School of Occupational Therapy, Social Work and Speech Pathology

Navigating a Way Forward: How Women Survivors of Breast Cancer and Their Partners Face Challenges Adapting to Their Changed Lives

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This thesis is presented for the Degree of
Doctor of Philosophy
of
Curtin University

June 2018

Author's Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Human Ethics

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number # HR 51/2014 dated 08.04.2014

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Date May 17th 2018

Statement of Contributors

As co-authors of the following article:

Keesing, S., McNamara, B., & Rosenwax, L. (2015). Cancer survivors' experiences of using survivorship care plans: A systematic review of qualitative studies. Journal of Cancer Survivorship, 9(2), 260-268. doi/10.1007/s11764-014-0407-x

We confirm that Sharon Keesing has made the following contribution:

· Conceptualisation and design of research;

· Collection of data;

· Analysis and interpretation of results; and

· Writing paper and critical appraisal of content

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Keesing, S., Rosenwax, L., & McNamara, B. (2016). A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship. BMC Women's Health, 16(1), 1-14. doi/10.1186/s12905-016-0337-z

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Keesing, S., Rosenwax, L., & McNamara, B. A call to action: The need for improved service co-ordination during early survivorship for women with breast cancer and partners. Accepted for publication in Women and Health Journal on May 1st, 2018 (in press).

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Abstract

Background

The vast majority of Australian women diagnosed with breast cancer will survive at least five years following diagnosis, due largely to preventative screening, early diagnosis and successful treatment regimes. According to the literature, a diagnosis of breast cancer and its associated treatments may create a range of complex physical, psychological, relationship, social and resultant occupational consequences, often persisting for extended periods of time. Yet partners, family members, friends, work colleagues, health professionals and the broader public often assume that women will simply resume their usual lives following treatment. Many women experience significant challenges during survivorship as they attempt to resume their usual daily routines, meaningful activities and important life roles; these challenges are not well recognised.

Breast cancer also impacts the lives of significant others including partners, family members and friends. Partners may experience disruption to their own daily routines, activities and roles during the survivorship period as they continue to support their spouse and as both individuals attempt to adjust to the many challenges experienced. As individuals, and as a couple, women and their partners often have ongoing unmet needs during survivorship; however, the extent and range of partner's needs are not widely acknowledged or sufficiently addressed.

Many different models of breast cancer survivorship care are offered within the Australian healthcare context. Survivorship care has historically focused on women's medical and physical needs as well as surveillance for recurrence of breast cancer. However, the consequences of breast cancer are not limited to medical and physical issues, with a range of further challenges reported by women during survivorship. Identification of these complex needs, referral for services and access to multidisciplinary health professionals, including occupational therapy, are not consistent and vary considerably according to the existing model of care.

This study aimed to explore the occupational experiences of women and their partners as they engaged in their usual activities and important roles following cessation of treatment for breast cancer. The objectives of the study were to identify the met and unmet occupational needs of women and their partners and to appraise the current services

available to meet these needs. Recommendations to improve care during this period for women and partners, as well as the shared needs of couples, are provided.

Methods

A mixed method research design, conducted over four stages, was employed to address the research aim. Prior to the commencement of stage one, a comprehensive literature review was completed to explore the current research relating to the occupational needs of women survivors of breast cancer, their partners, and the shared needs of couples. Information was obtained regarding the many factors impacting the delivery of supportive services including models of care, the contribution of health professionals, assessment tools and the use of formal planning resources including survivorship care plans.

Stage one used a qualitative approach to explore the lived experiences of women and their partners as they engaged in daily activities and usual roles during survivorship. In-depth interviews with women survivors of breast cancer (n=18) and their partners (n=8), living in Perth, Western Australia, were completed between June and November 2014. Questions were directed initially at women participants, including the management of any ongoing symptoms and their engagement in a variety of occupations, including activities of daily living and instrumental activities of daily living, leisure, social and productive activities. Further information was sought regarding participation in meaningful roles as well as the maintenance of relationships with their partner. Partners were asked the same series of questions, with modifications, regarding their individual and shared needs as a couple during survivorship.

Stage two consisted of the development and distribution of a cross-sectional questionnaire emailed to known providers of breast cancer supportive services (n=34) in Perth, Western Australia between March and April 2015. These organisations offered a variety of services, including medical surveillance and the management of ongoing physical issues, as well as psychological, emotional and relationship concerns. A variety of question formats were used to obtain information regarding the type and scope of the service, format, delivery, cost, target audience, staffing and the use and content of survivorship care plans. Specific questions were also asked relating to the provision of services for partners and families.

In stage three, two focus groups during February 2016 were conducted with women (n=6) and some of their partners (n=4). Further opportunity was provided for participants to discuss and verify the findings of the previous two stages and to expand upon the activity limitations and role restrictions experienced by individuals and couples. Questions explored the occupational needs of women and their partners following completion of treatment, the key services required or used, and their suggestions regarding strategies to meet existing needs.

The final stage consisted of the implementation of a Delphi survey disseminated to occupational therapists (n=40) between April-July 2017, who identified as having had recent work experience in oncology in Australia. This three-round survey required participants to provide their views regarding the important occupational needs of women and partners, enablers and barriers associated with the provision of current care and the contributions made by occupational therapists during early survivorship.

Results

The study found three major themes. First, women and their partners experience activity limitations and role restrictions resulting in occupational disruption during survivorship. The second theme was that comprehensive and co-ordinated care is required during early survivorship, including rehabilitation and access to a formal personalised care plan which considers the occupational needs of women, their partners and the needs of couples. Third, occupational therapy has a role in assisting women and their partners to address many unmet occupational needs during survivorship. These themes are presented as part of four research publications and are presented in Chapters Four, Five, Six and Seven. An additional published paper is presented as part of Chapter Two-Background.

Women were generally satisfied with their medical care, including surveillance for recurrence of cancer and management of physical symptoms, however many unmet needs were identified. These resulted in problems resuming meaningful activities including self-care, household management tasks, leisure and social interests and productive occupations. Consequently, the valued roles of self-maintainer, parent, partner, friend and worker, as well as others, were significantly disrupted. Partners also reported challenges during this time as they attempted to maintain their usual activities and roles. These included continuing as the primary support person for their spouse, while juggling practical tasks including home management and child-care, paid employment and completing most of the social and emotional labour with family and friends. Couples also identified many unmet needs relating to their ability to maintain their relationship, with difficulties described as a disconnection between each other, changes to communication and problems with their intimate relationship.

While this study found that survivorship care services were available, many women and partners were not aware of how and where to access these services. This was, in part, due to the absence of a formal plan as well as a poorly co-ordinated approach to care during early survivorship. The current emphasis of care was to reduce physical symptoms and provide surveillance for cancer recurrence. While these issues were recognised as essential requirements, important occupational needs were not addressed and occupational therapy was not included as part of continued care. Participant women, partners and occupational therapists identified the need for a holistic approach to survivorship care that addressed individual and shared concerns regarding activity and role participation using high quality, effective and timely services. The summary findings of this study indicate that for women survivors of breast cancer who have partners, services must consider the individual needs of both women and partners, as well as the interrelated needs of couples.

Implications for occupational therapy

This thesis discusses four key findings that offer a unique contribution to the survivorship literature. Women survivors of breast cancer and their partners experience occupational disruption, demonstrating many difficulties adapting to the changes in valued routines, activities and roles following cessation of treatment. They would greatly benefit from the provision of rehabilitation, with occupational therapists positioned to play an integral role in the delivery of services. Occupational therapists are well positioned to offer individualised assessment and interventions to address these needs and improve occupational engagement and role participation, contributing to improved quality of life for women and their partners during survivorship.

Acknowledgements

There are so many people who assisted me during this research and I am forever grateful for your help. First, I offer my sincere thanks and appreciation to my Research Supervisors, Lorna Rosenwax and Bev McNamara. Lorna placed her trust in me over ten years ago when I approached her to help me negotiate a pathway to complete research. What started as many hours of discussion in her office, multiple drawings on the whiteboard, completion of coursework units, development and submission of my Masters' degree, now culminates in the submission of this thesis. While juggling multiple commitments in her role as Head of the School of Occupational Therapy and later many other roles, Lorna has offered me her time, limitless energy and expertise, together with her 'no-nonsense' view of the world which has required me to think for myself and critically reflect on all that I do and what I write. Lorna, you have truly made such a difference to my role as a student and my working life. There really are no words to describe how thankful I am to you.

Bev, although you entered my research journey a little later, you have also helped me immeasurably. Your expertise in qualitative research has helped me negotiate some pretty tricky decisions and to make sense of the findings over many stages, during my studies. I really appreciate the way you approach problems in such a calm and methodical manner, often at times when I just felt that the mountain that needed to be climbed was especially insurmountable (think submission of journal articles!). I am very grateful that you have been a part of my Masters' degree and this research project and I cannot thank you enough.

To the many women and their partners who kindly volunteered to participate in the study, I am very appreciate of your help. Many of you gave not only your time, but private and personal insights about what it's like to live with the legacy of breast cancer, which made me realise that it really is a life-long disease. The way it changed your sense of self, relationships with your partner, friends, family members and even work colleagues is so under-recognised and I hope that I have been able to give your stories the voice that it deserves.

I am also very privileged to have been assisted by many supportive care services and agencies both here in Perth, but also interstate to progress the project. To Andrew Smith, other staff at Peter McCallum Cancer Centre, Paula Howell and Elizabeth Pearson I would like to thank you all for willingness to help me. I am also thankful to Dr Nic Tsokos and St John of God Health Care for assistance in the early stages of the project.

There were also many individuals and organisations who helped to recruit participants, Cancer Council W.A., Breast Cancer Network Australia (BCNA), Curtin University, Curtin FM, The Canning Times, W.A. Cancer Survivorship Collaborative and Cancer Support W.A. I thank each of you sincerely.

To the occupational therapists who kindly volunteered to participate in the Delphi survey, I would like to express my gratitude for spending time thinking about and preparing your responses, particularly during the first round of the survey and for replying in a manner which helped me to meet tight deadlines. Sincere thanks to Richard Parsons and Elinda Lee who provided assistance with statistical analyses and review of data bases. To the many colleagues who also helped me to problem solve challenges I faced along the way, particularly, Marina Ciccarelli, Megan Hatfield, Alison Kelly, Claire Morrisby, Julie Netto and Allyson Thompson I am so thankful.

To Pete and Mandy, Zona and Tonie, and your families, this is for you.

Finally, thanks to my family, you made it all worthwhile.

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List of Publications and Conference Presentations

This thesis consists of the following peer-reviewed publications:

1. Keesing, S., McNamara, B., & Rosenwax, L. (2015). Cancer survivors' experiences of using survivorship care plans: A systematic review of qualitative studies. **Journal of Cancer Survivorship**, 9(2), 260-268. doi/10.1007/s11764-014-0407-x
2. Keesing, S., Rosenwax, L., & McNamara, B. (2016). A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship. **BMC Women's Health**, 16(1), 1-14. doi/10.1186/s12905-016-0337-z
3. Keesing, S., Rosenwax, L., & McNamara, B. A call to action: The need for improved service co-ordination during early survivorship for women with breast cancer and partners. Submitted to **Women and Health Journal**. Accepted for publication on May 1st, 2018. doi/ 10.1080/03630242.2018.1478362 (in press).
4. Keesing, S., Rosenwax, L., & McNamara, B. (2018). The implications of women's activity limitations and role disruptions during breast cancer survivorship. **Women's Health**, (14), 1-11. doi/10.1177/1745505718756381
5. Keesing, S., Rosenwax, L., & McNamara, B. (2018). Identifying the contribution of occupational therapy in meeting the needs of women survivors of breast cancer. **British Journal of Occupational Therapy**. doi/10.1177/0308022618762080

The following presentation was completed as part of the research:

1. Keesing, S., Rosenwax, L., & McNamara, B. (2018). The untapped potential of occupational therapy: Making a difference for women and their partners during early breast cancer survivorship. **World Federation of Occupational Therapists (WFOT) Congress**, Capetown, South Africa, May 21-25, 2018.

List of Abbreviations

AIHW	Australian Institute of Health and Welfare
BCNA	Breast Cancer Network of Australia
COSA	Clinical Oncology Society of Australia
GP	General Practitioner
ICF	International Classification of Functioning
IOM	Institute of Medicine
NCI	National Cancer Institute
NCSI	National Cancer Survivorship Initiative
NGOs	Non-Government Organisations
OT	Occupational Therapist/Occupational Therapy
SC	Survivorship Consultation
SCP	Survivorship Care Plan
WHO	World Health Organisation

Glossary of Terms

Active treatment: Typically involves surgical removal of a tumour and a course of radiotherapy and/or chemotherapy, all of which would normally be completed within 18 months of diagnosis (Kemp-Casey et al., 2016).

Activity limitation: A difficulty encountered by an individual in executing a task or action (World Health Organisation, 2018a).

Cancer rehabilitation: The assistance offered to a person with cancer to help himself or herself to obtain maximum physical, social, psychological, and vocational functioning within the limits imposed by disease and its treatment (Fialker-Moser, Crevenna, Korpan, & Quittan, 2003).

Multidisciplinary care: A team of health professionals who work together to manage a woman's treatment and care (Breast Cancer Network Australia, 2018).

Participation restriction: A problem experienced by an individual during involvement in life situations (World Health Organisation, 2018a).

Occupational engagement: The involvement in an occupation with current positive personal value attached. This is a fluctuating state influenced by many complex internal and external factors (Morris & Cox, 2017).

Quality of Life: An individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (World Health Organisation, 2018b).

Survivorship: The period after active treatment for cancer (i.e. surgery, chemotherapy, and/or radiotherapy) is completed (Breast Cancer Network Australia, 2018).

Survivorship Care Plan: A tool designed to deliver patient-centred care by enhancing communication between the oncology team and the patient as well as communication and co-ordination of care between the oncology team and the primary care practitioner. It is made up of three components: a treatment summary, a follow-up plan and a post-treatment care plan (Wiley, Kinnane, Piper, Jefford, & Nolte, 2015).

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Kemp-Casey, A., Roughead, E., Saunders, C., Boyle, F., Lopez, D., Bulsar, M., & Preen, D. (2016). Breast cancer recurrence following active treatment: Determining its incidence in the NSW population. *Public Health Research and Practice, 26*(1), 1-8. doi:10.17061/phrp2611607

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Chapter 1 Introduction and overview of the thesis

For most women a diagnosis of breast cancer is devastating. Treatment can be extremely challenging to their health and well-being. Fortunately the majority of women diagnosed in Australia will survive, largely due to preventative screening, early diagnosis and access to effective treatment. However, the consequences of breast cancer and its associated treatments are not well known by the wider community and general public. The stories of women as they attempt to resume their previous lives are often hidden from others, with the misconception that they should be happy and well, with very few ongoing difficulties. The reality of early survivorship is that it is often fraught with challenges for many women, their partners and family members.

This research aimed to investigate several important issues pertaining to the survivorship period including the occupational experiences of women and their partners following treatment, and the supports and resources accessed by women and their partners. Further information was sought from healthcare providers, including occupational therapists, regarding the type and range of supports available and to determine whether the supports provided were sufficient to address the occupational needs of women and their partners following breast cancer treatment.

This introductory chapter provides an overview of the research and contextualises the four stages of the thesis. Pertinent information is explored and supported by relevant literature in order to provide a background to the methods, findings and discussion provided in subsequent chapters.

1.1 Breast cancer prevalence

Breast cancer is currently the most commonly diagnosed type of cancer for Australian women (Australian Institute of Health and Welfare, 2017). The incidence of breast cancer in Australia is increasing and it is estimated that by the year 2020 there will be 17,210 new cases diagnosed for women (Australian Institute of Health and Welfare, 2012). Although it is acknowledged that breast cancer is also diagnosed in men, the frequency is much less and estimated to be 144 men in 2017 (Australian Institute of Health and Welfare, 2017). The risk factors for breast cancer are extensive and include: the personal factors of age, place of residence, socio-economic status, height and weight at birth, as well as being overweight and other lifestyle factors including a diet high in saturated fat, smoking, alcohol consumption, gender (being female), genetic predisposition, and a family history of the disease. Other factors include environmental, genetic, and reproductive factors as well as a woman's medical history are also known to be associated with an increased chance of breast cancer (Australian Government, 2019a; McPherson, Steel, & Dixon, 2000).

