iii) Someone who has had breast cancer in the past (National Health Service, 2007).

While the experiences of women with breast cancer have widely been studied, most oncology research focuses on the immediate, and short-term effects of cancer including primary diagnosis, the treatment process, and impacts within the first year of treatment (Deimling et al., 2006; Stanton, Danoff-Burg, & Huggins, 2002). With an ageing population and advancing medical treatments, a further rise in the incidence of females living with breast cancer related issues is predicted. By the year 2020, the national incidence of breast cancer is estimated to be 18,235 (Australian Institute of Health and Welfare, 2017). As the incidence and rate of survival from breast cancer increases, so must the availability and quality of survivorship care.

Breast Cancer as a Chronic Disease

Improving survivorship care, involves recognition of the ongoing impact of breast cancer beyond active treatment. Emerging research has identified patterns of ongoing cancer-related limitations and challenges, and classified it as a chronic disease (Hamilton & Hurley, 2010; Short, Vasey, & BeLue, 2008). Short et al. (2008) discusses that disabilities in the workplace associated with cancer survivorship, is similar to those resulting from other chronic conditions. Body changes following breast cancer treatment including swelling, limited range of motion of the upper limbs, weight gain, and lymphoedema are also recognised as unique chronic features of breast cancer survivorship (Thomas-MacLean, 2005). Thomas-MacLean (2005)

highlights that despite indications of body acceptance, these body changes are reminders of illness, disability and limitation, so that even beyond treatment, an individual may be constantly experiencing their breast cancer survivorship status. Contrasting to other chronic conditions including diabetes and arthritis however, ongoing disability for cancer survivors result often from associated treatment rather than the disease itself (Short et al., 2008).

As with other chronic conditions, cancer survivors require additional clinical and psychosocial services to maximise quality of life (Short et al., 2008). Providing adequate support for breast cancer survivors, and other chronic conditions however, has proved challenging in the current Australian health-care system, which typically: fails to emphasis the individual needs of self-management; focuses on treatment of acute illnesses; overlooks the importance of secondary prevention; and provides inconsistent disease specific-follow-up (Phillips & Currow, 2010). To progress with development of improved cancer survivorship care, it is recommended that potential barriers of the Australian health-care system, also be investigated.

The landmark United States Institute of Medicine (IOM) report '*From cancer patient to cancer survivor: lost in transition*' has given new impetus to the categorisation of breast cancer as a chronic condition in international (Bodai & Tusso, 2015; Hewitt, Greenfield, & Stovall, 2005) as well as Australian literature (Phillips & Currow, 2010). This report not only highlighted the ongoing challenges present for cancer survivors, but proposed a number of changes to ensure better provision of care for those living with this chronic and complex condition. Identifying and categorising breast cancer as a chronic condition in Australia is required to enhance funding opportunities for ongoing care and support for survivors.

SIDE-EFFECTS OF BREAST CANCER AND TREATMENT

Stanton et al. (2002), highlights the intense personal and interpersonal challenges an individual with breast cancer meets in their first year of diagnosis. These individuals are faced with complex decisions around treatment procedures, while processing

potential threats to well-being, relationships, role fulfilment, and even continuation of life (Stanton et al., 2002).

Body Image

Mastectomies, being the surgical removal of one or both breasts are one intervention option for women with breast cancer, often followed by a reconstruction to reinstate the breast shape. Breast conservation therapy (lumpectomy) is therapeutically equivalent to mastectomies for most breast cancer patients, and in a large sample of American breast cancer survivors (n = 1450), long-term satisfaction with cosmetic outcomes for both procedures were overall equally quite high (Jagsi et al., 2015). However, breast surgery has also been identified as a source of negative body image for many women. Da Silva and Dos Santos (2010) describe the breast as a symbol of sensuality, sexuality and femininity, and discuss that the surgical removal of natural breasts can contribute to a poor self-image. Furthermore, scars and asymmetrical outcomes resulting from surgical intervention can pose as constant reminders of loss which has been found to greatly impacting quality of life for breast cancer survivors (Da Silva & Dos Santos, 2010; Jagsi et al., 2015; Wilson, Andersen, & Meischke, 2000). Brendin (1999), however, suggested that any advantages of a positive body image gained through undergoing conservations surgery over a mastectomy, may at times be considerably overshadowed by the fear of cancer recurrence in the remaining breast tissue.

The Fear of Recurrence

Once cleared of breast cancer, an individual is essentially 'disease free', yet a large risk of cancer recurrence remains, which can elicit intrusive thoughts and obsessive fears for the individual (Taha, Matheson, & Anisman, 2012).

Provision of information and support to breast cancer survivors, has been suggested to alleviate psychological distress associated with a fear of cancer recurrence (Raupach & Hiller, 2002). It has also been identified, that despite an ability to successfully put an experience of breast cancer in the background post-treatment, the fear of recurrence will bring it to the foreground (Loerzel & Aroian, 2013).

This literature review, like the vast majority of research papers discussing similar themes, applies the term 'survivor'. This term has been interpreted to position the woman as a hero having endured and conquered hardship, and being stronger for

this experience (Powers, Gullifer, & Shaw, 2016). The ever-present risk of breast cancer recurrence however, makes identifying as a 'survivor', quite challenging for some, as complete remission cannot be guaranteed (Powers et al., 2016).

Lymphoedema

Second only to the fear of cancer recurrence, breast cancer related lymphoedema (BCRL) is the most feared outcome of breast cancer treatment for the survivorship population (Radina, Fu, Horstman, & Kang, 2015). BCRL involves the accumulation of fluid and consequent swelling of the upper limb and chest which can also result in pain, tenderness, numbness, stiffness and limited range of motion in the effected arm (Radina et al., 2015). Up to 40% of breast cancer survivors will develop lymphoedema which has been found to limit functional engagement and participation in work, housekeeping, leisure activities and exercise, above existing psychological and emotional challenges expected in survivorship (Da Silva & Dos Santos, 2010). In relation to the ICF framework, BCRL is a secondary condition which contributes its own impacts on body functions and structures, activity and participation (Imms, 2006).

Cancer Related Cognitive Changes

A common side effect of breast cancer treatment, is change in cognitive function, which research indicates is experienced by 30-60% of breast cancer survivors (Player, Mackenzie, Willis, & Loh, 2014). Symptoms may be subtle or dramatic, and include changes in memory, concentration, language, and executive function. These symptoms can all impact personal and productivity roles of breast cancer survivors (Kanaskie & Loeb, 2015; Player et al., 2014). Although there is debate as to causation (Lewis, Chapparo, L., & Ranka, 2016), cognitive changes have been reported to last years beyond the end of active treatment, which for some can lead to emotional distress and negatively impact quality of life (Kanaskie & Loeb, 2015). Of concern, is the lack of routine assessment for subtle cognitive change for breast cancer patients undergoing chemotherapy, and investigation of objective, functional assessments to detect such changes is encouraged (Kanaskie & Loeb, 2015; Player et al., 2014). One key area impacted by cancer related cognitive change is work, which as discussed in Erikson's theory, contributes to a healthy sense of identity in

middle-age (Slater, 2003). Diminished capacity to focus, decreased work efficiency, and memory problems can limit a woman's ability to return or remain in work following breast cancer treatment (Lewis et al., 2016; Player et al., 2014).

Mental Health

Approximately 50 per cent of women with breast cancer will experience depression or anxiety within the first-year post-diagnosis (Breast Cancer Network Australia, 2017). Loerzel & Aroian (2013) investigated baby boomer views on surviving breast cancer. This study focussed on the time period immediately following the end of treatment, which has been recognised as a time in which developing physical and psychological issues often get "lost in transition". The authors investigated survivorship experiences through semi-structured interviews, however the identified leading questions possessed negative connotations by asking the participants to comment on the *challenges* associated with breast cancer survivorship. By provoking the participants to focus on the challenges, opinions on how their breast cancer experience may have shaped their lives and perspectives in positive ways, were limited (Loerzel & Aroian, 2013). Contrary to this, Wade and Lee (2005a) identified reports of a renewed vigour for life, and stronger interpersonal relationships for some women following a breast cancer diagnosis. Evidently further research is required to investigate the holistic experiences of baby-boomer's survivorship experience beyond, and including associated challenges.

SUPPORT FOR SURVIVORS

The support of family and friends is an essential aspect of breast cancer survivorship (National Breast and Ovarian Cancer Centre, 2010). Strong epidemiological evidence exists that social and medical supports for women with breast cancer will improve psychological outcomes (Wade & Lee, 2005b).

Social support has been identified to facilitate successful coping with the immediate and long-term outcomes of breast cancer and breast cancer treatment (Elmir, Jackson, Beale, & Schmied, 2010), and has been found to reduce anxiety, distress, uncertainty and improve quality of life (Raupach & Hiller, 2002).

A number of studies have examined the impact of social support and partnerships in coping with, and overcoming challenges related to, breast cancer. Loerzel and Aroian (2013) interviewed 20 breast cancer survivors on their cancer experiences. Those who identified having had support during treatment from friends, family and medical professionals, discussed how this had alleviated the burden, and instilled a sense of normalcy. Those without such supports, found it more difficult to move on from their 'cancer patient' identity (Loerzel & Aroian, 2013).

When the Treatment Stops

Uncertainty exists around the optimal method and frequency of follow-up for breast cancer survivors in remission, which leaves many women feeling distressed about the end of care (Corner, 2008; Powers et al., 2016). Once active breast cancer treatment is over, frequency of interactions between a patient and their doctor significantly reduces, which can be very challenging when a trusting relationship has been formed and the doctor was a source of support and reassurance (Powers et al., 2016).

Research has described the period following breast cancer diagnosis to be regulated by the medical system, including omnipresent check-ups, appointments, and reporting to medical professionals (Powers et al., 2016). When regular contact stops however, some survivors report significant distress, as they perceive a loss of the reassurance of their treating clinician's expertise and monitoring for signs of recurrence (Allen, Savadati, & Levy, 2009; Powers et al., 2016). A sense of vulnerability has also been identified during this period of treatment withdrawal, along with a sense of burden as the patient must assume responsibility for self-monitoring (Allen et al., 2009).

Minstrell, Wizenberg, Rankin, Hughes, and Walker (2008) highlight a necessity for ongoing needs assessment for breast cancer survivors in remission in order to shape a health care system that is more sensitive and responsive to consumers. A call for greater information sharing for what to expect and how to prepare for life after treatment results from evident vulnerability, uncertainty and stress at the end of treatment. Cappiello et al. (2007) explored information needs in 20 female breast cancer survivors, finding that almost half of the women (45%) reported receiving no information on what to expect after treatment. Many of those who had received some information however, reported it to be insufficient in preparing them for the

challenges of survivorship.

Rehabilitation Care

Historically, cancer care and research has reflected a curative approach, with the oncologist's goal being to rid the patient of the disease (Hewitt et al., 2005; Vivar & McQueen, 2005). Increased survivorship rates, and attention given to the ongoing challenges that exist beyond the end of active treatment has seen emerging development of survivorship rehabilitation teams.

Rehabilitation following breast cancer, aims to increase mobility, minimise pain, and optimise function, well-being and participation (Egan et al., 2013). Egan et al. (2013) discuss that while rehabilitation care for cancer survivors is an expanding field, it remains relatively new. Furthermore, literature has not yet sufficiently been synthesised to support best practice and guide decision making for clinicians and researchers. Further investigation of current rehabilitation care teams will allow for examination of different approaches, which may then contribute to the generation of comprehensive Australian guidelines for breast cancer care.

The Role of Occupational Therapy

As the experience of breast cancer survivorship is dynamic, complex and unpredictable, individualised support requires a holistic approach from multi-disciplinary professionals (Corner, 2008). Cancer rehabilitation, has been defined as “coordinated, inter-professional care, designed to enable people to maximise physical, social and psychological function within limits imposed by the disease and treatment effects, and to engage in personally valued activities within their social contexts” (Egan et al., 2013, p.2246).

Occupational therapy is one component of multidisciplinary teams and focuses on functional engagement and participation within the context of everyday life, with an emphasis on personally valued activities (Occupational Therapy Australia, 2015; Pergolotti, 2016). These core principles, highlight the appropriateness of occupational therapy in cancer rehabilitation.

Challenges of breast cancer survivorship including reduced range of motion in upper limbs, cancer related cognitive changes, body image challenges, and challenges in

daily living have been identified as areas that would benefit from occupational therapy intervention (Buckland & Mackenzie, 2017).

Occupational Therapy Australia's (2015) Position Statement: *Occupational Therapy in Oncology*, calls for greater involvement from occupational therapy in the rehabilitation and management of cancer survivorship challenges. It is believed that occupational therapy should be an integral part of the oncology team by engaging in person-centred care/service delivery, education, research and quality, and policy development (Occupational Therapy Australia, 2015). However, current Australian clinical guidelines for the involvement of allied health throughout breast cancer survivorship have yet to be developed. Such guidelines must consider the current service delivery model for survivorship in Australia, which stems from a health care system unique to other countries. Further research into the functional limitations and needs of breast cancer survivors in an Australian context will highlight areas requiring rehabilitation and need for occupational therapists to help return women to pre-cancer activities and roles.

Survivorship Care Plans

To prepare for survivorship after acute treatment has finished, treating oncologists are advised to develop a survivorship care plan (SCP) (Hewitt, Bamundo, Day, & Harvey, 2007). SCPs are formal, written documents which include a comprehensive care summary, potential post-treatment challenges and a personalised follow-up plan (Hewitt et al., 2007; Peter MacCallum Cancer Centre, n.d.). The American Institute of Medicine's (IOM) 2006 report, *From Cancer Patient to Survivor: Lost in Transition* recommends that on completion of primary treatment, each cancer survivor should receive an individualised SCP, however application of this tool, especially in Australia, is limited (Hewitt et al., 2007; Peter MacCallum Cancer Centre, n.d.).

Hewitt et al. (2007), explored attitudes towards SCPs in breast cancer survivors, nurses and physicians, all of whom expressed great interest in this strategy. This report also suggested barriers to implementation of SCPs, including the timely process involved in developing them without adequate reimbursement, and that they did not meet oncologist's reporting obligations to other health providers and insurers. Findings from Hewitt et al. (2007's), as with much of the research on breast cancer

survivorship, was written from a US standpoint, examining US subjects. While barriers for the implementation of SCPs have been identified (Hewitt et al., 2007), transferability of these findings to an Australian context is restricted, as there is a lack of measured SCP implementation in Australia.