Although increasing in incidence, early diagnosis, regular screening and successful treatment regimes for women with breast cancer have resulted in high rates of survival. The five-year relative survival rate has increased from 72% during 1984-1988 to a rate of 90% during 2009-2013 (Australian Institute of Health and Welfare, 2017). In 2012, approximately 66,000 Australian women were living with a history of breast cancer (diagnosed within the previous five years), with a further 193,000 women diagnosed up to 31 years earlier (Australian Institute of Health and Welfare, 2017).

1.2 Diagnosis and treatment: The acute period

A diagnosis of breast cancer is classified according to the type and stage of cancer and is categorised as follows: ductal carcinoma in-situ, lobular carcinoma in-situ, early breast cancer, locally advanced breast cancer and metastatic breast cancer, as well as rarer forms including Paget's disease and inflammatory breast cancer. Treatment of breast cancer varies considerably. Women diagnosed with lobular carcinoma in-situ are generally monitored for progression of the disease via regular mammograms, while women with ductal carcinoma in-situ may require breast surgery, radiotherapy and/or hormonal therapy (Cancer Australia, 2017b).

Recommended medical treatment for early breast cancer, locally advanced and inflammatory breast cancer will vary according to the stage of cancer, but may include lumpectomy or mastectomy, chemotherapy, radiotherapy, targeted drug therapies and adjuvant hormone therapy, or a combination of these treatments (Cancer Australia, 2017a). Treatment for women diagnosed with metastatic breast cancer may include a combination of active treatment as well as the provision palliative care (Cancer Australia, 2019).

A breast cancer diagnosis and treatment may result in a range of physical, psychological and social consequences for women. During the period of ‘active’ treatment (surgery, chemotherapy and radiotherapy), women are often hospitalised and required to attend a tertiary hospital for regular review and treatment with an oncologist, breast surgeon or plastic surgeon and attend clinics for chemotherapy and radiotherapy. Active treatment interrupts women’s usual activities, responsibilities and roles, requiring time away from their daily personal, work, leisure and family routines. (Australian Government, 2019b)

The impact of a breast cancer diagnosis and treatment has been widely researched with findings indicating that this period is considered to be stressful, treatment may be painful and may result in a vast range of physical and psychological symptoms (Binkley et al., 2012). Surgery to remove or reconstruct the affected breast/s and removal of lymph nodes may result in pain, reduced range of motion and lymphoedema in the affected area and corresponding upper limb (Shah & Vicini, 2016). The side-effects of chemotherapy include hair loss, nausea, anorexia and toxicity as well as reduced fertility and neuropathy (Rivera & Cianfrocca, 2015), while radiation treatment may result in skin sensitivity, redness and burns as well as blistering (Perez, Schootman, & Hall, 2017).

Many women are also prescribed additional drug therapies including adjuvant hormone therapy; this may be associated with additional side-effects including hot flushes, mood disturbance, diarrhoea, muscle and joint pain and stiffness, osteoporosis, vaginal dryness and weight gain (Tchen et al., 2003). A myriad of other potential consequences of breast cancer treatment are also reported, including cognitive dysfunction or ‘chemo-brain’ (Player, Mackenzie, Willis, & Loh, 2014; Selamat, Loh, Mackenzie, & Vardy, 2014), chronic pain (Sun, Borneman, Piper, Koczywas, & Ferrell, 2008), fatigue (Wu & McSweeney, 2004) and insomnia (Fiorentino & Ancoli-Israel, 2009).

While the breast cancer literature does not provide a definitive prediction of outcomes for each type of cancer, the type and stage of breast cancer as well as the many different treatments undertaken all contribute to the overall experience of women and their partners. A systematic review conducted in 2014 indicated that the supportive care needs of women varies considerably according to the clinical, demographic, emotional, psychological and psychosocial variables impacting them and their families (Fiszer, Dolbeault, & Sultan, 2014). Women diagnosed with invasive, advanced, recurring or metastatic cancer are generally known to experience more concerns, particularly regarding uncertainty for the future as well as for their significant others (Kirsten & Hobbs, 2017).

Historically, a radical mastectomy was often required to reduce the risk of breast cancer spreading to other organs and this was often associated with poor cosmetic results contributing to significant changes in body image (Brunet, Sabiston, & Burke, 2013). More recently, women with early or non-invasive breast cancer are able to access breast-conserving surgery as a result of segmental mastectomy as opposed to radical mastectomy which may result in improved physical and psychological outcomes (Kim et al., 2015).The side-effects associated with many of the other treatment types including chemotherapy, radiotherapy and hormonal therapies may also contribute to reduced quality of life (Hodgkinson et al., 2007; Trusson, Pilnick, & Roy, 2016). Women who are diagnosed at a younger age (45 years or less) may also experience unique concerns. Younger women are more likely to experience aggressive forms of breast cancer as a result of the complex range of treatment options and express greater concerns relating to their body image, nausea and fatigue (Sammarco, 2001).

In addition to the well-researched and documented physical side-effects, women also report significant psychological, emotional and existential issues affecting them during treatment. Studies exploring the experiences of women completing breast cancer treatment in the 1980's assisted with understanding many of the issues that continue to impact women currently (Ganz, 2008). These include changes to their body image and self-identity (Brunet et al., 2013), difficulties with intimacy and sexual functioning (Rowland et al., 2009), anxiety and depression (Knobf, 2011) and difficulty making important decisions due to the complexities of treatment (Rutherford & Zdenkowski, 2017).
Existential concerns are also reported, with some women questioning their own mortality and fearing the future, particularly concerning cancer recurrence (Hodgkinson et al., 2007). Despite the increasing number of women completing active treatment for breast cancer

and the achievement of ‘survivorship’, the experience of diagnosis and treatment creates a significant disruption to the individual’s life and may result in many ongoing consequences that continue to impact their health and well-being. The period following treatment is generally referred to as ‘survivorship’ as women transition from a period of active treatment (sometimes for months or years) and attempt to return to their previous activities and roles (Palmadottir, 2009).

1.3 Breast cancer survivorship and unmet needs

Following completion of active treatment, women’s usual regular and frequent contact with their healthcare team reduces significantly. While many women experience great relief that their treatment is finally over and have hope for the future, others experience a range of negative emotions (Allen, Savadatti, & Gurmankin Levy, 2009). These include feelings of abandonment as their usual health and medical supports are no longer part of their daily routine (Jefford et al., 2008), fear of cancer recurrence or hypervigilance (Allen et al., 2009), difficulties with relationships, work discrimination and decreased capacity to return to previous work (Banning, 2011) as well as changes to their social network (Bloom, Stewart, D'Onofrio, Luce, & Banks, 2008). Some women refer to this transition as an adjustment to the ‘new normal’ (Trusson et al., 2016).

The literature also reports that many of the physical, psychological, emotional and existential issues identified during treatment continue in the longer term, contributing to further health challenges. Chronic conditions may develop, including cardiac and bone disease, (Stein, Syrjala, & Andrykowski, 2008), secondary primary malignancies and thromboembolic events (Bodai, 2015). Women may experience symptoms associated with treatment-induced early menopause (hot flushes, night sweats, vaginal dryness, difficulty sleeping, depression and dyspareunia) as well as anxiety, depression and sexual dysfunction (Lemieux, Bordeleau, & Goodwin, 2007). Furthermore, many women continue to be impacted by changes to self-identity and expectations of themselves (Fobair, 2007). Age at diagnosis is also relevant during this time. Younger women (aged under 50 years) report greater difficulties with social and emotional functioning (Ganz, Greendale, Petersen, Kahn, & Bower, 2003) while older women (aged 65 years and above) report greater problems with physical functioning (Ganz, Guadognoli, et al., 2003).

1.4 Activity engagement and role participation

While the breast cancer survivorship literature is well established with regard to the physical and psychological consequences of diagnosis, treatment and survivorship, there is very little recognition regarding the activity limitations and role restrictions experienced by women during this period. The World Health Organisation's (WHO) model for understanding the links between health and disability, the International Classification of Functioning (ICF), identifies the significant interaction between illness, the environment and an individual's capacity for successful engagement in meaningful activities and valued roles (World Health Organisation, 2013). The benefits of occupational engagement are known to include the development of skills and interests, identity and purpose; contributing to a sense of self-worth and meaning as well as life satisfaction (Polatajko et al., 2007). The negative effects of activity disengagement and role restrictions include many long-term consequences such as depression, anxiety and social isolation. These can result in chronic health outcomes as well as reduced quality of life (Fox, Morrow-Howell, Herbers, Battista, & Baum, 2017; Lyons, Svensborn, Kornblith, & Hegel, 2015). Women who experience activity disengagement and role disruption during survivorship may be at risk of complex health concerns in the longer term.

Although there has been some reference to activity disengagement and role disruption in the breast cancer survivorship literature, researchers have called for greater exploration regarding the resultant complex and chronic consequences of surviving breast cancer. These include women's capacity for resuming personal care, parenting, engaging in social opportunities, leisure and hobbies as well as the resumption of work and other productive roles (Amatya, Khan, & Galea, 2017; Khan, Amatya, Ng, Demetrios, & Pallant, 2012; Loh & Jonsson, 2016).

1.5 Impact of breast cancer on significant others

Research has begun to identify not only the experiences and difficulties of women survivors of breast cancer but recognises that family members may also be significantly impacted during survivorship. Some researchers have noted that partners and children may even be considered as 'secondary survivors'(Bowman, Rose, & Deimling, 2006). Lewis (2006) described potential difficulties for family members to include elevated levels of emotional distress, not knowing how to respond and express feelings, coping with tension in the family caused by cancer and struggling to maintain their usual roles. Research findings indicate that issues impacting family members are evident during the period from immediate (six months post-treatment) to extended periods of up to five years. Existing models of care do not always include survivorship as a distinct period for which people may need continued assistance, nor do they recognise the specific needs of family members during this time. The partners of women, their children, other family members, friends and work colleagues may all be potentially affected (Northouse, Katapodi, Song, Zhang, & Mood, 2010). While the impact of a breast cancer diagnosis on an individual is life-changing, many more people will have an experience of breast cancer as a partner, family member or friend. Partners of women with breast cancer are widely recognised as a support person or carer, a role which commences soon after diagnosis, continues through treatment and may extend during survivorship (Zahlis & Lewis, 2010). This experience may create ongoing difficulties for partners as they continue to juggle varied roles and responsibilities, for example, full-time employment, financial management, homemaking, communicating with family and friends as well as supporting the ongoing health needs of their spouse (Antoine, Vanlemmens, Fournier, Trocme, & Christophe, 2013).

Partners of women may continue to experience personal and emotional issues, with a lack of information pertaining to the survivorship period potentially contributing to poor adjustment (Pauwels, De Bourdeadhuij, Charlier, Lechner, & Van Hoof, 2012). Others report difficulty managing expectations, coping with changes in the relationship including communication issues and reduced intimacy as well as adjusting to previous roles (Harrow, Wells, Barbour, & Cable, 2008). Partners may feel that they are unable to prioritise their own needs while continuing to support their spouse as they experience persistent consequences of breast cancer, despite having completed active treatment (Feldman & Broussard, 2006). Partners may feel unsupported during the survivorship period, with few established resources offered to assist them during this transition. The impact of continuing to maintain the role of a support person may result in a range of health issues, ambiguity and uncertainty, with evidence that the long-term consequences of these issues may contribute to fatigue, sexual dysfunction, anxiety, and depression (Alfano & Rowland, 2006).

Conversely, other studies support some positive outcomes of the diagnosis, with couples stating their relationship improved as a result of the many challenges faced while attempting to manage the persistent consequences of breast cancer (Chung & Huang, 2012; Dorval et al., 2005). A recent Australian publication stressed that new models of care were urgently needed to include the carers of women survivors of breast cancer as important ‘co-users’ of services, during all stages of care, as well as the development of timely interventions to address their ongoing needs (Girgis, Levesque, Smith, Durcinoska, & Gerges, 2017).

The complex nature of a couple’s relationship is also beginning to receive attention within the breast cancer survivorship literature. Holmberg, Scott, Alexy and Fife (2001) reported relationship difficulties for couples regardless of the quality of the pre-cancer relationship, with communication becoming less open as well as challenges to the way couples managed conflict. Other findings stressed the importance of spousal and dyadic coping being important factors in a woman’s successful adjustment to breast cancer (Ben-Zur, Gilbar, & Lev, 2001; Dorros, Card, Segrin, & Badger, 2010). A recent study concluded that the physical and psychological distress of women and their partners during survivorship is interdependent, which provides further evidence regarding the need for targeted services and supports for both women and partners during survivorship (Segrin & Badger, 2014). As attention to partners is still at the development stage in the literature, this thesis considers the experience of partners as integral to the survivorship period and partners of women survivors of breast cancer were purposively included in the study.

1.6 Occupational therapy and breast cancer survivorship

The overarching philosophy of occupational therapy is to assist individuals, groups, communities and populations to engage in activities and participate in roles that they want to do or need to do as part of everyday life (World Federation of Occupational Therapists, 2011). The primary method facilitating this engagement and participation is by utilising activities or occupations that are meaningful to the individual. Many women survivors of breast cancer and their partners report a range of unmet needs as a result of complex physical, psychological, emotional, relationship and social problems impacting their day to day life during early survivorship, yet there is a distinct lack of research focus on the resultant activity limitations and role disruptions affecting them during this period.

Currently, occupational therapy does not have an established role supporting women during breast cancer survivorship, with scant knowledge regarding the potential explanation for this. Historically, cancer survivorship support has had a medical focus, with the primary goal of care being surveillance for cancer recurrence and minimisation of physical symptoms. A medical model is usually employed during diagnosis and treatment, with medical and nursing health professionals often continuing to provide ongoing care following cessation of treatment (Jefford et al., 2012). However, with the increasing recognition that many women experience a multitude of psychosocial, emotional, social and other complex difficulties, some literature is available to support a broader philosophy of care, together with the acknowledgement that the expertise of other health professionals is warranted (Ganz & Hahn, 2008).

To date, very few studies have been published to support the value of occupational therapy for women survivors of breast cancer, however, some studies are available to substantiate the role for cancer survivors more broadly. While largely focusing on symptom management, interventions to support cognitive dysfunction, lymphoedema and fatigue have been recognised as valuable for cancer survivors (Polo & Smith, 2017; Vrkljan & Miller-Polgar, 2001). Occupational therapy is also noted to contribute to improvements in upper-limb movement, strength and function (Lattanzi et al., 2010) as well as facilitate the resumption of employment and sexual activity (Hunter, Gibson, Arbesman, & D'Amico, 2017). The potential for occupational therapy to improve women's activity engagement and role participation during breast cancer survivorship is not well explored. This study attempts to address these gaps in knowledge as well as contribute valuable research findings regarding the occupational experiences of women and their partners during early survivorship.

1.7 Research aim and objectives

This research aimed to contribute to the knowledge regarding the occupational experiences of women survivors of breast cancer and their partners as they attempted to re-establish previously valued activities and roles. Mixed methods were utilised over four stages: in-depth interviews, a cross-sectional questionnaire, focus groups and a Delphi survey. The views of service providers who currently support women and partners were also obtained.

Recommendations are made regarding the planning, development and implementation of strategic services to this population living in Australia.

1.7.1 Aim

To explore the occupational experiences of women survivors of breast cancer and their partners as they engaged in daily activities and usual roles following treatment cessation.

1.7.2 Objectives

1. Identify the met and unmet occupational needs of women and their partners during the early survivorship period.

2. Identify and describe the range and type of current supports available to women survivors of breast cancer and their partners, from the perspective of the support organisations providing these services.

3. This objective was twofold:

   a) Explore the activity limitations and role restrictions of women, their partners and couples during the early survivorship period; and

   b) Recommend a suitable framework to assist women and their partners to resume valued activities and roles during early survivorship.