The preliminary evaluation of SCPs in Australia however, has forecast promising outcomes (Peter MacCallum Cancer Centre, n.d.). Further research specific to SCPs used with breast cancer survivors in Australia will allow exploration of what is predicted to be a highly valuable tool to alleviate the uncertainty, stress and fragmented care, and in an aim to meet the unmet needs of women with breast cancer.

CONCLUSION: A NEED FOR FUTURE RESEARCH

Breast cancer survivorship includes a multitude of functional and psychosocial long-term impacts and needs, some of which remain unmet by the current service delivery model in Australia. Middle-aged women remain the largest group of breast cancer survivors in Australia, necessitating a focus on their age-specific experiences and how these might impact survivorship. The classification of breast cancer survivorship as an ongoing or chronic illness is increasing in international research. However, public discourse typically focusses on the disease with little attention toward ongoing survivorship experiences post-treatment. This results in limited knowledge of what to expect after treatment in the absence of being informed by treating clinicians (Powers et al., 2016).

Information related to what to expect, as well as referrals to appropriate rehabilitation services can be expressed through survivorship care plans, which are not routinely used in Australia (Peter MacCallum Cancer Centre, n.d.). Rehabilitation teams are able to provide ongoing support for survivorship challenges including poor body image, fear of cancer recurrence, lymphoedema, stress and decreased mental health, as well as cancer related cognitive changes. Occupational therapy in particular, can address both functional and psychosocial implications of breast cancer, and therefore should be an integral part of rehabilitation teams. Rehabilitation teams, including occupational therapists are under-represented in current breast cancer survivorship care in Australia. An Australian-focused examination of breast

cancer survivorship experiences will contribute to the limited Australian research on this population's needs, as well establish how survivorship care plans, including referral to multidisciplinary care teams can be developed.

In order to explore such experiences, it is necessary to capture the lived experiences of women across Australia including those with, and past an active breast cancer diagnosis.

The proposed study will therefore analyse responses to open ended survey questions in order to explore the experiences of middle-aged female breast cancer survivors in Australia. The study aims to investigate these self-reports specific to middle-aged women in order to inform breast cancer survivorship service provision for this population.

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SECTION II: JOURNAL MANUSCRIPT

TITLE: “Beyond Breast Cancer: An exploration of the experiences of middle-aged female breast cancer survivors in Australia”

Running Title: Breast Cancer Survivorship

Target journal: Psycho-Oncology (See Appendix A - Author Guidelines.)

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ABSTRACT

Objective: Middle-aged women (40 – 65 years) who live with, through and beyond breast cancer (survivors), are a relatively under-researched population group, particularly within an Australian context. The unmet needs reported within this population include fatigue, psychological distress, body image concerns, early onset menopause, and a lack of information of these issues. The present study aims to explore how the experiences of breast cancer survivorship impact the lives of Australian middle-aged women (n = 644), and to inform future provision of care and support.

Methods: This qualitative study used secondary survey data from the Australian Longitudinal Study of Women's Health (ALSWH) middle-age cohort gathered between 1996 – 2013. Researchers conducted a thematic analysis using consensus coding on data collected from participants in this group who reported breast cancer (including metastasised) in any survey.

Results: This cohort reported a unique experience of breast cancer survivorship due to their age. Analysis developed the following themes: the middle-aged context of breast cancer; care and support, body changes, overcoming fears and maintaining balance; and finding a 'new normal'.

Conclusions: Breast cancer survivorship is a subjective experience; for many it involves chronic limitations and challenges. Investigation and application of survivorship care plans in Australia would benefit from greater inclusion of multidisciplinary professionals. This will help satisfy heretofore unmet information needs and associated psychological distress of breast cancer survivors which go above their biomedical concerns. Further recommendations include development of online support groups providing access to rehabilitation professionals, especially for otherwise isolated rural women.

Key words: breast cancer, oncology, survivorship, occupational therapy, neoplasm, rehabilitation care, chronic illness

BACKGROUND

Breast cancer survivors, including those living with, through, or beyond a breast cancer diagnosis (1), experience specific challenges resulting from their illness and treatment. This population continues to report unmet needs, despite considerable attention on the long-term psychological and emotional impacts of breast cancer in the literature (2, 3). Women diagnosed with breast cancer in Australia today have a 90% chance of surviving beyond 5 years (4). Rising breast cancer survival rates may be due to increased early detection, through screening and improved treatments (4).

The largest group of breast cancer survivors in Australia are middle-aged women (40-65 years old), who are seven times more likely to be diagnosed than younger women (2). Compared to older women, this group is expected to suffer greater adversity related to physical, mental and social functioning due to higher involvement in vocational, parental and social roles (2).

Detailed accounts of lived experiences need to be analysed to explore the unmet needs of breast cancer survivors (3). Open-ended survey responses have potential to elicit detailed responses, yet are seldom used in breast cancer survivorship research due to the laborious coding procedures required for analysis, particularly with large sample sizes (3).

The present study will analyse responses to open ended survey questions to explore the experiences of middle-aged female breast cancer survivors in Australia. This study aims to investigate self-reported breast cancer experiences specific to middle-aged women, and to identify areas for improvement in breast cancer survivorship service provision. Greater involvement of occupational therapists in a multidisciplinary approach to cancer survivorship care may benefit in addressing activity and participation limitations expected to be discussed by participants.

METHOD

A qualitative approach was used to guide the study as it promotes the exploration of human experiences from the perspective of those who are experiencing it (5).

The study analysed secondary data in the form of open written survey responses which were collected as part of the Australian Longitudinal Study on Women's Health (ALSWH) (6). Data was collected on average every three years since 1996.

Responses from the first seven studies were available at the commencement of this study. The ALSWH has been described in further detail in previous published work (6, 7).

The use of secondary data eliminated the opportunity to shape or design the questions, or probe for further information. However, this method enabled researchers to avoid researcher bias, costs, and time typically required to execute a study involving interviews with the same number of participants (n = 644).

Sample and Recruitment

The middle-aged cohort of the ALSWH included women born 1946-1951 (aged 45-50 years in 1996). Participants were recruited to the ALSWH through the Medicare database (national public health insurance for Australia) which is accepted as the most comprehensive and up-to-date national population record (6). Survey information, consent forms and the first surveys were posted at random to 106,000 women across Australia (8). Participants were randomly sampled with over-sampling for women living in rural and remote locations to capture the heterogeneity of health experiences of women living outside of metropolitan areas (8).

The middle-aged cohort was selected due to the unique life experiences that occur during this time for women, including menopause, motherhood and changing work commitments (9) that contribute to age specific experiences of breast cancer survivorship (10). To be included in the present study, women had to have consented to and participated in the middle-aged cohort of the ALSWH, and identified through a yes/no question that they had breast cancer in any of the surveys.

Data collection

All surveys were self-reported and returned in a prepaid envelope. Consent included the use of their responses for secondary studies. Participant responses were protected by a project identification number ensuring confidentiality and anonymity (11). Ethical clearance for the current study to use the data was granted from the Publications, Analyses and Substudies (PSA) Committee of the ALSWH on 19/05/2016 (EoI # A631) (Appendix B.).

The final question of the survey provided participants the opportunity to share information that had not otherwise be addressed in the surveys. Responses to this question became the data of the present study. This question was:

“Have we missed anything? If you have ANYTHING else you would like to tell us, please write on the lines below”.