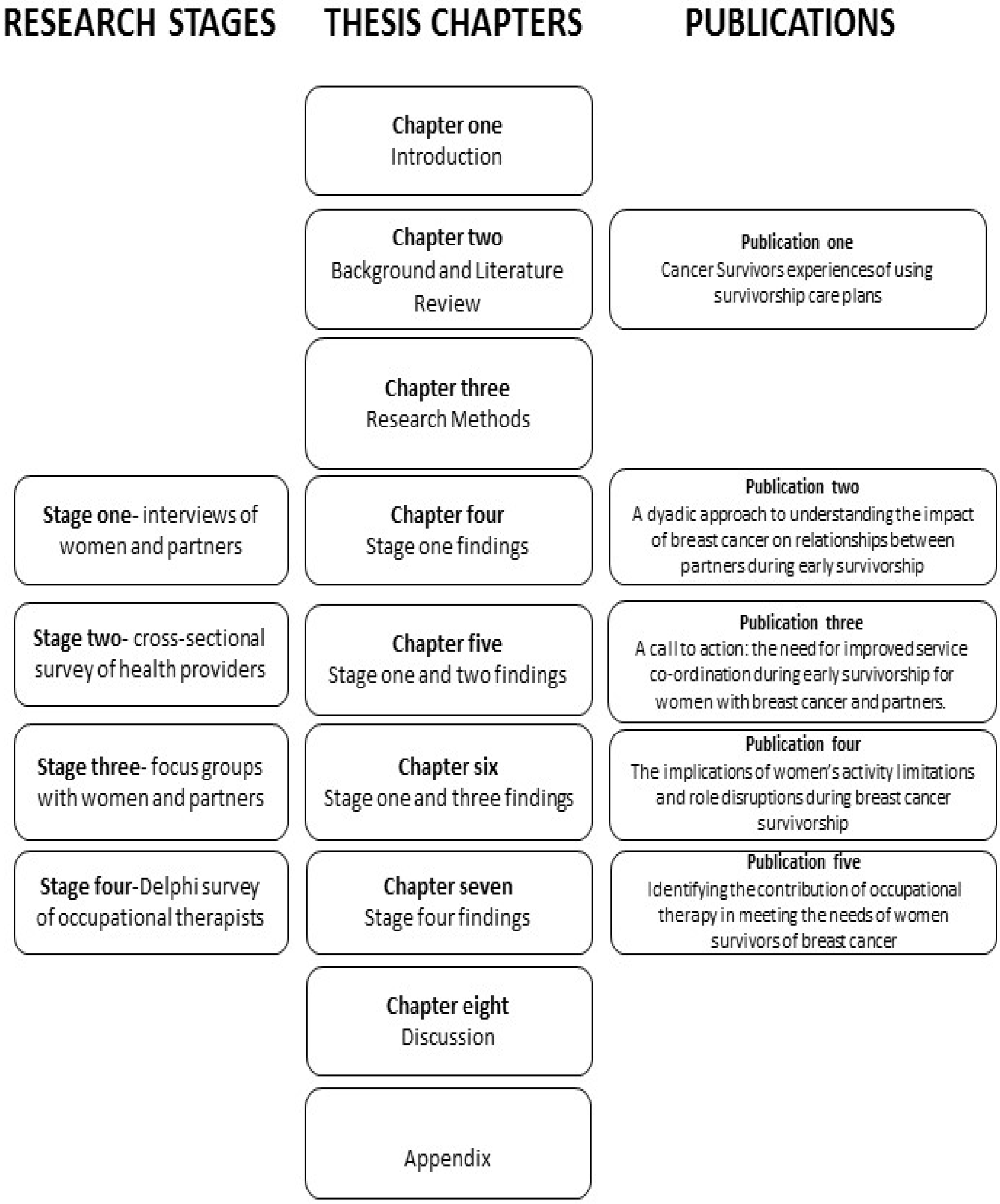
4. Determine the views of occupational therapists regarding the enablers and barriers concerning the provision of occupational therapy services for women survivors of breast cancer and their partners as they attempt to resume previously valued activities and roles during the period of early survivorship.

1.7.3 Significance

This research is significant for several reasons. First, the Australian population is ageing, with older women at increased risk of breast cancer and the likelihood of survival after diagnosis is also continuing to increase (National Breast and Ovarian Cancer Centre, 2009). Consequently, the cost of funding services for women survivors of breast cancer will continue to rise. Second, as an Australian national health priority area, research into cancer treatment is well-resourced; however, the broader and long-term effects of the illness for individuals and their partners in largely under-researched and poorly resourced (Brennan, Butow, Spillane, & Boyle, 2010; Girgis et al., 2017). This is particularly problematic for the potentially complex issues identified by survivors and their partners. Third, international studies in survivorship have reported a move away from the traditional medical focus to a well-co-ordinated framework of care that emphasises an individualised approach, choice, and the inclusion of the family as essential participants of care (Gage et al., 2011). Understandably, a priority during survivorship is surveillance for further cancer and management of ongoing symptoms; however, most women have attempted to resume their previous activities and roles and therefore may be at risk of ongoing problems which have not been identified or addressed. Fourth, given that the majority of women diagnosed with breast cancer have high rates of survival, improved attention must be directed to understanding more about the challenges of women and their partners in re-establishing valued activities and important roles, essential for their future health and well-being.

1.8 Structure of thesis

This thesis is presented as an exegesis and consists of the following sections and corresponding peer-reviewed publications, as represented in Figure 1.1.



RESEARCH STAGES	THESIS CHAPTERS	PUBLICATIONS
	Chapter one Introduction	
	Chapter two Background and Literature Review	**Publication one** Cancer Survivors experiences of using survivorship care plans
	Chapter three Research Methods	
Stage one- interviews of women and partners	**Chapter four** Stage one findings	**Publication two** A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship
Stage two- cross-sectional survey of health providers	**Chapter five** Stage one and two findings	**Publication three** A call to action: the need for improved service co-ordination during early survivorship for women with breast cancer and partners.
Stage three- focus groups with women and partners	**Chapter six** Stage one and three findings	**Publication four** The implications of women's activity limitations and role disruptions during breast cancer survivorship
Stage four-Delphi survey of occupational therapists	**Chapter seven** Stage four findings	**Publication five** Identifying the contribution of occupational therapy in meeting the needs of women survivors of breast cancer
	Chapter eight Discussion	
	Appendix	

Figure 1. 1 Structure of thesis

1.9.1 Introduction and overview (Chapter one)

This (current) chapter provides an overview of the research aims and objectives, structure of the thesis and summary of each of the subsequent chapters.

1.9.2 Background (Chapter two)

A comprehensive literature review was conducted to determine the current evidence concerning the research aim. Attention was directed towards the current models, frameworks, contributions of health professionals, co-ordination of care and formal planning resources utilised in this field of healthcare. A thorough review of the literature indicated that survivorship care plans (SCPs) were a key strategy in helping to direct services and support women survivors of breast cancer, yet there were several concerns about their use. This finding suggested a detailed review was required to fully understand the implications of their future use. A peer-reviewed publication is included in this chapter, representing the work completed:

Keesing, S., McNamara, B., & Rosenwax, L. (2015). Cancer survivors' experiences of using survivorship care plans: A systematic review of qualitative studies. Journal of Cancer Survivorship, 9(2), 260-268. doi/10.1007/s11764-014-0407-x. *Citations recorded by Scopus to date (20).*

1.9.3 Research methods (Chapter three)

Research Methods are presented and provide a rationale for each of the research objectives, study design, sample, inclusion and exclusion criteria, the procedure used and the data analysis for each of the four stages of the thesis.

1.9.4 Stage one findings (Chapter four)

Women survivors of breast cancer and their partners participated in interviews with the aim of exploring their occupational experiences during survivorship following cessation of treatment. Emphasis was placed on current activity engagement during this period as well as questions concerning changes to their relationship and participation in meaningful roles. Additional findings from stage one are presented in chapters five and six.

A peer-reviewed publication is published as chapter four, representing part of stage one findings:

Keesing, S., Rosenwax, L., & McNamara, B. (2016). A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship. BMC Women's Health, 16(1), 1-14. doi/10.1186/s12905-016-0337-z. *Citations recorded by Scopus to date (2).*

1.9.5 Stage two findings (Chapter five)

A cross-sectional questionnaire was distributed to known providers of breast cancer services to determine the type, scope and content of supports available to women survivors of breast cancer and their partners. A peer-reviewed publication is presented as chapter five, representing the results of stages one and two:

Keesing, S., Rosenwax, L., & McNamara, B. A call to action: The need for improved service co-ordination during early survivorship for women with breast cancer and partners. Submitted to Women and Health Journal. Accepted for publication on May 1st, 2018 (in press).

1.9.6 Stage three findings (Chapter six)

Focus groups were completed with women survivors of breast cancer and their partners in order for these participants to explore the findings of stages one and two and to discuss the shared views of couples. Questions focused on unmet occupational needs, services needed or utilised and suggestions regarding preferred options regarding the organisation, referral and co-ordination of required supports. The work completed during this stage is published in chapter six:

Keesing, S., Rosenwax, L., & McNamara, B. (2018). The implications of women’s activity limitations and role disruptions during breast cancer survivorship. Women’s Health, (14), 1-11. doi/10.1177/1745505718756381

1.9.7 Stage four findings (Chapter seven)

A three-round Delphi survey was completed with occupational therapists to obtain their views regarding the ongoing activity and role engagement needs of women and their partners during survivorship. Further information was also sought regarding the current enablers and barriers impacting the provision of care and contributions of occupational therapists during this critical period. This stage is represented in chapter seven as a peer-reviewed article:

Keesing, S., Rosenwax, L., & McNamara, B. (2018). Identifying the contribution of occupational therapy in meeting the needs of women survivors of breast cancer. British Journal of Occupational Therapy. doi/10.1177/0308022618762080

1.9.8 Discussion (Chapter eight)

This chapter provides a synthesis of the overall findings of the thesis as well as a discussion concerning how the findings support or contrast current research. Implications for future service delivery including recommendations regarding occupational therapy practice using a suggested framework are presented. Strengths and limitations of the research and suggestions for future research are also discussed.

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Chapter 2 Background to the research

2.1 Introduction

Internationally, services for women survivors of breast cancer vary considerably, particularly with respect to the many complex issues currently influencing the provision of care. These include the current models of clinical support, service delivery frameworks and practice guidelines. In addition, there are many tools available to facilitate education, assessment of needs and a range of interventions to improve the transition from treatment to survivorship. Survivorship care plans (SCPs) are also proposed in the current research literature as an essential strategy for improving care co-ordination, identification of ongoing needs and to direct important services. However, there are several limitations associated with their use, resulting in varied and inconsistent implementation. The information presented in this chapter assists to highlight a potential gap in the literature concerning the use of SCPs. This appears to be particularly related to qualitative studies, with the first publication of the thesis assisting to meet the gap evident in the broader cancer survivorship research literature.

The findings of publication one and the four stages of the research assisted with the identification of many disparities relating to the provision of services for this population of cancer survivors. As the research progressed, it was evident that as well as the many unmet needs identified by participants, broader gaps in the provision of services existed. Furthermore, the findings of this thesis also supports the potential for the increased involvement of a broad range of health practitioners, including occupational therapists. The literature pertinent to each stage of the thesis is discussed in the relevant publications and located in chapters four-seven.

2.2 What is cancer survivorship?

There is currently some debate in the oncology literature regarding the concept of 'cancer survivorship' and the definition of 'survivor'. The term 'cancer survivorship' is defined using a range of different measures and can be complex to determine, with health professionals, researchers and even women themselves finding difficulty in reaching consensus regarding the term. Mullan (1985) considers survivorship to be separated according to acute, extended and permanent phases. The World Health Organisation (WHO) considers survivorship as the period recognising people who have been cured of cancer, recovered from all evidence of the disease, attained minimal risk of relapse and achieved restoration of functional health (World Health Organisation, 2008).

The Clinical Oncology Society of Australia (COSA), adopts a broader approach, being ‘an individual is considered a survivor from the time of diagnosis through the balance of his or her life’ (Clinical Oncology Society of Australia, 2016, p. 5). Other definitions consider that survivorship is ‘the health and life of a person with a history of cancer post-treatment until the end of life’ (National Cancer Institute, 2014, para 1). Some sources consider that a survivor is a person diagnosed with cancer and living beyond five years (Feuerstein, 2007), while others consider a survivor to be ‘any person who has been diagnosed with cancer from the point of diagnosis through the remaining years of life’ (Knobf et al., 2012, p. 1). While a consensus regarding the term ‘survivorship’ is yet to be reached, what is common to all these definitions is that the impact of cancer may extend from diagnosis to the end of life, therefore affecting women for many years following treatment. This thesis utilises an operational definition of early survivorship being ‘having completed surgery, chemotherapy and radiotherapy, yet may still be receiving other treatment, eg., adjuvant hormone therapies’ and seeks to explore the views of women who completed treatment from six months to five years previously. However, cancer survivorship may be separated according to ‘early survivorship’ and ‘survivorship’ more broadly as a recognition of it being a life-long disease. For many women, a diagnosis of breast cancer can be life-altering and the consequences of diagnosis, treatment and consequent poor health may result in long-term difficulties requiring further care and support.

2.3 The international context

Research dedicated to cancer survivorship has increased significantly over the last 30 years as a result of increased numbers of survivors and funding opportunities available to investigate these phenomena (Harrop, Dean, & Paskett, 2011). Increasingly, breast cancer is being considered as a chronic illness as opposed to a life-threatening disease, with health professionals modifying their approach to care accordingly (Bodai, 2015). Researchers in middle to high income countries including Australia, Canada, United Kingdom (UK) and the United States of America (USA) have all contributed to the understanding of the ‘survivorship’ period, reporting on a range of models, frameworks and tools to assist with supporting cancer survivors (Jefford et al., 2012). A further important contribution was made in 2006 when the USA’s Institute of Medicine (IOM) published the report ‘From cancer patient to cancer survivor: lost in transition’ (Hewitt, Greenfield, & Stovall, 2006). Key recommendations were made to assist cancer survivors in the longer term, including:

1. Prevention and detection of new cancers or recurrent cancer
2. Surveillance for recurrence or new primary cancer
3. Interventions for long-term and late effects of cancer and its therapies, and
4. Co-ordination between specialists and primary care providers to ensure that all survivors’ needs are met.

Apart from the essential message that medical surveillance for cancer recurrence is implemented, these recommendations indicate that cancer survivors require co-ordinated care from health professionals to ensure that the long-term effects of treatment are managed. The approaches employed by healthcare professionals to ensure this occurs are varied; however, one of the essential elements recommended is the use of a Survivorship Care Plan (SCP). The SCP aims to include a summary of the individual’s treatment, strategies for the prevention of further cancer and to determine resources to assist with the maintenance of a healthy lifestyle and identification of suitable supports. To date, the use and application of SCPs have not been fully evaluated with some studies indicating a lack of consistency regarding content and structure, poor cultural sensitivity and the high cost associated with development and monitoring (Ashing- Giwa et al., 2013; Grunfeld et al., 2011; Martin et al., 2013; Palmer et al., 2014).

While a variety of clinical guidelines are also available to support the care of women during treatment for breast cancer, there is a recognition that guidelines should also be developed for care during survivorship. In 2017, The American Cancer Society published the ‘Breast Cancer Survivorship Guideline’, which aims to guide practitioners in providing individualised care and to assist women to address their varied physical and psychosocial needs, including health promotion and addressing the co-morbid chronic conditions often associated with breast cancer (Runowicz et al., 2015). The guideline provides recommendations based on current evidence and expert opinion and is suggested to be used with a SCP. Very few high-level intervention studies are available to support these areas of survivorship practice and this is recognised as a limitation within the research.

Supportive services available to women survivors living in Canada are inconsistent due to the delivery of healthcare according to the individual province, with many variations. The current priorities for cancer survivorship in Canada include the development of various models and standards of care, research to explore the unmet needs of cancer survivors as well as how SCPs may be used in practice (Ristovski-Slijepcevic, Nicholl, & Bennie, 2008). Wiljer et al., (2013) also discusses the use of the survivorship consult (SC) as an interactive tool to assist women to explore and address their needs for education and goal-setting as part of an individualised plan during survivorship. The approach to survivorship care used in the UK using the National Cancer Survivorship Initiative (NCSI) consists of a recovery-focused model, provision of education, information, development of a treatment summary and care plan, as well as the use of self-management strategies (Jefford et al., 2012).