Data Analysis

The International Classification of Functioning, Disability and Health (ICF) framework guided analysis. The ICF presents a holistic perspective of health, and prompted researchers to consider how functioning related to the body, activities, and participation may be influenced by personal and environmental factors associated with middle-age and breast cancer (12). An inductive thematic process, described by Braun & Clarke (13), was applied to analyse survey responses. Emerging themes were continually reviewed against the complete data set and field diary notes to ensure rigour. Consensus coding with supervisors, and reflexive thinking on the subjective interpretation of data was used to further enhance credibility (13). The analysis process comprised of six steps:

Phase 1: The researcher read through all comments to ensure familiarity with the data, noting ideas in a field diary. Data was manually categorised into broad ideas through colour-coding sections of comments. This was done manually so the researcher could ensure a thorough comprehension of the data.

Phase 2: Initial codes were generated through expanding on the broad categories. An extensive list of 58 codes, which became subheadings in an excel spreadsheet, were developed based on notes made during phase one, and the existing literature.

Phase 3: Classification of content into codes occurred through line by line coding. This involved allocating meaningful segments into the appropriate columns of the Excel spreadsheet.

Phase 4: On review, codes were consolidated based on similarity; those that did not have enough support were discarded; and others were renamed to suit data content.

Phase 5: Through refining the codes, a number of themes were defined. Themes were classified based on the 'essence' of its content. Themes were structurally supported by subthemes based on comments with a similar focus.

Phase 6: The narrative production involved analysis of data within and across each theme. Key quotes were extracted to illustrate participant experiences related to each theme. Project identification numbers were cited after quotes in parentheses so that available demographic information could be cross-checked.

Determination of themes was subject to personal bias by the researcher. This was overcome by recognition of the occupational therapy lens through which this data was being interpreted, and discussion of the interpretations of data with two research supervisors.

RESULTS

Participant profile

Participants were aged 45-50 years in survey one (1996). By survey seven (2013), data was collected for women up to 67 years. Mean age of breast cancer diagnosis was 55.6 years, Demographic information for these participants are outlined in figures 1 and 2, as well as table 1 (See Figures and Tables).

Findings

Participant responses revealed high variation in the length of written responses, level of openness, and content. Five overarching themes emerged from written comments including the middle-aged context of breast cancer, care and support, body changes overcoming fears and maintaining balance, and finding a 'new normal'.

THEME 1: THE MIDDLE-AGED CONTEXT OF BREAST CANCER

The middle-age context is important to understand as it captures the experiences of this life-stage which may be intensified by a breast cancer diagnosis. These experiences may also impact the interpretation of breast cancer, or the ability to cope (2).

Physical Well-being

Many women in the study, reported they were slowing down and *"finding it much harder to do things"* (808125) due to age related changes. Participants also reported arthritis, diabetes, depression, thyroid disease, and osteoporosis, which served as co-morbidities to their breast cancer diagnosis.

Weight gain was discussed widely across the surveys, due to menopause, being too busy to focus on own health, cancer treatment, diet, and exercise. For many this contributed to a negative body image and poor mental health. Losing weight was seen as challenging: *"Each time I lose weight I have difficulty with maintaining the loss! Which was not a problem when I was younger!"* (800966).

Roles and Expectations

Roles of being a mother and member of the workforce were noted as major identity factors of middle-aged life. Strain and changes related to these roles existed for participants prior to their breast cancer, which for some meant that their diagnosis occurred during an already stressful time.

Some participants acknowledged that their children moving out of home, made them *"mourn the lack of being needed"* (801398). A large number of participants also discussed stress related to caring for children. This stress was heightened for some, who supported children that were experiencing mental health issues, substance abuse, brain injury, unemployment, and divorce: *"The impact on me was very stressful as my daughter turned to me constantly for support"* (812511).

Some participants were fulfilling a number of caring roles for elderly parents, siblings and friends, as well as children. This left little time to focus on themselves, resulting in feelings such as: *"my health has been 'pushed to the limit'"* (806869).

Work related stress and illness was also identified: *"I am aware that problems with my health are due to my age and the fact that I'm working too hard"* (805996).

Conversely some felt participation in paid work was beneficial: *"I picked up extra work which I feel has improved my mental health-I don't worry quite so much about surviving financially"* (807135).

THEME 2: CARE AND SUPPORT

Professional Support

Many felt *"women need more help"* (811080) regarding their treatment for breast cancer. Approaches in professional support was inconsistent across participants as some women praised empathetic clinicians, however others reported their medical care was unsupportive and pessimistic. Concerns were also raised about the lack of information sharing from medical professionals with many participants feeling ill-informed. Some participants felt *"I was only part of their cash flow"* (810171), while others felt left out of decision-making processes:

"I question where the "healing" has gone in the healing arts...What about compassion? And the rights and needs of the patient to determine her own course of action, to be treated respectfully regardless of the decision made." (804370)

Those living in rural/remote locations highlighted that they lacked access to supportive medical services:

"There is no help for rural Australia ... living in a rural environment it is very difficult to access medical resources and being a one doctor town if you don't get on with him/her you have to travel long distances to have a doctor of your choice." (810120).

Mammography is a conventional routine screening procedure which for many is the first contact with professional care and support in their breast cancer journey. Mammography was praised by a number of participants: *"I would not have been aware of my condition had it not been for a routine mammogram"* (810104). However, concerns also existed related to false negatives: *"The two times I had lumps neither showed up on mammograms"* (807856). In recognising a lack of 100 percent reliability in mammograms, as well as in self-check and ultrasounds, participants discussed a need for vigilance in all detection measures:

"Six months ago, went and had mammograms/scan ultra sound etc. because of lump felt in breast. Report from these was negative for cancer. I was told I did not need another check for 2 yrs. 3 1/2 months later went to specialist because lump was growing. He did lumpectomy and it was cancerous tumour" (807465).

Community Support

Many participants discussed how support from communities helped them to cope with survivorship challenges. Some also sought new communities based on their diagnosis, for instance: *"I became involved in a cancer support group, it helps to talk to others going through the same journey"* (802458).

Most women endorsed friends and family to be their main source of strength. As one participant shared, these supports: *“kept me from 'cracking' many times”* (806679). For some, these social networks failed to withstand the stress: *“Only to say [when you have] a breast removed... people don't want to know you. Mention breast cancer they are gone like a shot”* (806281).

Committed partnerships including marriage and defacto relationships, were seen as great supports for participants. While many found solace in a significant other, some women shared that their breast cancer occurred within the context of divorce. The termination of marriage was uplifting for some, realising: *“I now can make my own decisions and control my own life”* (808665), while others found it an overwhelming and devastating experience, impacting their ability to cope.

THEME 3: BODY CHANGES, HEALTH AND WELL-BEING

Treatment Outcomes and Side Effects

Participants described the experiences of chemotherapy, radiotherapy and surgery. Problematic treatment side effects included: *“fatigue, lack of strength, cramp pains, aches and pains. Waking up aching all over and tired, feeling the cold”* (801297). A number of women also reported cancer related cognitive changes, described by one participant: *“because of the cancer treatment my mind was dull and confused...I was unable to carry out all of my work duties, and I felt sleepy whilst I was working”* (813396).

Hormone treatments used in breast cancer survivorship to manage oestrogen levels, were also discussed: *“It has reduced my sleeplessness, anxiety and hot flushes but I am sure I have put on weight”* (806604). Fear accompanied knowledge of the side effects of hormone treatment, as one participant described: *“I hate the need to take it as the side effects scare me (every time I have a leg ache I think it's a blood clot!)”* (800132).

Mastectomies were discussed by a number of participants, with some praising the procedure and subsequent breast reconstruction: *“the best thing I've had...made me feel "normal" again”* (805362). Others who had not continued with the breast

reconstruction however, were not as positive: *“Double mastectomy is the pits!... it’s really ugly”* (810964).

Some participants identified that they had not been informed of the challenges following surgery, such a lymphoedema which was a recurrent issue for women in the study. For many, this meant limited upper limb use and pain: *“I have lymphoedema in my right arm ... due to the arm, heavy gardening is out altogether”* (811090).

Following a breast cancer diagnosis, early onset menopause exacerbated the *“feeling of not being entirely in control of my body”* (810440). Menopausal symptoms induced by treatment impacted participants to a varied extent.

Hormone replacement therapy (HRT) is often prescribed to alleviate side effects of menopause, however presents a small risk of breast cancer (14). Women in the study described adverse outcomes of being taken off their HRT following diagnosis:

“I was diagnosed with breast cancer almost 12 months ago. At the time, I was on HRT. This was controlling severe depression, anxiety and some physical symptoms. Since the diagnosis I am unable to have HRT so my emotional health is suffering to some degree” (801496).

Focus on Health and Well-being

Regaining a healthy exercise routine following breast cancer was viewed as important, however, as one participant shared, is *“a battle with the will”* (800557).

A number of women spoke of decreased physical activity following their breast cancer treatments: *“After undergoing a mastectomy, chemotherapy and radiotherapy I find I am physically unable to do exercise, household chores etc. due to fatigue”* (808276).

The benefits of exercise were recognised in managing treatment side effects, for instance: *“I walked a lot to help with my breast cancer related lymphoedema”* (803752). One participant praised a particular initiative exemplifying the benefit of support groups in maintaining health and well-being:

“The YWCA in the Byron Bay area offered free exercise classes for women who have breast cancer. It was a 10-week course in Oct 2012. I found this very useful in regaining shoulder movement, and preventing lymphoedema in my upper arms” (805535).

THEME 4: OVERCOMING FEARS AND MAINTAINING BALANCE

Psychological Challenges

Participants who had received a diagnosis of breast cancer, reported many concerns beyond those typical to a middle-aged life stage including fear of cancer recurrence and coming to terms with a life-threatening illness. Fear of recurrence was addressed by a number of women following active treatment: *“I remember every day that I have had cancer and that it can recur” (802413).*

Optimism and Hope

Some women revealed that their breast cancer experience had brought about optimism and determination to live their best life, for instance:

“After being diagnosed with breast cancer nearly 10 years ago, my approach to life has changed for the better. I'm living each day as it comes - as fully as possible, and taking every opportunity to appreciate and celebrate all the little things. My biggest realisation has been that no one gets a guarantee about anything in life, so the present moment we're in is all we have... Life can be challenging but it's a rich experience. I'm deeply grateful to be here!” (804370).

Often, a cause for optimistic outlooks and resilience, was the presence or anticipation, of grandchildren: *“I still feel optimistic and although in the terminal stage I hope to live long enough to see my daughter give birth to my first grandchild in November” (806587).*

Meditation and Reflection

To maintain good mental health and regain optimism, some participants described, the importance of meditation:

“The most important factor in my health, mental, physical, spiritual and emotional is my practice of pure meditation.... The balance this gives me enables me to cope with life stresses, such as bereavement, frustrations, work and family stress” (804362).

Others found that the process of engaging in the ALSWH surveys, prompted them to reflect, and realise what they have to be grateful for. One participant recognised: *“this is probably the only time I look at my lifestyle” (801398).*

THEME 5: A ‘NEW NORMAL’

Many women in the study highlighted that their breast cancer and related treatments required change, adaptability, and adjustment to activities and participation in their daily lives: *“The hardest part was the end of treatment...the 'not having' cancer, the return to normality” (809418).*

Changes in sexual activity resulting from physical discomfort, fatigue, and a decreased libido were discussed. A sense that no-one is able to help with these challenges was also discussed by one participant: *“[I] hate that I have completely lost my libido and all sexual feelings and no one can help me to get it back. No matter who I consult, there seems to be nothing they can suggest” (804092).*

Regarding work, a number of participants had to retire earlier than planned: *“I did not retire of my own volition. I was replaced in my casual job when I had breast cancer” (804282).* Work was replaced for some with fulfilling volunteering roles or leisure engagements such as travel. A number of participants found this early retirement to be a relief from stressors: *“It is amazing experiencing the layers of calmness, peace, satisfaction, after stopping paid work - the tension peels off slowly day by day” (808091).* For others however, a loss of work led to financial strain and a loss of meaning or purpose.

Overall, the reality noted by many participants, was that they had changed from their pre-cancer selves: *“Being diagnosed with breast cancer was a big turning point in my life and health. Although I have completed treatment and done well, I don't feel like I used to” (804256).*

DISCUSSION

This study sought to explore the experiences of female middle-aged breast cancer survivors in Australia, and applied the ICF framework to guide comprehension and analysis of data (12). Body structures and functions, activities, and participation difficulties were discussed by participants in relation to their middle-aged life context. Results highlighted that middle-aged life compromised participant's adjustment to breast cancer, and survivorship experiences. This is consistent with literature, where experiences of breast cancer were mediated by environmental factors including the attitudes of medical professionals (15), relationships with a significant other (16), and social supports (10, 17). Furthermore, personal factors including menopausal status (18) and motherhood roles (19) are also relevant. Whilst common themes were found within the data, there was also variation in reported circumstances and issues, which confirms that the survivorship phase of breast cancer is a highly subjective and diverse experience (10).

ONGOING INFORMATION NEEDS OF BREAST CANCER SURVIVORS

Study findings confirmed that breast cancer survivors experience long-lasting sequelae following their cancer diagnosis and treatment. Breast cancer research presents emerging classification of breast cancer as a chronic disease, however the experiences of women with breast cancer suggest that this perspective is not being translated into continued professional support (20).

Vivar and McQueen (10) suggest that the lack of a standardised approach to cancer survivorship may be because many clinicians consider post-treatment survivors to be cured and therefore no longer in need of further intervention. Findings in this study highlight that breast cancer survivors are still experiencing unmet needs within Australia. This was particular related to information sharing and personalised involvement in decision-making regarding their treatment and ongoing care (1). Australia's public health care system is increasingly managed in a business fashion (21). This substantiates concerns of some participants who felt that they were part of the cash flow for doctors who were less concerned about them as people. A continued shift towards tailored provision of client-centred care is therefore required.

Cappiello and colleagues (1), explored information needs in 20 women within 5 years post-diagnosis of breast cancer, finding that almost half of the women (45%) reported they did not receive any information on what to expect after treatment. For those who did receive information, many reported it to be insufficient. Similarly, women of the present study reported insufficient information sharing regarding treatment outcomes. This led them to feel disrespected and distressed over treatment side effects including weight gain, fatigue, lymphoedema, sexual concerns.