2.4 The Australian context

Provision of care for women survivors of breast cancer living in Australia is complex, partly due to the range of survivorship care practices that underpin the delivery of services. The Clinical Oncology Society of Australia has only recently (2016) published its Model of Survivorship Care, in recognition of the considerable variation regarding service delivery across Australian states (Clinical Oncology Society of Australia, 2016). The model advocates a wellness, recovery-oriented practice, and a shift from the traditional biomedical view to a holistic, multidisciplinary approach. Stratified pathways of care, comprehensive needs assessment, provision of a treatment summary and SCP, improved care co-ordination and evidence-based resources are also recommended. Due to the recency of this document, it is not possible to determine the success of its implementation or changes to service delivery in the current context.

There are many varied service delivery formats utilised in Australia, including the shared care model, where the general practitioner (GP) oversees post-treatment care in consultation with the oncologist, the specialist nursing model, peer-support model and the use of telehealth (Bessen et al., 2014; Jefford et al., 2015; Porter-Steele, Tjondronegoro, Seib, Young, & Andersen, 2017; Rankin, Williams, & Girgis, 2004). Results of recent work undertaken by Australian clinicians and researchers indicate that some progress has been made towards the development of a comprehensive approach to survivorship care. Research to evaluate the efficacy of alternative models of care, improved transition pathways from tertiary based services to primary care, establishment of shared-decision making, the inclusion of community organisations and a sustainable approach have been completed with positive findings (Butow, 2017; Kinnane et al., 2017). Objective two of this thesis aims to identify and describe the range and type of supports available to women survivors of breast cancer and their partners from the perspective of the support organisations providing these services. Publication three discusses the range of services available, together with the many barriers identified in delivery of these services.

Increasingly, women survivors of breast cancer are seeking to obtain individualised services during survivorship to help them manage their broad and often complex care needs. Historically, survivorship support consisted of medical and nursing services only, but these may not meet the needs of women survivors as psychosocial, emotional and occupational needs may not be met. In the future, there is also a possibility that there will be insufficient expert medical specialists available to provide services for women (Brennan, Butow, Marven, Spillane, & Boyle, 2011). While many women are able to resume their previous levels of health and well-being, others report a broad range of resultant issues that may be a symptom or treatment-related consequence of breast cancer. Formal pathways for rehabilitation are also not routinely offered following treatment cessation and this may have potential to restore skills and function to reduce disability, improve skills and participation and contribute to improved quality of life (Amatya, Khan, & Galea, 2017).

A range of online resources (including those suited to people from cultural and linguistically diverse backgrounds), the development of a multidisciplinary health workforce and further focus on self-management tools have all received favourable outcomes (Kinnane et al., 2017). Australian researchers have identified several targeted areas that require further investigation. These are identified as the effectiveness of the various models of care, impact of breast cancer survivorship on caregivers, the long-term effects of cancer as people grow older, the use of SCPs, hair loss following chemotherapy, communication and sexual dysfunction, cognitive dysfunction, mental health concerns and the unique issues impacting women living in rural and remote locations (Butow, 2017; Jefford, Mann, Nolte, Russell, & Brennan, 2014). With the recognition that an increased focus is required regarding the effects of breast cancer on caregivers, a central tenet of this thesis is the inclusion of partners’ experiences and needs within each stage of the research.

2.5 Survivorship care plans

Survivorship care plans are internationally recognised as a key strategy for improving the continuity of care between treatment and survivorship (Miller, 2008; Shalom, Hahn, Casillas, & Ganz, 2011). There are many barriers associated with the delivery of SCPs including the variability of content and mode of delivery, the time taken to prepare, insufficient reimbursement for preparation and significant training required to implement them. These barriers contribute to wide variations in their uptake amongst providers (Daudt et al., 2014; Powel & Siebert, 2017). Survivorship care plans are not used consistently in Australia, although the potential for them to identify needs and direct services regarding ongoing health concerns is recognised. They may also provide women survivors of breast cancer with an opportunity to receive an individualised plan to maximise health outcomes in the longer term (Martin et al., 2013). Australian researchers also suggested that SCPs could offer benefits to younger women, particularly those with unmet needs relating to their psychological health or fear of cancer recurrence (Brennan, Butow, Spillane, & Boyle, 2014; Lawler, Spathonis, Masters, Adams, & Eaking, 2011; Lotfi-Jam, Schofield, & Jefford, 2009).

2.6 **Publication One** ‘Cancer survivors’ experiences of using survivorship care plans: a systematic review of qualitative studies’

The background literature discussed in this chapter has highlighted many concerns regarding the period of survivorship for survivors of cancer. The availability of a supportive services, resources, practice guidelines and the use of SCPs varies considerably according to geographical location and models of health care. Internationally, significant efforts are being made towards the development and implementation of SCPs for use during survivorship and this is an essential consideration for the future.

The aim of the first publication in this thesis was to discuss the available qualitative literature that explored the views of cancer survivors regarding their experiences of using SCPs. As critical stakeholders in survivorship, it is essential to determine the perceived barriers and facilitators regarding the use of SCPs in practice according to consumers. The systematic review determined that SCP’s may be a useful and practical tool that women survivors of breast cancer could utilise to assist them during the critical transition from the treatment period to survivorship.

The findings of this publication assists to inform the subsequent stages of the research and to provide substantial background evidence to support further exploration of the unmet needs of women survivors of breast cancer.

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J Cancer Surviv
DOI 10.1007/s11764-014-0407-x

REVIEW

Cancer survivors' experiences of using survivorship care plans: a systematic review of qualitative studies

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Received: 17 August 2014 / Accepted: 7 October 2014

Abstract
Purpose Cancer survivorship care plans (SCPs) are currently used in care settings to assist survivors during the transition from treatment to survivorship. In this paper, the experiences of cancer survivors are examined to provide their perspective of how survivorship care plans are used in practice.
Methods A systematic review and critical review of the qualitative literature regarding the experiences of cancer survivors using survivorship care plans was completed. Databases reviewed included CINAHL, AMED, Embase, MEDLINE, Informit, ProQuest, PsycINFO, ScienceDirect, Wiley Online Library, Scopus and Web of Science from 2000 to 2014.
Results Eleven qualitative studies were appraised for methodological quality and content. They revealed four key themes: stakeholders agreed that SCPs should be used as a key strategy for cancer survivors; there was a lack of consensus on the format, content and who should develop the SCP; cancer survivors do not consistently receive SCPs; and there was a lack of evidence to support the use of SCPs in practice.
Conclusions There is great potential for SCPs to assist cancer survivors and this is supported by the range of qualitative literature examined in this study. Further research is required to examine the many practical issues relating to the delivery of SCPs and how they may be used across a variety of care contexts as well as providing further evidence to support their use.
Implications for Cancer Survivors With further research, refinement and contributions made by survivors, health researchers and health care professionals, the survivorship care plan is proposed to be a useful and practical tool aimed at supporting the survivorship continuum of care.

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Keywords Survivorship care plans · Experiences · Long-term · Qualitative research

Introduction

The proportion of people surviving cancer is increasing in many parts of the world due, in part, to early diagnosis, increased rates of detection and significant improvements in treatment [1–3]. However, many cancer survivors experience a range of ongoing difficulties related to the disease itself and the treatments used. These difficulties continue to impact upon survivors during, immediately after and, for some individuals, many years after completion of their treatment [4–6]. Well-recognised physical problems include chronic pain, weight gain, osteoporosis, premature menopause and memory and sleep disturbances. Additional consequences of cancer and cancer treatments can contribute to further difficulties including a range of chronic health conditions including heart disease and diabetes [7]. Psychological difficulties including depression and anxiety may also be experienced, and these may be associated with ongoing symptoms of fatigue, sexual dysfunction, fear of recurrence and changes to relationships [8, 9]. A recent Australian study identified that long-term survivors of cancer reported increased levels of vulnerability, loneliness and anxiety about their health and the possibility of the cancer returning [10]. It is evident that many cancer survivors experience significant ongoing problems with resuming their usual roles and relationships as well as returning to their previous routines and habits.

There are many less-recognised and sparsely publicised issues for survivors following cessation of treatment including social difficulties, maladjustment to work responsibilities, intimacy problems, organisational difficulties and cognitive processing issues [11–13]. The literature also identifies a range of existential problems affecting cancer survivors including challenges pertaining to self-identity and personal expectations [14]. Globally, survivors are increasingly seeking a wider range of supports and services during the post-treatment period to assist them with the breadth of physical and psychological difficulties experienced in the longer term [13, 15, 16]. In most developed countries, a range of strategies are currently available to assist cancer survivors with these ongoing difficulties, including access to health services, support groups, online forums and educational tools. However, it appears that there is a lack of recognition of this period with referral and coordination for follow-up care needed during cancer survivorship [6].

The Survivorship care plan (SCP) is postulated as a potential resource to improve survivorship care. The SCP is recognised as an important tool that may be used during the survivorship period and one which is attracting further research in the international context because of its potential to assist survivors to direct and navigate their own ongoing care [8, 10, 13, 17–19].

Use of survivorship care plans across the world

Researchers in the United States of America (USA), Canada and the United Kingdom (UK) have made significant contributions to the study of the survivorship phenomenon [4]. In 2005, the Institute of Medicine (IOM) (USA) published its report 'From cancer patient to cancer survivor: lost in transition' [8]. This report outlined key recommendations to assist cancer survivors in the longer term including the use of SCPs. The SCP usually includes a summary of diagnosis and treatment, methods of surveillance for the potential development of malignancies, maintenance of healthy lifestyle, legal and financial rights and identification of support services [20]. These recommendations have been widely accepted in many countries as critical to the care of survivors yet have not been fully evaluated. In a randomised control trial conducted by Grundfeld [21], it was found that there was little evidence to support the use of the SCP in practice. However, this study was limited to survivors of breast cancer and its generalisability to other types of cancer, as well as the context of care, has not been investigated [22].

Canada has had a national cancer strategy since 2007 which identifies key priorities for survivorship: the development and implementation of national standards and models of care; promotion of survivorship research, knowledge and communication plans and advocacy groups; and an emerging interest in the use of SCPs [23]. In the UK, the National Cancer Survivorship Initiative (NCSI) articulates the care of survivors using a recovery-focussed, personalised approach with explicit outcome measures to determine the effectiveness of the services provided. It recommends that all survivors are offered a treatment summary and care plan as well as appropriate education and information [4].

Australia does not have a national cancer plan or consistent model of care for cancer survivors. Models of care across the states of Australia vary and include the disease-specific model, general survivorship model, consultative clinic, multidisciplinary clinic, integrated care model and transition to primary care model [24]. This has resulted in each state providing a different framework of care, a variety of practice guidelines and a range of state-based services. According to one Australian author, Jefford et al. [4], the 'traditional' medical follow-up currently offered may not meet survivors' needs due to its focus on cancer recurrence and not on other important, but less obvious, concerns. The SCP which offers a summary of treatment, surveillance and recommendations for follow-up care is a key resource used in many other countries, however, to date, not used consistently in Australia and other countries.

There is a range of published literature that explores the use of SCPs in many different countries and contexts of care with sources of input from oncologists, primary care physicians/general practitioners and oncology nurses. More recently, systematic reviews of the quantitative literature have been conducted that consider a range of issues including survivorship models of care [25] and the effectiveness of the SCP [3]. While these studies contribute to the range and breadth of the literature, there has been very little consideration of survivors' own perspectives regarding their experiences and views about the use of the SCP [20, 26, 27]. As SCPs are used by a range of health professionals, it is essential that the preferences of survivors, as key stakeholders in the continuum of care, are explored and articulated to ensure services and supports are directed appropriately.

The aim of this systematic review is to document and review the available published qualitative literature that describes cancer survivors' experiences of using survivorship care plans.

Methods

An examination of existing published systematic reviews and protocols was undertaken to determine whether the research question was appropriate due to previously published literature on the subject. The following sources were initially reviewed: Cochrane Collaboration, Joanna Briggs Institute, Database of Abstracts of Reviews of Effects (DARE), PROSPERO and Trip. It was established that no existing systematic reviews of the research question had been registered or published to date.

Search strategy and data sources

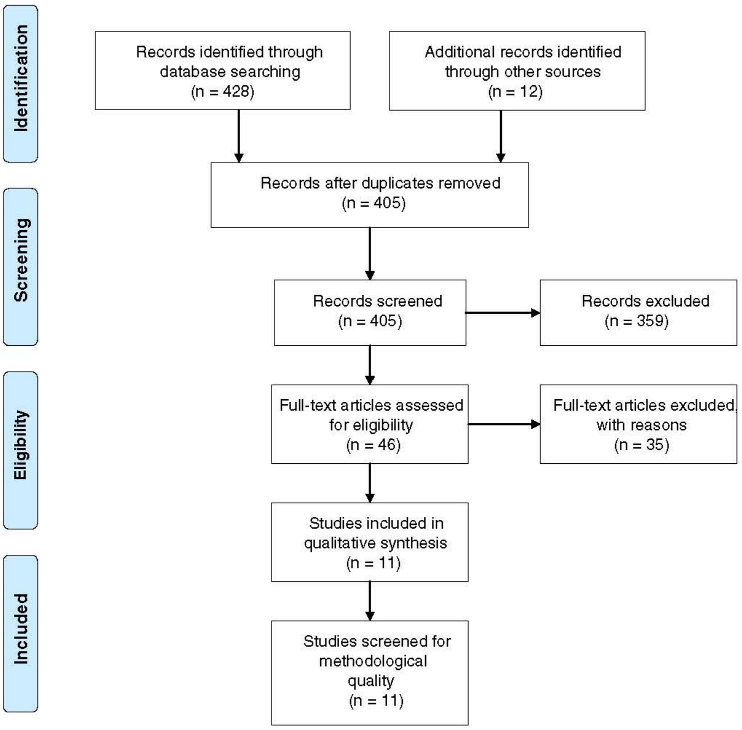
A protocol for searching was established prior to commencement of the search. Priori inclusion criteria were determined as follows: adults only (18 years and above), date range from 2000 to 2014 and published in English. Publications were excluded if they reported on the experience of cancer treatment or the palliative phase of care and were conference presentations or abstracts only. Searches of electronic databases completed were CINAHL, AMED, Embase, MEDLINE, Informit, ProQuest, PsycINFO, ScienceDirect, Wiley Online Library, Scopus and Web of Science. The *Journal of Cancer Survivorship* was also reviewed for publications that met the inclusion criteria. Permutations of the following search terms were truncated and exploded: cancer, neoplasm or malignancy survivor, experiences, opinions, ideas, views or preferences, survivorship care plan, post-treatment care, forward care, survivorship program, individualised care plan and comprehensive care plan.

The searches identified a total of 428 records using the search terms above. Hand searching of reference lists identified an additional 12 articles for review. Thirty five records were excluded as duplicates. The title and abstracts of the remaining 405 records were reviewed by the first author and 46 of these met the prior inclusion criteria for full review. The full-text articles were then reviewed independently by the first and second authors using the eligibility criteria of any of the following: qualitative studies including systematic reviews, interviews, focus groups, case studies, descriptive studies, observational and narrative studies; action research as well as the qualitative components of mixed methods studies. Additional eligibility criteria included survivors' experiences of using a SCP and analysis and discussion about the findings of the study (refer to Fig. 1 for details of data screening). In total, 11 papers were determined as eligible for critical appraisal of methodological quality.