MULTIDISCIPLINARY REHABILITATION CARE

Few participants discussed the role of a multidisciplinary team in managing their survivorship concerns. Fleissing and colleagues (22) suggest that the limited referral to allied health professionals by oncologists may be due to the limited understanding of their specialist skills for cancer rehabilitation. These authors further suggest that this lack of understanding may limit access to high quality, holistic care available for rehabilitation. For example, occupational therapy has had little involvement in cancer survivorship, yet could promote participation in meaningful activity, while also addressing physical, social and emotional needs (23). These issues were identified in the current research.

Many participants in the present study identified satisfaction gained through leisure activities, travel or volunteering after losing their jobs during the cancer treatment process. This echoes the literature, which highlights that early retirement can be satisfying when there is something meaningful to take the place of work (24). Therefore, support in the workforce as well as exploration of alternative activities should be within the purview of the oncology rehabilitation team.

There is evidence that interventions for chronic illnesses involving occupational therapy can improve quality of life, coping skills, self-management and functional performance in everyday activities (25). Occupational Therapy Australia's Position Statement: *Occupational Therapy in Oncology*, calls for greater involvement from occupational therapy, and that occupational therapy should be an integral part of the oncology team by engaging in person-centred care/service delivery, education, research and quality, and policy development (23). However, current Australian clinical guidelines for the involvement of occupational therapy throughout breast cancer survivorship have yet to be developed.

SURVIVORSHIP CARE PLANS

Survivorship care plans (SCP) are one way to ensure that cancer survivors have access to the care they need. These are formal, written documents including a comprehensive care summary, potential post-treatment challenges and a personalised follow-up plan provided by the oncology team before the end of active treatment (26, 27). The American Institute of Medicine's (IOM) 2006 report, *From Cancer Patient to Survivor: Lost in Transition* recommends that on completion of treatment, each cancer survivor should receive an individualised SCP (26, 27). However, none of the 644 breast cancer survivors in the present study mentioned an SCP. Hewitt et al. (8), examined perspectives on the application of SCPs from consumers (cancer survivors), nurses and physicians, all of whom expressed great interest. While this report was written from a US standpoint, it suggests reasons why SCPs are poorly implemented worldwide. Oncologists in the study suggested that SCPs did not appear to meet their reporting obligations to other health providers and insurers involved in the patient's care. SCPs were also viewed as time consuming to create without adequate reimbursement (8). These barriers may not be as important in the Australian context, and little evidence exists on the application of survivorship care plans in an Australian context. The preliminary evaluation of SCPs in Australia however, has forecast promising outcomes (7).

SUPPORT NEEDS

Women in the study frequently discussed the strain they experienced with caring for both their parents and children. The phenomenon of caring for both younger and older relatives simultaneously, referred to as the 'sandwich generation' (28), is typical of a middle-aged life stage. An experience of breast cancer co-occurring with these generational demands will present unique challenges for women in this age group (28).

Lazarus & Lazarus (24), identify that during a personal crisis, when coping is difficult, emotional support from others is important. Spousal support was praised in the study, reflecting findings that partnered women generally have better emotional and psychological well-being than single women when newly diagnosed with breast cancer (2). For those without social support, a need for structured support may be necessary. A participant of the current study identified personal benefits resulting from engagement in the YWCA Encore group, which is a mixed-modality group exercise and information support program for breast cancer survivors (29). Sherman,

Heard & Cavanagh's (29) evaluation of this community-based program, similarly found psychosocial benefits resulted from engaging in this intervention as participants reported statistically significant greater satisfaction in quality of life, functional ability, and energy levels as well as social support compared to controls.

For those living rurally, challenges related to distance from medical services and isolation from social supports were discussed. Minstrell et al. (30) discussed that rural women are two and a half times more likely to experience unmet needs than their urban counterparts, and often receive less ongoing psychosocial support due to their isolation. Research findings have commended the use of online support groups for women facing the geographic and transportation barriers to face-to-face support found by many rural women (31).

REFLECTION, MEDITATION AND RELAXATION

Many women reported that the ALSWH study was the only time they reflected on their health and well-being. Similarly, a number of women discussed the benefits they experienced through meditation and reflection when going through both menopause and breast cancer. Literature endorses engagement in reflective practice, such as journaling or writing (32),(33), as well as engaging in relaxation therapy and meditation as complementary therapies to mainstream treatments (34). This reflective practice could be integrated into a more frequent activity, and the benefits could assist breast cancer survivors, particularly those of middle-age required to fulfil multiple roles, to find balance in a chaotic life (28).

Implications and Recommendations

Findings from this study highlight a range of unmet needs of middle-aged breast cancer survivors in Australia. These findings contribute to the otherwise limited selection of breast cancer survivorship research covering a national sample, and aids in the recognition of age-specific challenges of middle-aged women that require attention in survivorship care.

A number of recommendations based on the discussion of findings result. Firstly, continued research related to the ongoing challenges of breast cancer survivorship will add momentum to recognising breast cancer survivorship as a chronic illness in Australia. This will facilitate greater involvement of allied health

professionals such as occupational therapists who can help to reduce functional limitations in chronic illnesses. Secondly, participants discussed dissatisfaction related to their medical care, however more research into the comparison of public and private health care will allow richer understanding on contributing factors to this dissatisfaction, and inform health care reform. Thirdly, in order to support autonomy and independence of cancer survivors, and address reported unmet information needs, it is recommended that the survivorship phase also include avenues for health promotion and education for the long-term health concerns of patients. Finally, further research specific to SCPs for breast cancer survivors in Australia will allow exploration of one mechanism to alleviate the uncertainty, stress and fragmented care reported by this population.

Strengths and limitations:

This study has used a credible source of data. The ALSWH study provided a large, representative, national sample. However, it is known that many ALSWH participants are middle-class, educated women (35). Despite random sampling, those who did not return surveys, or provide relevant responses may disproportionately represent those ALSWH participants who report low education, low literacy, or who are from non-English speaking backgrounds.

The use of secondary data also eliminated the opportunity to shape or design the questions, or probe for further information from participants using interviews. However, using existing survey data, avoided researcher bias, costs and time typically required to execute a study involving interviews with the same number of participants.

CONCLUSION

The current study offers a distinct contribution to the literature on breast cancer survivorship experiences of Australian middle-aged women. The representativeness of the sample allows for generalisability of findings for an otherwise considerably understudied group. Findings highlight that women of a middle-aged life stage have unique age-related experiences which can impact the experience of breast cancer survivorship.

ACKNOWLEDGEMENTS

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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FIGURES AND TABLES

FIGURE 1: Demographic graph – survey year that breast cancer diagnosis was identified.