Data analysis

Critical appraisal of methodological quality was completed using the 'Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields' by Kmet, Lee and Cook [28]. This tool uses a numeric score (0–2) to rate the quality of ten categories considered essential to the research credibility. The categories assessed

Fig. 1 Data screening flow chart



are as follows: research question or objective stated clearly, explanation of the study design, context clearly defined, connection to a theoretical framework, justification of the sampling strategy, description of data collection, clearly defined analysis of results, use of verification procedures discussed, conclusions drawn and reflexivity of authors considered. The first two listed authors independently assessed each paper using these criteria to determine a total score out of a possible 20. Where there was a difference in scores of greater than 1/20, discussion and consensus agreement was reached. The calculated scores were defined according to quality as strong (score of >80 %), good (70–80 %), adequate (50–70 %) or limited (<50 %). Studies were included if they received a quality score of 70 % and above. All of the 11 studies reviewed met the minimum requirement of 70 % on the assessment criteria. A list of each study's scores using the appraisal tool can be found in Table 1. The total number of participants included across all reviewed studies was 336 with one study not stating the number of participants.

Summary of results

The 11 studies included the use of interviews (four studies), focus groups (six studies) and action research (one study). Table 1 provides a comprehensive summary of each study including sample location, population, number of participants, gender, age range, cancer type, time since diagnosis, time since completion of treatment and marital/partnership status. A content analysis was undertaken to review and understand the breadth and depth of the themes discussed for each of the studies by each of the researchers [40]. These themes were discussed and refined and are presented as follows.

Data analysis and synthesis of results

Four significant themes were identified following content analysis of the 11 articles: (1) stakeholders agree that SCPs should be used as a key strategy for cancer survivors; (2) lack of consensus on what the SCP should contain and who should develop it; (3) cancer survivors do not consistently receive a SCP and (4) there was a lack of evidence to support the use of SCP in practice.

Stakeholders agreed that SCPs should be used as a key strategy for cancer survivors

The SCPs were identified as a key strategy during the post-treatment period for cancer survivors [29–39] by the authors of all studies. Significant points raised by researchers include the use of SCPs to reduce duplication of materials improved coordination of care and increased communication between health professionals and cancer survivors. Specific areas for improvement were that the SCP needed to be accessible and nontechnical and directed to address the cultural issues specific to particular groups of people.

A significant finding from the majority of authors [28, 30, 31, 34–37] was the recommendation that SCPs should be targeted to provide coordinated, individualised and patient-centred care. This was also the expectation of cancer survivors. There appeared to be many barriers preventing this occurring in practice due to the limitations of the time needed to complete them, the need for resources and a lack of training on how to complete them [30–32, 35, 36, 40].

The use of SCPs assisted cancer survivors to translate information from specialist providers to their primary care providers and gave direction for the future [31, 32, 34, 35, 39]. It was also noted that SCPs reduced duplication of information and helped to synthesise treatment information to provide patients with peace of mind, a written synopsis of treatment and a targeted surveillance strategy during follow-up [34, 38, 39]. Furthermore, a range of unique survivorship issues relating to cultural background were identified, and many authors stated the importance of considering these broader issues as part of the development of the SCP [29, 32, 35]. Ashing-Giwa et al. [29] and Burg et al. [32] noted the explicit concerns of African-American women survivors of breast cancer and discussed the importance of including resources to address questions regarding treatment-related skin pigment changes and the availability of genetic testing for family members. Singh Carlson et al. [38] noted concerns raised in their study regarding South Asian women living in Canada, including the significance of family relationships and importance of faith during and after the treatment period.

The use of patient-centred SCPs was thought to assist in the transition from treatment to survivorship but also needed to be used in conjunction with suitable models of care [31, 34, 37]. Many different models are used by cancer survivors including shared care, consultative care, the chronic illness model and transitional care which resulted in the use of a range of tools and strategies as well as the involvement of many health professionals. At times, the complexities of these models resulted in a breakdown in communication and coordination of care. Several authors commented that SCPs could be used as a resource to facilitate well-timed support and case coordination [32, 34, 36, 39].

Lack of consensus on what the SCP should contain, what format it should follow and who should develop it

The studies provided a range of findings regarding three important issues: what to include in the SCP, the format of the SCP and who should be responsible for developing it. Four studies indicated the essential components of the SCP should be diagnostic and treatment summaries, side effects of

Table 1 Demographic data of all studies

Author and year	Population and gender	No. of participants	Location	Age range (years)	Time since diagnosis	Time since completion of treatment	Cancer type	Type of study	SCP used	Experiences of survivorship?	Methodological quality using KMET/20
Ashing-Giwa et al. 2013 [29]	African-American women	28	USA	31–80	0–10 years	Not stated	Breast	Community-based participatory framework	Yes	Yes	16
Baravelli et al. 2009 [30]	Australian men	12	Australia	47–77	Not stated	Not stated	Bowel	Interviews and questionnaire	Yes	Yes	14
Brennan et al. 2011 [31]	Australian women	20	Australia	40–59	Range <2 to >10 years	Not stated	Breast	Interviews	Yes	Yes	17
Burg et al. 2009 [32]	African-American, Hispanic, Caucasian women	32	USA	18–65	Not stated	Not stated	Breast	Focus groups	Yes	Yes	18
Faul et al. 2012 [33]	American/not stated	7 survivors 7 oncology providers	USA	54–84	Not stated	Average 18 months	Colorectal	Interviews	Yes	Yes	15
Hewitt et al. 2007 [34]	American/men and women	36	USA	25–70	Not stated	Less than 5 years	All except skin cancer	Focus groups	Yes	Yes	14
Kantsiper et al. 2009 [35]	American women	21	USA	Not stated	Range <5 to >10 years	Not stated	Breast	Focus groups	Yes	Yes	18
Marbach et al. 2011 [36]	American men and women	40	USA	Not stated	Not stated	Not stated	Range	Focus groups	Yes	Yes	14
Parry et al. 2011 [37]	American men and women	51	USA	20–82	Not stated	3–48 months	Mostly lymphoma and leukaemia	Interviews	Yes	Yes	18
Singh- Carlson et al. 2013 [38]	Southeast Asian women	24	Canada	<44 to >65	Not stated	4–27 months	Breast	Focus groups	Yes	Yes	20
Smith et al. 2011 [39]	Canadian women	26	Canada	45–80	Not stated	3–12 months	Breast	Focus groups	Yes	Yes	16

treatment and signs and symptoms of recurrence [30, 32, 38, 39]. Two studies [34, 38] concluded that SCPs must not only consist of a generic template of key considerations but also include sections for personalised items relating specifically to the individual. These additional items included educational resources regarding lifestyle changes, nutrition, exercise and details of support organisations.

One author, Faul et al. [33], stipulated the need for SCPs to include a 'designated key provider' to assist with the transition between care environments and services. This was supported by Brennan et al. [31], who reported that the SCP could be used to improve care and coordination of key stakeholders during the survivorship period. Marbach et al. [36] indicated that an overview of late and long-term effects also needed to be included as well as referrals for health professional services.

A significant finding from ten of the 11 reviewed studies was that currently, SCPs do not identify or address the significant psychosocial needs reported by cancer survivors [29–32, 34–39]. Both Burg et al. and Kantisper et al. reported that the breast cancer survivors in their studies had specific concerns regarding the need for assistance regarding an altered body image, breast reconstruction issues and weight gain [32, 35]. Depression, fear of recurrence and difficulties with relationships, intimacy and sexual function were described by Singh-Carlson et al. [38]. A 'sense of abandonment' as survivors transitioned from the treatment phase to survivorship was also discussed by Parry et al. [37] and Burg et al. [32] who explained this period as being pivotal for the adjustment between these two periods. This period of transition was also commented on by Singh-Carlson et al. [38] who identified many uncertainties regarding returning to work as well as concerns about the future to be included and examined as key elements of the SCP. What was common to all these authors was the potential for the SCP to identify particular psychosocial concerns as well as provide resources and supports that could be used by survivors and health professionals in the longer term.

Interestingly, Baravelli et al. [30] reported that the use of the SCP may also cause some distress to some survivors particularly when information regarding the recurrence of cancer was highlighted. This is a key point of interest for all people involved in the development of the SCP and one which warrants further exploration.

Several ideas regarding the most suitable format for the SCP were raised. Singh Carlson et al. [37] stressed the need for the SCP to be written in a language suitable for the population group and presented as a written, portable document so that survivors could use it as a key resource when negotiating new services or engaging other health professionals. Other studies indicated the need for a 'living' document available in electronic format [33, 35] which could be modified and readily available to all stakeholders.

There were varied views regarding who was most suited to develop the SCP. The primary care physician (PCP) or general practitioner (GP) was identified as suitable [29, 32, 34, 39], as were the oncology or specialist provider [33] and oncology nurse [36]. Other studies did not reach a clear consensus about who should take primary responsibility for this [30, 31, 38]. Only three studies stressed the need for survivors themselves to be included in the development of their own SCP [29, 36, 37].

Many studies identified a range of barriers associated with incorporating the SCP into their current model of practice including a lack of training available to assist health professionals to prepare these [31, 32, 34, 35] and the time required to develop and prepare SCPs [29, 32–34, 38]. Also noted by Faul et al. [33] and Hewitt et al. [34] was the uncertainty regarding responsibility for the cost of developing SCPs with many models of care not providing financial assistance for these additional resources.

Cancer survivors do not consistently receive the SCP

There was a wide range of findings regarding availability and access to SCPs. Ashing-Giwa et al. [29] reported that only one of the 25 participants in their study had received a SCP. Other authors [34, 36] reported that 'few to some' had accessed the resource. Only one of all the reviewed studies [33] indicated a consistent provision of the SCP as part of the cancer survivorship period. Baravelli et al. [30] indicated that only one quarter of cancer survivors in their study received a written statement of any type regarding diagnosis. Ten percent had received a treatment summary and 15 % had received copies of diagnostic tests. While this information was recognised as important components of SCPs, it was also acknowledged that there was very little information provided regarding what to expect in the future such as long-term effects of treatment, potential psychosocial concerns and resources for ongoing problems. Four studies [31, 32, 37, 38] reported that this issue may be related to the varying models of practice, inconsistencies around the coordination of survivorship care and a lack of consensus regarding the most appropriate time to provide the SCP to survivors.

Lack of evidence to support the use of SCP in practice

Adding to the potential reasons for why SCPs are not used routinely is the lack of clear evidence to support the use of the SCP in clinical practice. Recommendations were made by all authors regarding the need to conduct both qualitative and quantitative studies regarding the efficacy and application of SCPs in the future. Of considerable interest was the essential research needed to determine the opinions and preferences of cancer survivors themselves contributing to the research dialogue concerning SCPs [30, 34]. Two studies [33, 37] indicated a dearth of research regarding whether SCPs resulted in improved care and outcomes for cancer survivors. Additional statements by two authors [29, 32] stated that prospective longitudinal studies were vital for determining the long-term benefits and any added value of using SCPs as part of the overall care of cancer survivors.

Further recommendations were made to suggest that both qualitative and quantitative studies were needed to support if and how the SCP could be integrated into standard oncology care [33] and the health professionals best suited to provide them [31, 35, 38]. Parry et al. [37] argued that research was needed to evaluate each component of the SCP to substantiate their use across the various contexts of use.

Discussion

This systematic review considered the range of data collected by the authors of 11 studies, all contributing to the qualitative evidence regarding the research question. According to the Institute of Medicine [8], the purpose of a SCP is to include a summary of cancer diagnosis and treatment, information regarding likely consequences of treatment and follow-up health information. It should also document information regarding health insurance, employment issues and psychosocial support. While the use of SCPs has varied amongst countries including the USA, Canada, UK and Australia, the availability and consistency of use is also not constant across the various contexts of care. According to the studies reviewed, there are a number of barriers and enablers influencing their acceptability and integration into the various models of care.

A key concern is that the survivorship period requires improved recognition as an integral period of the cancer journey. The reviewed studies support other literature regarding an emerging awareness and recognition of survivorship as a distinct part of the cancer journey [13, 41, 42]. It is apparent that health policies and the models of care that support cancer survivors also require attention so as to consider the many variables impacting this group of consumers [16, 24]. A consistent approach to the delivery of supportive services to cancer survivors, including the use of SCPs, is essential and must be prioritised for the future [6, 26, 32, 37].

According to the IOM [8], SCPs have the potential to empower and inform survivors about diagnosis and treatment, monitoring required and follow-up care available as well as act as a communication tool between stakeholders in order to maximise health [26]. However, greater consultation is needed between patients and the health professionals involved to ensure that the SCP is individualised and reflects the key concerns and issues for the cancer survivor. Cancer survivors are frequently not included in the development of the SCP, and therefore not targeted to the specific needs of individuals [3]. This is of particular concern as the need for consumers to be involved and 'in charge' of their health care requirements is regarded as an essential component of contemporary health practice [13, 16].

Further considerations for the development of SCPs might require adoption of a generic template with options for people with specific types of cancer and particular population groups. As noted by several authors, a much greater consideration of the psychosocial concerns experienced by cancer survivors is needed and included for discussion [9, 41, 43]. Some specific concerns include sexuality, intimacy, mood and adjustment to previous roles and relationships [6, 44, 45]. Additional educational information for financial, social, health and spiritual supports may also be required [8, 18, 46].

Agreement on many of the practical issues regarding use of the SCP is yet to be reached. Who is responsible for developing the SCP, what it should include and how it should be developed are still unclear. Some potential reasons for this may include time constraints, the cost of preparing the SCP and a lack of rigid evaluation regarding the efficacy of these [16, 18, 47, 48]. Also noted is the requirement to meet the needs of specific population groups, e.g. African-American, Southeast Asian and others with unique needs to address issues relevant to these cancer survivors.

Finally, there has been a growing effort by researchers to explore the effectiveness of SCPs for cancer survivors. In a recent systematic review conducted by Martin et al. [3], it concluded that while limited evidence existed regarding the effectiveness of SCP for a group of breast cancer survivors, the SCP did assist with the assessment and symptom management of survivors in the longer term. In contrast, other researchers concluded that the use of SCPs could assist health professionals to determine strategies for surveillance, increase communication amongst stakeholders and transition care from a medical model to a wellness model [17, 18, 20].

Conclusion

This systematic review examined the experiences of cancer survivors using survivorship care plans and explored many of the current issues relating to their use across a range of different contexts. While the period of cancer survivorship is gaining interest amongst clinicians and researchers, it is clear that further studies are needed to explore the range of SCPs available, the practicalities related to their use and how to best ensure they meet the needs of cancer survivors in the future.

Limitations

It is recognised that there are many published studies using quantitative methodologies in the subject area of SCPs and that these may offer additional data and discussion regarding the topic. This review also targeted the use of SCPs from the perspective of survivors and therefore the experiences of other key stakeholders (treating medical professionals and providers of support services) are not articulated.

Conflict of interest Author Keesing, Author McNamara and Author Rosenwax declare that they have no conflict of interest.

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Chapter 3 Research Methods

3.1 Introduction

The findings of the systematic review (Publication One), indicated that the survivorship needs of people with cancer were not being adequately met. A comprehensive and systematic approach was needed to determine how best to investigate the needs of women survivors of breast cancer and their partners during early survivorship. The methods discussed in this chapter provide an overview of this research, conducted over four stages, utilising mixed methods to obtain qualitative and quantitative data using a modified sequential exploratory design (Creswell, Plano Clark, Gutmann, & Hanson, 2003) (Figure 3.1). This adaptation of the sequential explanatory design provides an overview of the qualitative and quantitative methods used and their timing and sequencing relative to each stage of the research. Importantly, a combination of these research methodologies was chosen to obtain the broad range of data relevant to meet each of the research objectives (Liamputtong, 2010).