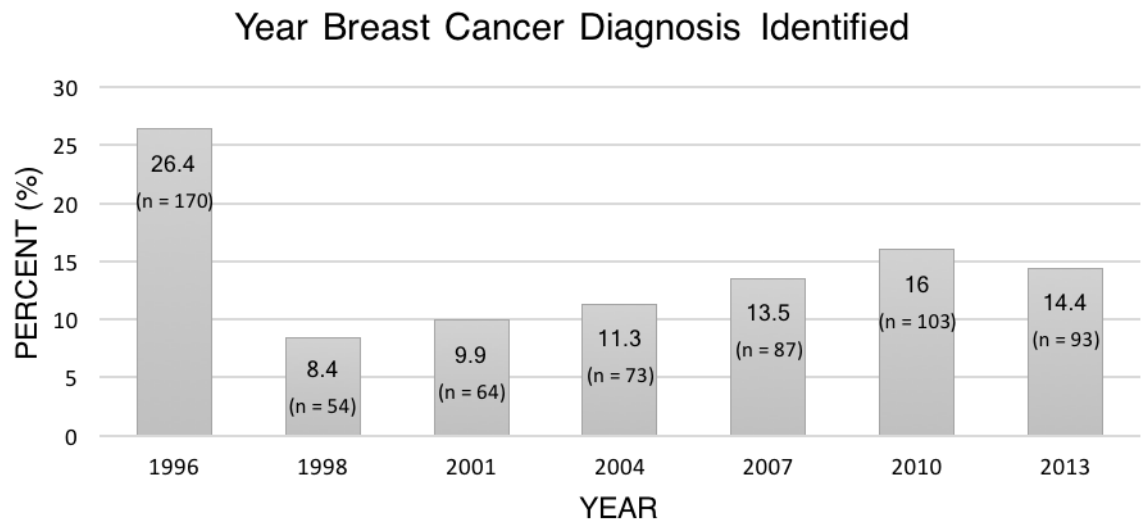


FIGURE 2: Demographic graph – participant age when breast cancer was diagnosed.

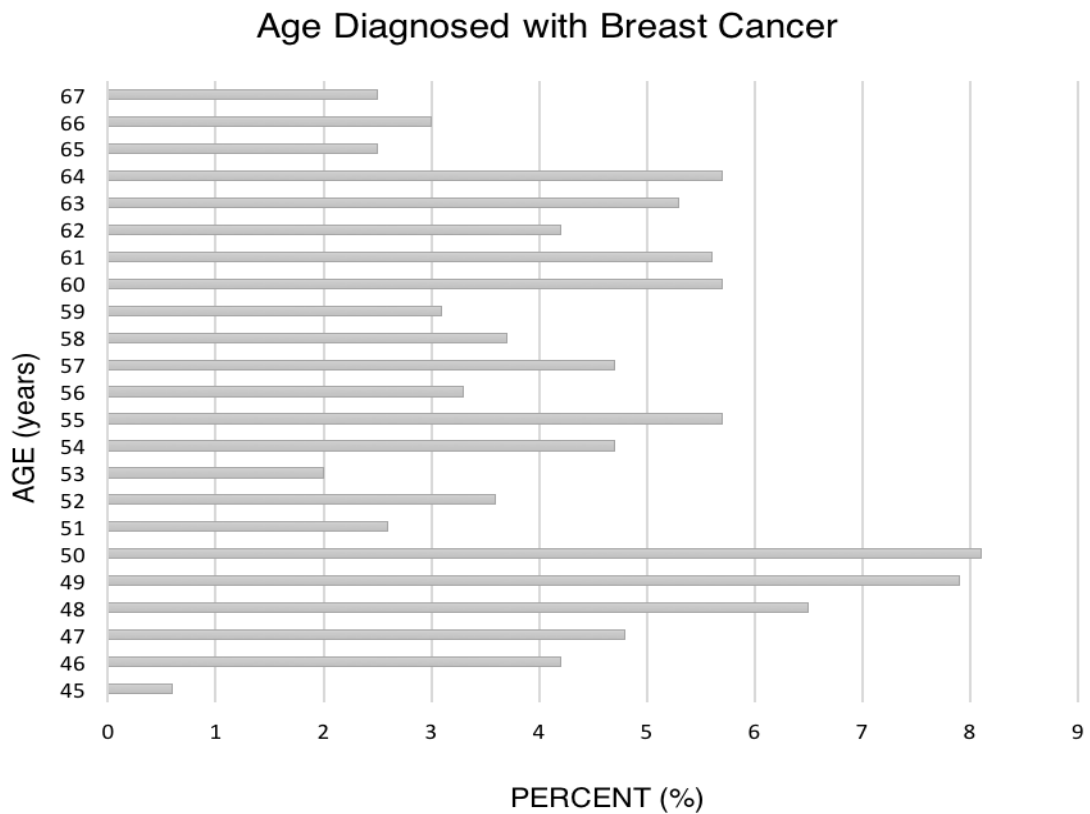


TABLE 1: Characteristics of study participants (n = 644)

Demographic variable	N (valid%)
IN A CARER ROLE (parent/child/ grandchild/ other)	
No/Never	63 (9.8)
Yes/Regularly	205 (31.8)
Yes/Occasionally	376 (58.4)
TOTAL	644 (100.0)
PARTNER (married/ defacto/ same sex)	
Yes	509 (79.5)
No	131 (20.5)
TOTAL	644 (100.0)
AREA OF RESIDENCE	
City/Metropolitan	236 (36.6)
Rural	374 (58.1)
Remote	34 (5.3)
TOTAL	644 (100.0)
EDUCATION	
No Education	91 (14.3)
School	295 (46.2)
Post school qualifications	252 (39.5)
TOTAL	644 (100.00)
OCCUPATION	
Never Paid Work	4 (.7)
Professional/ Management	279 (45.4)
Admin/ Sales	223 (36.3)
Trade	25 (4.1)
Manual Work	75 (12.2)
Other	9 (1.5)
TOTAL	644 (100.0)

APPENDICES

APPENDIX A: PSYCHO-ONCOLOGY –Author guidelines for manuscript submission

Sections

1. Submission
2. Aims and Scope
3. Manuscript Categories and Requirements
4. Preparing Your Submission
5. Editorial Policies and Ethical Considerations
6. Author Licensing
7. Publication Process After Acceptance
8. Post Publication
9. Editorial Office Contact Details

1. SUBMISSION

Thank you for your interest in *Psycho-Oncology*. Note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once you have prepared your submission in accordance with the Guidelines, manuscripts should be submitted online

at <https://mc.manuscriptcentral.com/pon>

The submission system will prompt you to use an ORCID (a unique author identifier) to help distinguish your work from that of other researchers. Click [here](#) to find out more.

[Click here](#) for more details on how to use ScholarOne.

For help with submissions, please contact Psycho-Oncology@wiley.com

We look forward to your submission.

2. AIMS AND SCOPE

Psycho-Oncology is concerned with the psychological, social, behavioral, and ethical aspects of cancer. This subspeciality addresses the two major psychological dimensions of cancer: the psychological responses of patients to cancer at all stages of the disease, and that of their families and caretakers; and the psychological, behavioral and social factors that may influence the disease process. Psycho-oncology is an area of multi-disciplinary interest and has boundaries with the major

specialities in oncology: the clinical disciplines (surgery, medicine, pediatrics, radiotherapy), epidemiology, immunology, endocrinology, biology, pathology, bioethics, palliative care, rehabilitation medicine, clinical trials research and decision making, as well as psychiatry and psychology. This international journal is published twelve times a year and will consider contributions to research of clinical and theoretical interest. Topics covered are wide-ranging and relate to the psychosocial aspects of cancer and AIDS-related tumors, including: epidemiology, quality of life, palliative and supportive care, psychiatry, psychology, sociology, social work, nursing and educational issues.

Special reviews are offered from time to time. There is a section reviewing recently published books. A society news section is available for the dissemination of information relating to meetings, conferences and other society-related topics. Summary proceedings of important national and international symposia falling within the aims of the journal are presented.