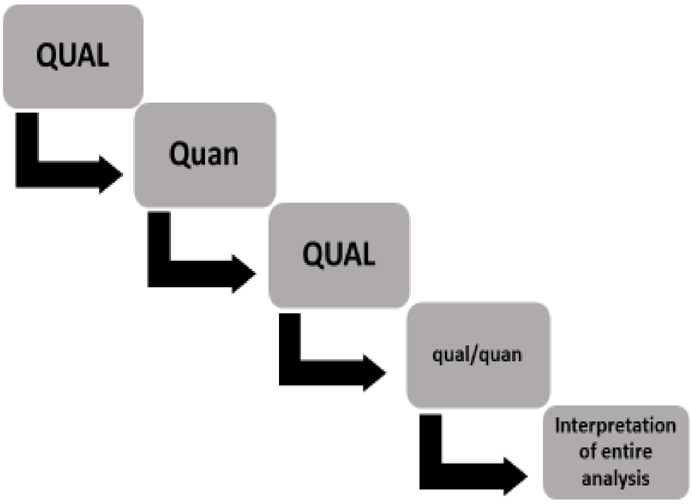

Figure 3. 1 Modified sequential exploratory design.
(Adapted from Creswell et al., 2003)

In addition, several key determinations were made as part of the research design: the value of contributions that could be made by the partners of women survivors of breast cancer; clearly defining what was meant by the 'survivorship' period; and a rationale for the age range of participants. There are few studies that explore the effects of early survivorship on the family (Lewis, 2006; Richardson et al., 2011). This is an issue worthy of exploration as rates of breast cancer survival increase and a greater recognition that family members may be significantly impacted by the diagnosis, treatment and resultant difficulties of breast cancer during the survivorship period (Schmid-Buchi, Halfens, Dassen, & van den Borne, 2011). Furthermore, the partner of a woman surviving breast cancer would be very well qualified to reflect on the continued impact of the illness due to their significant relationship with their spouse (Talley, Molix, Schlegel, & Betencourt, 2010). Importantly, extensive preparation for the study was completed by the researcher as part of the development of the study design. Networking with other researchers and health professionals with experience and knowledge of the subject matter assisted to improve understanding and to provide important background context to the study.

A definition of 'early survivorship' as previously discussed in Chapter Two was agreed to be between six months and five years since cessation of all active treatment and the person is understood to have survived the disease. The definition of survivorship is an important consideration as it was expected that as a period of time had elapsed since treatment cessation, the woman survivor of breast cancer would have attempted to return to many previous activities including self-care, leisure and employment and resume their usual roles of homemaker, parent, friend or neighbour. The age range of participants was also clearly defined to obtain rich information regarding a particular period in the woman's life. All participants were of working age and many were parents, had significant financial commitments and most had established relationships and families. It was anticipated that the issues impacting women in this demographic may be different to other women affected by cancer; e.g. young adults and older adults and consequently this research offers a unique perspective of breast cancer survivorship (Elmir, Jackson, Beale, & Schmied, 2010).

3.1.1 Rationale for mixed method design

Mixed methods research assists to answer the research aim using the combined approach of qualitative and quantitative data collection and analyses (Teddlie & Tashakkori, 2003;

Whalley Hammell, 2004). This research methodology also enables the triangulation of results from various stages of the research, contributing to trustworthiness and overall rigour of the research findings (Liamputtong & Ezzy, 1999; Taket, 2010). Conversely, early views regarding the use of mixed methods included the opinion that as the epistemological bases of the two different approaches were so different, they should not be used together (Denzin & Lincoln, 2000; Guba, 1987; Sale, Lohfeld, & Brazil, 2002). However, mixed methods may be used when limited information is available about the subject matter as was the case with this research, as little is known about the occupational experiences of women survivors of breast cancer and their partners. Understanding and explaining this type of occupational, social and related phenomena can be complex and integration of the different types of data was facilitated using a mixed methods approach (Creswell et al., 2003).

The rationale for using mixed methods is also substantiated by the overall aim and objectives of the research. The use of a qualitative method in stage one aimed to identify the occupational needs of women and their partners and these views are captured using in-depth interviews and a dyadic interviewing strategy. These methods permitted the researcher to listen to the many and varied accounts of the participants in order to develop an understanding of the themes expressed by this unique group. The participants contributing to this stage of the research discussed a range of experiences concerning their difficulties with resuming their usual activities, roles and relationships. Participants also discussed concerns regarding knowledge of, and access to various supports during survivorship.

The analysis of data obtained from the first stage yielded key findings utilised during the subsequent stages of the research. The difficulties described by participants during stage one assisted to meet the objective of the next stage of the research, whereby the perspectives of the service providers were sought. This stage required the use of quantitative methods as the number and type of services available were estimated to be many and varied. The use of an online questionnaire was also thought to benefit providers due to its ease of access, the minimum amount of time required to complete and the opportunity for the researcher to reach a large number of providers. This questionnaire was developed to scope the practices of a large group of West Australian services and designed to represent the types of supportive cancer care available in the local context. The findings

of the questionnaire provided univariate data reflective of the range and type of supports available to women and their partners living in Western Australia.
A qualitative approach was utilised in stage three to explore the impact of the activity and role restrictions of women survivors and their partners. The use of focus groups assisted participants to explore the range of information available and to share and discuss individual and couples' perspectives of their breast cancer survivorship experiences. Findings from the first two stages of the research were presented for discussion, providing background themes and information concerning the types of supportive services available in Western Australia. Each group explored their collective ideas regarding the barriers and enablers impacting the use of survivorship support services. Focus group participants also made suggestions regarding future service delivery and recommendations to assist others to be informed of, and access to much needed supports. These recommendations included the use of formal rehabilitation with an increased focus on biopsychosocial needs, inclusion of partners during survivorship, the use of a survivorship care plan and improved access to a range of multi-disciplinary health care providers, including occupational therapy.

As identified by the use of extensive triangulation of the research findings across stages one two and three, stage four aimed to determine the capacity for occupational therapists to contribute towards meeting the needs of women survivors and their partners. The use of the Delphi approach, a mixed method strategy, assisted to reach consensus for the range of questions presented, indicating the potential for occupational therapy to contribute to meeting the needs of this population.

3.1.2 Qualitative methods

Qualitative research methods were used during stages one, three and four to conduct interviews, focus groups and selected phases of the Delphi survey. These strategies of data collection assisted with the process of obtaining, interpreting and reporting on large quantities of verbal and written dialogue relating to participants' views and opinions concerning the research questions for the corresponding stage of the research (Denzin & Lincoln, 2000; Liamputtong, 2010; Sandelowski, 2000). Qualitative methods enabled a unique insight into the lived experiences of women survivors of breast cancer and their partners. This approach provided an opportunity to listen to women and partners' individual stories of their day to day lives as well as observe their interaction together as a couple (Carpenter, 2004).

3.1.3 Quantitative methods

A quantitative approach was used to direct the research in stage two, as part of a cross-sectional questionnaire sent to service providers, and for rounds two and three in the Delphi survey (stage four). Numerical data were collected and analysed using descriptive statistical analysis. This method facilitated an in-depth understanding of the collective characteristics of the data, further contributing to the development of evidence relating to the research aim (Schofield & Knauss, 2010).

3.1.4 Theoretical perspective: Phenomenology

Phenomenology was chosen as the overarching framework for the qualitative components of the research. This approach enables researchers to understand, document and make sense of the 'lived experience' as described by the participants (Schwant, 2007). First documented by Edmund Husserl in the early twentieth century, phenomenology offers a sound philosophical basis for the various stages and methods of data collection and analysis used in this research (Carpenter, 2013). Central to this tenet is the concept of applying 'meaning' to the subject under investigation; what are the subjective experiences of the individual, and how do these experiences impact their perception of the world and their role within it? (Liamputtong & Serry, 2013).

The overall aim of the research was to explore and understand the occupational experiences of women and their partners during early survivorship following cessation of treatment for breast cancer. Questions asked of participants in stages one and three were exploratory; what were their thoughts and feelings when treatment finished? What activities and roles did they engage in? What was their daily routine? Did the breast cancer experience change anything about their relationship with their partner during this period? Use of these broad questions facilitated rich, extended responses giving a unique insight into the individual's own personal reality of what the breast cancer experience meant for them and how the experience impacted their spouse.

Several key concepts must be observed during the preparation, data collection and analysis of information using phenomenological enquiry including phenomenological reduction and bracketing. Reduction aims to reduce large quantities of information (collected from participants) to manageable 'concepts' which are then used to explain the phenomena.

Using an inductive strategy, responses collected from interview and focus group participants were reduced and analysed using the six-step thematic analysis process described by Braun and Clarke (2006). This strategy facilitated the understanding, formulation and categorisation of responses from all participants into codes which were then developed and confirmed as ‘themes’ (Fereday & Muir-Cochrane, 2006). Data saturation was achieved when no new themes were identified as part of stages one, three and four, following analysis of the interview and focus group transcripts as well as a review of the questions included in the Delphi survey (Liamputtong, 2010).

The use of bracketing is a technique used by researchers to ensure that their own personal beliefs and values do not influence the interpretation of the participant’s stories (Clandinin & Connelly, 1998; Gearing, 2008). Bracketing was used extensively throughout all stages of the research to ensure that the responses from participants were representative of their own thoughts and feelings of having experienced breast cancer and not influenced by the researcher’s opinions, personal experience or preconceptions about breast cancer. As a researcher, it was essential to remain objective in order to gather information and use prompting questions throughout the stages of the study. As a health professional, with some experience of the health service delivery system, it was important that suggestions or solutions were not offered during contact with participants. This required a conscious effort to remain open to responses and not provide an opinion or react in any way that could be assumed as bias. When analysing both quantitative and qualitative data, the steps of the analysis process were documented and rigorously followed, discussed with research supervisors and reported systematically as part of an audit trail (Ritchie, 2001).

3.2 Stages of the research

The research aimed to meet four objectives over four stages, relating to the occupational experiences of women and their partners during the early survivorship period. It is important to note that although a single objective is linked to each stage, there is some crossover over of information. Objectives one and three aimed to explore the experiences of women and their partners as they undertook daily activities and roles as well as identify unmet occupational needs and services utilised during this period. Objective three also offered further opportunity for women and their partners to provide their opinions about strategies to improve services and support during this period.

3.2.1 Stage one

To identify the met and unmet occupational needs of women and their partners during the early survivorship period.

3.2.1.1 Study design

In order to meet this objective, a qualitative strategy was utilised consisting of in-depth interviews (between 45-90 minutes) with women survivors of breast cancer and where possible, their partner.

3.2.1.2 Study participants

Inclusion and exclusion criteria of participant and partner

Women were eligible for inclusion if aged between 35-70 years, could speak English and completed their treatment for breast cancer (surgical removal of a tumour, chemotherapy and radiotherapy) within the last six months to five years, with a potentially curative prognosis. Women who were undertaking adjuvant hormone therapy or yet to complete surgical breast reconstruction were also eligible for inclusion. A 'partner' was recognised as a person with an ongoing and significant relationship with the woman survivor, including married and defacto couples. Although not deliberately excluded, no same-sex couples volunteered to participate. Women who were currently engaged in active treatment (e.g. surgery, chemotherapy, radiotherapy) or were receiving palliative care were excluded.

3.2.1.3 Sampling and recruitment methods

Purposive sampling was used to identify women survivors of breast cancer and their partners living in Western Australia. While recruitment was targeted at women with partners (married or defacto), women without partners were also included. While recruitment was aimed at women living in both metropolitan and rural communities, only women from metropolitan locations volunteered to participate. A purposive recruitment strategy enabled both women and partners who were interested in contributing to the study to provide their individual and shared experiences (as a couple) of survivorship. Recruitment strategies included flyers distributed to Breast Cancer Network Australia (BCNA), an interview with a community radio station and information posted to a University intranet page (Appendix A). Contact was also made with existing support agencies including the Cancer Support Association, Cancer Voices and the Cancer Council of Western Australia using direct email and telephone contacts. Advertisements (Appendix B) were also placed in the community newspaper in an attempt to recruit participants who may not currently utilise existing services.

According to the Australian Institute of Health and Welfare, during 2014, there were 1,737 women diagnosed with breast cancer in Western Australia, which provides some background regarding the total number of women who may have been eligible to contribute to this stage of the study (Australian Institute of Health and Welfare, 2017). However it is not possible to estimate the total number of women meeting the study inclusion criteria, being aged between 35-70 years, English speaking, with a potentially curative diagnosis and diagnosed up to five years previously.

3.2.1.4 Instrument development

An interview guide (Appendix C) was developed following an extensive review of the literature and piloted with a non-participant consumer. Questions were asked of the women participants about their daily occupational experiences following the cessation of treatment. Where possible, partners were then interviewed immediately after their spouse and asked similar questions. When scheduling permitted, couples were interviewed together.

3.2.1.5 Procedure

Participants were interviewed in mutually agreed private locations, including the family home, where interruptions were minimal. Demographic data were collected at the commencement of the interviews and the interview guide was used to facilitate responses. A focus on the participants ‘day to day’ experiences included how they managed any symptoms, participation in their usual activities and responsibilities as well as their relationship with their partner. Additional topics were explored regarding their current roles including parent, worker, friend and neighbour as well as the range and type of services and supports utilised.

Partners were asked about their reflections on the breast cancer experience, specifically, any difficulties they experienced, how they supported their spouse, resources used and ability to manage their own activities and commitments during this period. The range of questions included their perspective on the personal impact for themselves, the relationship with their spouse and the barriers and enablers that presented during the survivorship period. Each interview was audio-recorded and transcribed.

3.2.1.6 Data Analysis

Information from the interviews was analysed using thematic analysis, as described by Braun and Clark (2006). This approach utilised six stages to understand, formulate, reduce and organise the meanings of descriptive content, describe the phenomenon and its fundamental structure and confirm themes. All transcripts were read line by line, with comments noted regarding initial content, followed by a description of each idea or event. These ideas were further classified into ‘codes’ and refined following review with research supervisors. Codes were grouped together and labelled with preliminary ‘themes’ which were modified and finalised following discussion during review meetings. Final themes were then labelled. Findings obtained during this stage assisted towards the development of the questionnaire used in stage two.

3.2.2 Stage two

The aim of this stage was to identify and describe the range and type of current services available to women survivors of breast cancer and their partners, from the perspective of the support organisations providing these services.

3.2.2.1 Study design

A quantitative strategy was utilised in this stage in order to develop a cross-sectional questionnaire that was presented, using an electronic format, to providers of cancer support services in Western Australia.

3.2.2.2 Study participants

Inclusion and exclusion criteria

Service providers who provided support for women survivors of breast cancer were approached using email to clarify the type of supports and services offered. It was recognised that many services provided assistance for women diagnosed with breast cancer during treatment as well as survivorship. Providers of services only during the ‘active treatment’ period of the cancer diagnosis e.g., surgery, chemotherapy and radiation oncology were excluded.

3.2.2.3 Sampling and recruitment methods

Purposive sampling using a pre-determined search strategy was utilised to target the range of organisations and individuals that provided support services to women survivors of breast cancer living in Western Australia (WA). Despite efforts to recruit services based across metropolitan and rural locations, only metropolitan services volunteered to participate. A review of various online directories including Cancer Services Directory (Australian Government, 2017), Cancer Council of Western Australia (WA), BCNA, WA Cancer and Palliative Care Network identified multiple agencies thought to provide services. In addition, the West Australian Survivorship Collaboration (a local community of practice organisations) was contacted to determine other organisations and individuals offering supportive services. These providers included organisations and individuals specialising in breast cancer care, eg; breast cancer clinics in public and private hospitals, oncologists and surgeons specialising in breast cancer, breast cancer nurses and allied health professionals, relevant non-government organisations (NGOs), health and wellness clinics and cancer support agencies.

3.2.2.4 Instrument development

The cross-sectional questionnaire was developed following a review of the literature and the detailed findings obtained from stage one, where the range of issues reported by women and their partners required during the survivorship period were determined. Using Qualtrics (2013) as the questionnaire platform, 20 closed and two open-ended questions were formulated. Services were asked to nominate a suitable health professional to complete the questionnaire. Development of the questionnaire considered the length of time to complete and readability to ensure that data obtained answered the research questions (Portney & Watkins, 2009b). Questions included the type and scope of the service/resource provided, the format of delivery, cost, target audience, staffing, use of SCPs, the evidence utilised to develop the service/resource and the (perceived) value of the service/resource (Appendix D). Respondents were also asked if they had completed any formal evaluations or determined the recipients’ satisfaction with the service/resource.

3.2.2.5 Procedure

The questionnaire was emailed to the list of service providers, together with a Participant Information Form (Appendix E), outlining instructions for completion and a proposed submission date of two weeks. If questionnaires were not returned within this time period, a follow-up email/phone call was completed as a reminder. De-identified responses were recorded in Qualtrics and presented as tables, together with open-ended responses.

3.2.2.6 Data analysis

Univariate statistical analysis was utilised to provide an overview of the current services available, including the type and frequency of these services and service provider's responses regarding the needs of women survivors of breast cancer. Content analysis was also used to interpret the qualitative responses of service providers (Liamputtong & Serry, 2013).This approach was chosen as the most appropriate, as qualitative information was sought from two-open ended questions, regarding suggestions for additional services and how existing services could be improved. Content analysis utilises a systematic approach to organise the data according to the pre-determined categories, which in this case, were the two open-ended questions asked of respondents. Using each question as the initial topic, ideas were grouped together to form key themes. Data obtained in stages one and two were used to assist with the development of stage three research aims.

3.2.3 Stage three

The aim of this stage consisted of two parts. The first part was to explore the activity limitations and role restrictions of women, their partners and couples during the early survivorship period. The second part was to recommend a suitable framework to assist women and their partners to resume valued activities and roles during early survivorship.

3.2.3.1 Study design

During stage three, focus groups were conducted to address the stated aim, with women survivors of breast cancer and their partners invited to participate in two consecutive sessions of approximately two hours each.

3.2.3.2 Study participants

Inclusion and exclusion criteria

Women were eligible to participate if they were aged between 35-70 years, spoke English and had completed their treatment between six months and five years previously (excluding adjuvant hormone therapy). Partners were eligible to participate during the first contact with their spouse via email or telephone, were either in a married or defacto relationship and spoke English. Although not deliberately excluded, no same-sex couples volunteered to participate. Women who had not completed treatment or were receiving palliative care were excluded.

3.2.3.3 Sampling and recruitment methods

Purposive sampling was used to identify women survivors of breast cancer and their partners living in metropolitan locations in Perth, WA. Contact was made with all previous participants from stage one as well as known support services including the Cancer Council of WA, BCNA and an interview with a community radio station (Curtin FM). Advertisements were placed in these organisations' newsletters as well as the local community newspaper (Appendix F). Of the group of women and partners who participated in stage one interviews, ten individuals agreed to join this stage of the study. While the cohort of participants were the same as stage one, the aim and method of this stage was different. Stage one aimed to identify the met and unmet occupational needs of women and their partners using in-depth interviews. Stage three consisted of two parts conducted during two focus groups; to explore the activity and role limitations of these unmet needs and to recommend a suitable framework to assist these individuals during survivorship.

3.2.3.4 Development of focus group questions

Findings from the two previous stages of the research were reviewed by the researcher and study supervisors. The key themes representing the opinions of women and their partners obtained during stage one as well as the results of the stage two questionnaire were triangulated and used to prepare questions that were directed to the group participants. Demographic data were obtained from individual participants using email and telephone contact. Questions posed to participants during focus groups were as follows: what are the daily occupational experiences of women and their partners during early survivorship? What are the activity and role limitations experienced? What are the individual and couples' shared needs? What are the key services and supports required and used, and, what are the group's overall recommendations concerning any additional care required during survivorship? Refer to Appendix G to view the PowerPoint slides and questions used during the focus groups.

3.2.3.5 Procedure

Focus groups are used extensively in qualitative research to elicit responses from individuals who have a similar concern or interest, to facilitate a collective view on a particular topic (Davison, Halcomb, & Gholizadeh, 2013). With this purpose in mind, two focus groups (approximately two hours each) were conducted at Curtin University and these provided opportunity for participants to explore issues relating to breast cancer survivorship as well as discuss and verify the findings of previous stages of the research. Focus groups were facilitated by the researcher, with research supervisors being co-facilitators.

3.2.3.6 Data analysis

Thematic analysis was used to analyse data from the focus groups (Braun & Clarke, 2006). At this stage of the research, three sets of data were available for analysis, providing an opportunity for extensive triangulation (Erzberger & Kelle, 2003). Triangulation allowed the researcher to demonstrate validity and reliability of the research conclusions and therefore contributing to the overall rigour of the research findings (Portney & Watkins, 2009a). Overall findings of the study at this stage indicated further gaps in the knowledge concerning the unmet activity and participation needs of women and partners during early survivorship, supporting the research aim of stage four.

3.2.4 Stage four

The final stage of the research aimed to explore the views of Australian occupational therapists regarding the enablers and barriers impacting the provision of occupational therapy services for women survivors of breast cancer and their partners during early survivorship.

3.2.4.1 Study design

A three-round classical Delphi survey was developed during this stage, using both qualitative and quantitative methods. In round one, open-ended questions (Appendix H) were directed to develop broad statements and opinions about each topic, with subsequent rounds using a combination of both qualitative and quantitative methods to achieve increasing consensus on each statement.

3.2.4.2 Study participants

Inclusion and exclusion criteria

Participants were included if they had a minimum of one year's experience (within the previous five years) as an occupational therapist working with individuals diagnosed with cancer and were currently registered to work as an occupational therapist in Australia.

3.2.4.3 Sampling and recruitment methods

A three-round Delphi survey was completed during stage four. Purposive and snowball sampling methods were was used to identify occupational therapists who were recruited based on their knowledge and experience of working with people diagnosed with cancer and were willing to participate in a three-round internet-based survey. Existing clinical and research networks, special interest groups and the Australian Association of Occupational Therapy 'e-notices' were used to assist with recruitment of participants.

3.2.4.4 Instrument Development

The findings of all previous stages were utilised to develop the questions used in this stage. For round one, a series of demographic questions were asked initially, followed by the presentation of a fictitious 'case scenario'. Nine open-ended questions based on the case scenario formed the basis of the survey.

3.2.4.5 Procedure

Mixed method research using the Delphi technique was used in the final stage of the research. The Delphi method is a formal technique that attempts to develop information and knowledge about a subject by considering the opinions, experiences and perspectives of ‘expert’ participants. The key principles of the Delphi method include structured, repetitive consultation with anonymous participants to establish a consensus of opinion (Pandaza, 2008). This method was well suited to the concluding stage of the research as it assisted to obtain a range of views regarding the important considerations of meeting the activity and role needs of women and their partners, as well as the perceived barriers of service delivery during this period of cancer care.

The Delphi method involved the presentation of questions to all participants over three ‘rounds’ where feedback from each round was de-identified, developed and presented again to obtain opinions regarding the level of agreement for a series of statements. Themes developed from round one data were used to create a series of statements which were presented in round two and three. Participants were then required to indicate their level of agreement using a Likert scale, with the aim of each round to reach a higher level of agreement between participants (Charlton, 2004).

3.2.4.6 Data analysis

Initial review of qualitative data in round one was undertaken using thematic analysis to identify key areas warranting further exploration (Braun & Clarke, 2006). Consensus for statements in rounds two and three was pre-determined as being 70% (Keeney, Hasson, & McKenna, 2011a). Further statistical analysis including measures of central tendency and levels of dispersion was completed for quantitative data obtained in rounds two and three (Hsu & Sandford, 2010). A final summary outlining the findings of the survey was provided to all participants following conclusion of the third round.

3.3 Trustworthiness

Methodological rigour was achieved by engaging in a range of strategies throughout the four stages of the research. For qualitative research, the essential elements of trustworthiness include credibility, transferability, dependability and confirmability (Johnson & Turner, 2003). Member checking is a strategy used to ensure credibility, where the researchers’ interpretation of the data reflects what was stated by the participants (Sandelowski, 1986). Transcripts of interviews and focus groups were sent to all participants in rounds one and three, with minor adjustments completed. Results of the previous two stages of the research were presented during stage three (focus groups), further validating the authenticity of findings.

Themes developed from stage three focus groups were ratified by both the researcher and supervisor who were in attendance during each of the sessions. Member checking was also inherent in the use of the Delphi design, as participants were provided with the results of each ‘round’ to verify as accurate and credible (Cresswell & Miller, 2000). Credibility was also achieved in the Delphi survey as the first round data was generated from participant’s opinions as opposed to pre-determined ‘themes’ from the literature, which is often used for this method (Hasson & Keeney, 2011). Triangulation of data from all stages of the study also contributed to the credibility of findings (Denzin, 1998).

Transferability refers to the degree that the research findings may be generalised to other contexts or settings (Koch, 1994). To determine this, rigorous description of the research process, information regarding all participants and the context of the study has been undertaken to facilitate an understanding of whether the findings are transferable. As three stages (stages one, two and three) of the study were completed in the Perth metropolitan context, care should be exercised regarding the applicability of findings to rural Western Australia and other Australian states. No attempt has been made to compare the findings to other locations due to the potential variability of resources and services available during the survivorship period. The focus on one Australian state and context created depth rather than a broad-based approach to the data which may not have been as useful in understanding women’s responses regarding service delivery.

The findings of stage four may be considered as applicable across Australia. Data obtained during stage four from occupational therapy participants across all Australian states focused on information pertaining to the profession’s philosophy and processes, barriers to service delivery and the potential role of occupational therapy in assisting to meet women and their partner’s needs during survivorship.

Strategies for dependability were achieved with the use of impeccable documentation and an audit trail, clearly describing decisions and actions taken throughout the study design, implementation and analysis. A journal containing memos and notes was kept and used to ensure the research followed a pre-determined structure and also used to assist in the writing of academic publications and the thesis (Lincoln & Guba, 1985).

Confirmability is an essential consideration of qualitative research as it ensures that rigorous methods of interpretation are used during data analysis, in order to reduce the risk of bias (Tobin & Begley, 2004). Examples used in the study included regular discussion with research supervisors regarding the development of the research aim and objectives, recruitment strategies, interview questions, analysis of data and development of themes.

A variety of strategies were implemented to improve methodological rigour for the stages of the research using quantitative methods. In stage two, a pilot questionnaire was completed by several health professionals working in the local practice context with appropriate modifications as recommended, to improve comprehension and reduce the length of time required to complete. As the questionnaire was developed to collect information regarding local service provision and specific to this context, it was not appropriate to use an alternate instrument (Heale & Twycross, 2015). For the Delphi survey, validity was achieved with the use of group responses as opposed to a single individual, with the participants recruited on the basis of their knowledge and experience. Each survey was completed independently and without the influence of others (to avoid group bias), with sound response rates between each round, further contributing to the reliability of the data (Keeney, Hasson, & McKenna, 2011b).

3.4 Ethical considerations

Ethics approval was obtained from the Curtin University Human Research Ethics Committee (CUHREC) (approval number HR 51/2014- Appendix I) on 8 April 2014. The submission considered the relevant chapters of the National Statement of on Ethical Conduct in Human Research (National Health and Medical Research Council, 2013), with particular reference to Section Two - Risks, Benefits and Consent and Chapter 3.1 - Qualitative Methods.

3.4.1 Informed consent

Informed signed consent was obtained from all participants in stages one and three using a Participant Consent Form (Appendix J). For stages two and four surveys, respondents were required to indicate ‘Yes’ to the survey question labelled as ‘Consent’.

3.4.2 Participant information

Details of stages one, three and four of the study were provided to all participants at the time of recruitment and prior to participation, in the form of a ‘Participant Information Form’ (Appendix K). The following information was included: introduction to the purpose of the study and the researcher’s contact details, supervisors and ethical approval, purpose of the study and participant involvement, confidentiality, benefits, discomfort and risk, voluntary participation and ability to withdraw from the study at any time, and that interview and focus group dialogue would be audio-recorded and transcribed.

3.4.3 Privacy and confidentiality

A written guarantee of privacy, confidentiality and anonymity was provided to all participants and survey respondents. Participants were de-identified using a numerical code or pseudonym. Details of each participant were known only to the researcher and these details were stored securely on a password-protected computer file. Transcripts and other data collected were stored either electronically or locked in a secure office on the University campus.

3.4.4 Risks, benefits and expected challenges

Consideration was given to the planning and organisation of all data collection to minimise any disruption to individuals’ personal and work routines. Adequate time was provided to ensure that the surveys completed during stages two and four were completed within the demands of the participants’ work schedules. It was anticipated that some of the questions asked during the interviews (stage one) and focus groups (stage three) would evoke emotional responses. The researcher has approximately 30 years of experience as an occupational therapist, highly developed interview skills and the expertise to manage these responses. In the case of an unexpected event, information was provided indicating that a referral to a suitably qualified health professional could be arranged to assist with the management of any issues. The Cancer Council of WA telephone helpline employs qualified counsellors who were available in the event of further assistance being required. No adverse events were reported during the research. While there were no direct benefits to participants as a result of this research; it was expected that non-direct outcomes would include modifications regarding the delivery of future services for women survivors of breast cancer and their partners. Small tokens of appreciation ($20 gift vouchers) were provided to focus group participants and follow up ‘thank you’ emails were sent to participants over all stages of the research.

3.5 Limitations

Several limitations were recognised within the various stages as follows;

3.5 1 Stage one

The use of dyadic interviews may have created a situation where either participant was reluctant to disclose information about their spouse or offered potentially conflicting information, creating feelings of discomfort. Also noted is the possibility that some information was withheld in an effort to ‘protect’ each other from potentially distressing comments. This is a well-documented limitation of dyadic interviewing (Eisikovits & Koren, 2010). However, when the findings of couples interviewed together and couples interviewed separately were analysed, there were no differences in the information gathered. Although participants were asked to comment on their use of supportive services and resources, they were not asked for their recommendations regarding improvements or modifications to these services and this was recognised as a potential question to be considered during stage three (focus groups).

3.5.2 Stage two

A comprehensive list of organisations and service providers was developed from existing cancer services and directories as well as known survivorship care services, however it is possible that not all services were approached to participate in this stage of the study. A total of 56 agencies were approached to complete the questionnaire, including metropolitan and rural agencies, with 34 completed questionnaires returned. The number of respondents for this stage was 61%, and therefore it may be probable that not all service providers returned completed questionnaires, limiting the generalisability of findings. Many of the organisations contacted may have offered services in both metropolitan and rural locations, however the questionnaire did not differentiate between locations and this is recognised as an important limitation. As rural service providers did not contribute to this stage of the research, it is not possible to determine the unique issues relevant for these services and consumers, and this is worthy of further focussed research. The limited sample size also prevented further analysis using multivariate methods and therefore data analysis was limited to univariate methods.

3.5.3 Stage three

Several limitations were identified relating to the use of focus groups. Of the couples who agreed to participate, all had completed interviews previously and two participants were known to each other as they currently worked together. Although extensive recruitment strategies were undertaken during this stage, a total of ten individuals were recruited. All women had participated in interviews previously, however the topics discussed in the focus groups were not a repeat of the interviews. The focus groups targeted the topic of survivorship care and participants ideas about what needed to improve in order to assist them. All participants shared similar demographic backgrounds including age, education and all were employed.

Of the ten individuals who attended the focus groups, all were married with the exception of one recently separated woman, limiting the generalisability of findings to single or divorced women. All participants were recruited from a large city, where they may have been able to access supportive services if required. Another limitation relating to the use of focus groups is related to privacy and confidentiality, it was likely that many individuals did not wish to disclose personal and intimate information in a group setting. Use of the researcher as moderator ensured that all participants were provided with an opportunity to contribute to the sessions; however, it is worth noting that in a large group discussion, it may not be possible to capture the in-depth views of every individual. However, a structured plan was developed prior to each focus group with various opportunities to capture the depth and breadth of participants’ opinions.

3.5.4 Stage four

Use of the Delphi method has some recognised limitations, importantly, that the literature does not provide an acceptable definition of what constitutes ‘consensus’ (Diamond et al., 2014). The agreed consensus was determined to be 70%, which is considered to be an acceptable level of agreement according to other health-related publications utilising this method (Aguilar, Stupans, Scutter, & King, 2013; de Villiers, de Villiers, & Kent, 2005; World Federation of Occupational Therapists et al., 2017). Recruitment of participants was directed towards occupational therapists with experience in oncology, with all Australian states represented; however, the proportion of occupational therapists and the number and location of services in each state was varied and this is regarded as a limitation of the study. Strict inclusion and exclusion criteria determined that participants were representative of the profession with sound knowledge and experience of this area of practice, reducing selection bias. Retention of participants between each round was determined as 83% between rounds one and three.