Manuscripts should be confined to work relating to cancer and AIDS-related tumors. The criteria for publication are originality, high scholarly quality as determined by peer review, interest to a wide audience of those concerned with psycho-oncology.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Psycho-Oncology publishes a number of different article types including:

- **Original Paper**

Original research papers should contain reports of new research findings that make a significant contribution to knowledge. Original papers should not exceed 4,000 words (including no more than four figures and/or tables) plus up to 40 references.

- **Reviews**

Reviews should be critical reviews of the literature, including systematic reviews and meta-analyses and should not exceed 6,000 words, excluding references. Please complete and supply an [AMSTAR](#) checklist for systematic reviews which are narrative reviews and not meta-analyses.

- **Editorials**

Editorials are usually invited but unsolicited material may be considered. Please approach the Editorial Office (Psycho-Oncology@wiley.com) before submitting this material. Editorials have a limit of 1,000 words.

- **Letters to the Editor**

Letters to the Editor are welcomed and should not exceed 400 words. Please note

that if Letters to the Editor include a comment on a previously published paper the authors of said paper should be allowed 4 weeks in which to respond. If there is no response after 4 weeks, the Letter will simply be accepted with an Editor's footnote: "The authors of [title of previously published paper] offered no comments"

- **Book Review**

Proposal for book reviews, may be submitted to the book review Editor, Errol Philip (ejphilip@gmail.com)

- **Clinical Correspondence**

Clinical Correspondence may include feasibility studies, case studies, phase I/II clinical trials, questionnaire development studies, service development, commentary and novel clinical techniques. They must include five succinct key points (and no abstract), not exceed 1,500 words (including no more than two figures and/or tables), excluding reference. They should also be limited to ten references maximum.

- **Invited Perspective**

Invited perspectives are opinion pieces written by select individuals within the field on certain topics. They are usually invited by the Editors.

- **Invited Commentary**

Commentaries are usually written by an expert investigator who is invited by the Editors. They are usually written in response to a previously published article or Editorial.

Qualitative manuscript submissions should usually be based on a minimum of 20 respondents. Authors may contact the Editors (hollandj@mskcc.org; maggie.watson@live.co.uk) if they require further details.

4. PREPARING YOUR SUBMISSION

Manuscripts must be submitted as a Word or rtf file and should be written in English. The manuscript should be submitted in separate files: main text file; figures.

Text file

The text file should be presented in the following order:

(i) Title; (ii) a short running title of less than 70 characters; (iii) the full names of the authors; (iv) the author's institutional affiliations at which the work was carried out, (footnote for author's present address if different to where the work was carried out); (v) abstract; (vi) main text, (vii) acknowledgements, (viii) conflict of interest statement, (ix) references, (x) tables (each table complete with title and footnotes) (xi) figure

legends, (xii) appendices (if relevant). Figures and supporting information should be supplied as separate files.

Title

The title should be a short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's [best practice SEO tips](#))p>

Authorship

Please refer to the journal's authorship policy the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

Acknowledgements

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

You will be asked to disclose conflicts of interest during the submission process. See the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section for details on what to include in this section. Please ensure that you liaise with all co-authors to confirm agreement with the final statement. The Conflict of Interest statement should be included within the main text file of your submission.

Abstract

Please provide an abstract of no more than 250 words. Abstracts should be structured according to the following headings: objective, methods, results, conclusions.

Keywords

Please provide up to 10 keywords and list them in alphabetical order. Please ensure that the keywords, cancer and oncology, are used for indexing purposes. Keywords should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at <https://www.nlm.nih.gov/mesh/>.

Main text

Where possible, the text should be divided into the following sections: Background, Methods (including statistical methods), Results and Conclusions. All papers must include within the Conclusions section a paragraph explaining the study limitations

(with subtitle “study limitations”) and a paragraph explaining the clinical implications of the study (with subtitle “clinical implications”).

A statement explicitly describing the ethical background to this study and any institutional or national ethical committee approval (including approval number) must be included within the manuscript.

For clinical trial reports, the clinical trial registration number must be included within the manuscript.

References

All references should be numbered consecutively in order of appearance and should be as complete as possible. In text citations should be superscript numbers. Journal titles are abbreviated; abbreviations may be found in the following: [MEDLINE](#), [Index Medicus](#), or [CalTech Library](#).

Submissions are not required to reflect the precise reference formatting of the journal (use of italics, bold etc.), however it is important that all key elements of each reference are included. Please see below for examples of reference content requirements.

For more information, please see the [Vancouver Reference Style Guide](#)

Sample references follow:

Journal Article

1. Wood WG, Eckert GP, Igbavboa U, Muller WE. Statins and neuroprotection: a prescription to move the field forward. *Ann N Y Acad Sci* 2010; 1199:69-76.

Book

2. Hoppert, M. *Microscopic techniques in biotechnology*. Weinheim: Wiley-VCH; 2003.

Electronic Material

3. Cancer-Pain.org [homepage on the internet]. New York: Association of Cancer Online Resources, Inc.; c2000–01 [Cited 2015 May 11]. Available from: <http://www.cancer-pain.org/>.

Tables

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Author Guidelines Updated 9th May 2017

Appendix B. Ethics clearance

Jo Lewis

From: Leigh Tooth <l.tooth@sph.uq.edu.au>
Sent: Thursday, 19 May 2016 10:43 AM
To: Jo Lewis; julie.byles@newcastle.edu.au; tazeen.majeed@newcastle.edu.au; Lynette Mackenzie; Rob Heard
Cc: Leonie Gemmell; Megan Ferguson
Subject: ALSWH PSA Committee approval of EoI # A631: Workforce participation patterns in middle age women with breast cancer

Dear Joanne and colleagues,

Thank-you for submitting your proposal **EoI # A631: Workforce participation patterns in middle age women with breast cancer** to the ALSWH Publications, Substudies and Analyses (PSA) committee. The EoI has been approved, and you have permission to use ALSWH data in this project. In their review, committee members returned the following comment, which you may find useful:

- Perhaps the breast cancer researchers could consider work hours as a barrier to screening. This has been previously noted for Pap test.

The committee also noted that the analysis plan lacked some details - references were mentioned in the text but the actual citations were not included, and language usage was not consistent. Although it did not hold up approval of this EoI, we suggest that you check these details in any future applications to the PSA Committee.

All collaborators who receive permission to use ALSWH survey data must abide by the following conditions of approval:

- That collaborators ensure that only researchers who have received permission to use the data (that is, are named on the EoI) and who have signed all appropriate agreements have access to the data.
- That the survey data provided by the ALSWH are securely stored and protected by the use of firewalls, automatic screen locking and/or secure encrypted pathways;
- That if the analysis plan or the people involved with the project change at any time, the collaborator/s will submit a revised EoI for consideration by the PSA committee. All changes require approval before they can be implemented.
- That collaborators will complete regular 6-monthly progress updates when requested by the ALSWH;
- That the lead collaborator ensures the collaborators or students involved have adequate facilities and resources to enable the project to progress in a reasonable manner to its conclusion;
- That in the event of unforeseen circumstances such that the project cannot proceed, the PSA is notified so the project can be terminated;
- That any outcome (that is, manuscripts for publication, abstracts for conferences/symposia, other reports for funders) from an EoI is reviewed/approved by the ALSWH liaison person before it is circulated beyond the collaborators named in the EoI;