The aim of this stage was to seek the views of occupational therapists only; however, the opinions of other stakeholders (health professionals and women survivors of cancer) were not obtained and these views are noted as worthy of future consideration. The findings of this stage may not be transferable to other service locations as the models and policies used to deliver survivorship services may not be comparable to the Australian context.

3.6 Conclusion

The preceding chapter aims to provide an overall summary of the research methods as well as explanation regarding the rationale for each stage of the thesis. Details regarding the design, participants, sampling and recruitment methods, instrument development or questions used, procedure and data analysis have also been discussed. Links between the various stages of the thesis have also been described, particularly to determine how the findings of a single stage are connected to the subsequent stage or stages of the thesis. Where required, appendices have been used to refer the reader to comprehensive information regarding interview questions, questionnaire and focus group PowerPoint slides.

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Chapter 4 Publication Two ‘A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship’

This chapter represents the findings of stage one of the research. In-depth interviews were completed with women survivors of breast cancer and their partners and addresses the first objective of the research; ‘identify the met and unmet occupational needs of women and their partners during the early survivorship period’. The publication outlines the background literature, qualitative research methods, and findings as well as a discussion of results with particular reference to the communication, relationship and role changes experienced by women and partners during breast cancer survivorship.

The findings of this publication indicate that there are limited options available to women survivors and their partners to meet their shared needs for support. Recommendations include the need for further research to develop a suitable care framework, timely assessment and appropriate interventions for these individuals. Some limitations exist for this stage of the research. Participants were recruited from urban locations, were English speaking and most were married to a heterosexual partner. The findings of this study are therefore not transferrable to women living in rural locations, those from culturally and linguistically diverse (CALD) backgrounds or single women.

The findings obtained during this stage assisted to inform the subsequent stages of the research and the development of the questionnaire used in stage two of the research.

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Keesing *et al. BMC Women's Health* (2016) 16:57
DOI 10.1186/s12905-016-0337-z

BMC Women's Health

RESEARCH ARTICLE

Open Access

A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship

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Abstract

Background: The shared impact of breast cancer for women and their male partners is emerging as an important consideration during the experience of a breast cancer diagnosis, particularly during survivorship. This study aimed to explore the experiences of women and their partners during early survivorship and contributes a range of insights into the lives of those intimately affected by breast cancer.

Methods: In-depth interviews were completed with Australian women survivors of breast cancer ($n = 8$) and their partners ($n = 8$), between six months and five years following cessation of treatment. Questions included a focus on the women and their partners' daily experiences during early survivorship, including the management of ongoing symptoms, engagement in leisure and social interests, returning to work, communicating with each other, maintenance of the current relationship and other important roles and responsibilities. Thematic analysis was employed to determine key themes arising from the dyadic accounts of women and their partners' experiences during early breast cancer survivorship.

Results: Women and their partners experienced many changes to their previous roles, responsibilities and relationships during early breast cancer survivorship. Couples also reported a range of communication, intimacy and sexuality concerns which greatly impacted their interactions with each other, adding further demands on the relationship. Three significant themes were determined: (1) a disconnection within the relationship - this was expressed as the woman survivor of breast cancer needing to prioritise her own needs, sometimes at the expense of her partner and the relationship; (2) reformulating the relationship - this reflects the strategies used by couples to negotiate changes within the relationship; and (3) support is needed to negotiate the future of the relationship - couples emphasised the need for additional support and resources to assist them in maintaining their relationship during early survivorship.

Conclusion: It can be concluded that the early survivorship period represents a crucial time for both women and their partners and there are currently limited options available to meet their shared needs and preferences for support. Findings indicate that a suitable model of care underpinned by a biopsychosocial framework, access to comprehensive assessment, timely support and the provision of targeted resources are urgently needed to assist women and their partners during this critical time.

Keywords: Qualitative, Breast cancer, Survivor, Partner, Dyads, Relationships

Abbreviations: SCP, Survivorship care plan

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Background

Breast cancer is one of the most common cancers affecting women worldwide [1]. Advances in early detection and improved treatments have resulted in almost 90 % of women in Australia achieving a five-year survival [2]. The period following cessation of treatment, 'survivorship', is increasingly being recognised as an important time in the care of women diagnosed with this disease, due, in part, to the many physical, psychological and emotional sequelae of breast cancer [3]. In addition, the usual treatment regimes offered to manage breast cancer (e.g. surgery, chemotherapy, radiotherapy, adjuvant hormone therapy or combinations of these methods) can produce significant physical, psychological and emotional consequences for women in the longer term [4, 5].

Supportive care to address the consequences of breast cancer during survivorship has historically been focussed on the range of physical problems such as pain, lymphoedema, cognitive impairment, fatigue, premature menopause, sleep disturbances and other chronic health conditions [6, 7]. Also recognised are a range of psychological issues relating to a diagnosis of breast cancer including; changes in body image and self-identity, fear of recurrence, mood disturbances and significant disruption to activities, roles and relationships [8–11]. Internationally, targeted care during survivorship is increasingly recognised as critical to successful outcomes following a diagnosis of breast cancer. However, great diversity exists regarding service delivery models, the use of clinical guidelines, needs assessment tools, treatment summaries, survivorship care plans and care co-ordination [12–15]. Recent studies have also begun to explore other approaches to care including the use of self-management strategies, use of a chronic disease management approach, and the use of patient navigators [16–18]. Research findings indicate that a more focussed approach to comprehensive survivorship care is essential, with targeted interventions developed to address the unique and individual needs of women during this time [19–22]. Some progress has been made to evaluate the benefits of these interventions with promising results [23–26].

While the priority for survivorship care has been targeted towards women who are recovering from breast cancer, there is a recognition that the partners of women may also be considerably impacted by the experience of a breast cancer diagnosis [27–30]. Commonly reported concerns of partners during survivorship include a lack of information and education about survivorship, difficulty managing the expectations they have of themselves, difficulty coping with changes in the relationship with their partner, and problems re-adjusting to their previous role and responsibilities within the family [27, 31–33]. The shared experience of breast cancer may also create ongoing psychological issues for partners long after the cessation of treatment, including emotional withdrawal, guilt, anxiety, depression, difficulty communicating feelings of loss and grief, and fears of disease recurrence [5, 34, 35]. Partners may experience the same or higher levels of psychological distress as women and these may contribute to psychiatric issues in the longer term [36–38].

Supportive care which has focussed on the partners of women affected by breast cancer is predominantly confined to the period of diagnosis, treatment and end of life care [39–41]. However, several recent studies have explored the experiences and potential needs of partners during early survivorship [32, 38, 42, 43]. Women's health and well-being can be significantly affected by their partner's responses and unmet needs in the longer term [44, 45]. The potential for communication breakdown, relationship worries and intimacy concerns between couples during survivorship is increased, hence it was found to be vital to consider the needs of both women and partners across the entire continuum of care, being diagnosis, treatment and survivorship [32, 46].

Cessation of treatment marks a milestone in the breast cancer journey yet many women report increased difficulties at this time as a result of less formal supports evident, fewer appointments with medical and health professionals, and the expectation that life will return to 'normal'. Many women and partners find that life does not return to their previous level of function or routines and they are often unprepared for resultant changes [47, 48]. For women, the expectation is that their partner will move from caregiver and support person to their usual role, routines and responsibilities experienced before the breast cancer event. The literature reports inconsistencies regarding the impact of the breast cancer experience on relationships during this time. Some studies report an exacerbation of women and their partners' existing problems relating to the expression of emotions, less open communication and changes in the usual resolution of problems, all of which may lead to increased stress and conflict [33, 49]. Partners may not respond in a helpful way due to their own distress, resulting in further communication and relationship difficulties [50, 51].

Conversely, several studies found that a diagnosis of breast cancer resulted in positive changes with couples becoming closer, perhaps from the development of sophisticated communication skills required to manage the challenges of the diagnosis and treatment [28, 52]. Our study supports recent literature which calls for further exploration of the interactions between women and their partners during diagnosis, treatment and survivorship to further understand this complex phenomenon [40, 53]. Specifically, we focus on the early survivorship period as there is a lack of strong evidence to understand the challenges experienced during this critical time. Some authors state that women and their partners should be considered as a 'dyad'- with each person bringing their own experiences and coping strategies to the partnership, but with an interdependent approach to managing their relationship during survivorship [39, 53–57]. Our study suggests that the dyadic approach provides a comprehensive and in-depth view of survivorship and aims to extend the existing knowledge of this critical period for both women and their partners.

Survivorship models of care and the Australian context

Since the publication of the Institute of Medicine's (2006) report 'From cancer patient to cancer survivor: lost in transition', there has been an increased focus on research and evaluations dedicated to the improvement of models of care and guidelines, as well as services and tools directed to survivors of cancer worldwide [58, 59]. In Australia, there continues to be considerable variation regarding the models of care offered to women survivors of breast cancer. These include specialist (oncologist) led consultations, primary care (physician or general practitioner) led services, shared care (often using a clinic-based model) directed by nurses, and patient initiated models [60–62]. The range of services offered to women is also varied according to the preferred model of care, location, public versus private health service coverage and the availability of suitably experienced health professionals.

Consistency regarding the use of essential tools including survivorship care plans (SCP's), treatment summaries and improved co-ordination of care is needed [62]. There are also limited available resources targeted towards the partners and families of women survivors of breast cancer during survivorship, with an increasing recognition that holistic models of care must consider the needs of partners and families when developing resources [63, 64]. In 2015, the Clinical Oncology Society of Australia (COSA) called for urgent attention to recognise the limitations of current survivorship practices and effect a range of improvements to survivorship care in Australia [65]. Further research must be directed towards improving the range of supports directed at partners and couples to address ongoing concerns.

Aims

The aims of the study were to: identify changes in the way couples communicate with each other during early survivorship; determine the behaviours and actions used by women and their partners in maintaining their relationship during early survivorship; and identify the needs and supports required by women and their partners during early survivorship.

Methods

The research used a dyadic interview methodology to explore and understand the experiences of couples during early survivorship of breast cancer. The use of dyadic interviews offers a range of benefits regarding the phenomena of concern [66–68]. Demonstration of both consensus and disparity between the interviewees, corroboration, improved levels of comfort and support between participants, observations regarding non-verbal behaviours, and a broader scope of the experience may all be evident using this technique [69]. The advantages of dyadic interviewing extend further to allow insight into how both individuals react and respond within the dyad, providing an alternative interpretation of the experience [70]. There are a growing number of studies utilising a dyadic approach to consider the experience of cancer for partners and spouses [39, 51, 71]. The benefits of a dyadic approach are relevant for exploring breast cancer survivorship, as during this period women and their partners usually need to negotiate and reconsider their previous relationship, routines and responsibilities. Dyadic interviewing has some potential disadvantages such as withholding of information due to the presence of an intimate partner, disagreement and interviewer bias [70]. The use of peer review, member checking and a reflexive journal were strategies used to minimise potential bias [72]. Well-developed interview techniques were also used to ensure each participant had adequate time to consider questions and acknowledge potential disagreements.

In-depth interviews of women ($n = 8$) and their partners ($n = 8$) were completed, with six couples interviewed together and the remaining two couples interviewed individually due to scheduling difficulties. All participants were asked to describe their experiences regarding diagnosis, treatment and survivorship of their (or their partner's) breast cancer with particular emphasis on the period following cessation of treatment (early survivorship) [73]. In-depth interviews allowed the researcher to 'have a conversation', listen, understand and make sense of the participant's experience of the phenomena they were describing [74, 75].

Interview questions were developed following review of the literature [76, 77]. The questions were further refined following a pilot completed with a non-participant couple. The first author commenced each interview with a series of demographic questions, including age, occupation, level of education and marital status, which assisted to build rapport with each participant. Demographic information is presented in Table 1. Open-ended questions about the women's experiences during diagnosis and treatment were completed with prompting questions to target the thoughts and feelings of the particular period in the participants'

Table 1 Demographics of women and men participants

Participant	Current age range (in years)	Education	Marital status	Parenting and number of children living at home	Partner interviewed separately	Date of diagnosis	Time since treatment completed	Treatment	Service type	Religious or cultural background
1	45–50	University Degree	Married	Yes/2	No	May 2011	3 years	Bilateral mastectomy, chemotherapy, hormone therapy, preventative hysterectomy, Breast reconstruction	Private	Nil identified
2	45–50	University Degree	Married							Nil identified
3	35–40	Year 12	Married	Yes/2	No	October 2012	1 year	Bilateral mastectomy, chemotherapy radiotherapy, hormone therapy, breast reconstruction	Private	Nil identified
4	30–35	Year 12	Married				10 months			Nil identified
5	40–45	University Degree	Married	No	Yes	April 2013	1 year 3 months	Unilateral lumpectomy, chemotherapy radiotherapy, hormone therapy	Private	Nil identified
6	45–50	University Degree	Married							Nil identified
7	45–50	Year 10	Married	Yes/1	No	May 2009	5 years	Unilateral lumpectomy, chemotherapy radiotherapy, hormone therapy	Public	Nil identified
8	45–50	Not known	Married							
9	50–55	Diploma	Married	Yes/2	Yes	August 2013	1 year	Unilateral lumpectomy, chemotherapy, radiotherapy, hormone therapy	Mix	Nil identified
10	50–55	University Degree	Married							Nil identified
11	50–55	University Degree	Married	Yes/0	No	October 2012	2 years	Unilateral lumpectomy, radiotherapy	Public	Jewish
12	50–55	Not known	Married							
13	45–50	Year 12	Married	Yes/1	No	July 2012	2 years	Bilateral lumpectomy, chemotherapy, Mastectomy, hormone therapy	Private	Nil identified
14	45–50	Year 12	Married				2 months			
15	50–55	University Degree	Married	Yes/2	No	February 2013	1 year	Unilateral lumpectomy, Chemotherapy, Unilateral mastectomy, hormone therapy	Mix	Nil identified
16	50–55	University Degree	Married				6 months			

life [78]. Further questions were asked regarding their experiences following the conclusion of treatment and the transition to survivorship (Table 2).

Focus was directed towards the daily experiences of each participant including the management of ongoing symptoms, mood, engagement in leisure, hobbies and interests, social activities, returning to work, communication with others, relationships and current roles (parent, partner, worker and friend). The questions were rephrased for the woman's partner. Each interview commenced with the woman initially and then moved to her partner; however, participants were invited to contribute at any stage of each other's interview. Each interview (between 45 and 90 min per participant) was conducted by the first author face to face, recorded and transcribed using electronic media [79]. A numeric code and pseudonym was assigned to each participant to maintain confidentiality of data.

Sampling and recruitment

Purposive methods were used to recruit eight women who identified as breast cancer survivors and their eight partners (all men); living in Perth, Western Australia [80]. Participant women were included if they met the stated inclusion criteria of age (35–70 years), had completed their treatment for breast cancer (excluding adjuvant hormone treatment) between six months and five years previously and spoke English. Purposive recruitment was identified as a strength to the study as this allowed women and their partners to offer their own unique perspectives on how the early survivorship experience affected their lives, both from the perspective of the individual as well as part of a dyad [81].

Potential women participants were excluded if they were receiving ongoing active treatment (e.g. surgery to remove a tumour, chemotherapy, radiotherapy) or palliative care. Participant women were recruited using a variety of strategies including written invitations on a network home page, community newspaper, local breast cancer network, community radio station and flyers posted on University noticeboards. Partners were invited to be interviewed if they identified as having an ongoing and significant relationship (married or defacto) with their wife/partner. They were asked to be involved in the study at the initial contact with participant women. All participants were provided with an information brochure outlining the purpose of the study, their time commitment to complete an interview on a voluntary basis, an assurance of confidentiality, benefits of the study, potential for discomfort and the opportunity to withdraw at any time.

Participants were also provided with information regarding telephone support services should they require assistance following completion of the interview, as it was acknowledged that some of the questions might have elicited negative memories regarding previous experiences. Interviews were conducted either in the participant's home, place of work, or at the first author's workplace. Written informed consent was obtained from all participants in the study. Ethical approval from the Human Research Ethics Committee of Curtin University was obtained prior to commencement of data collection (Approval number: HR 51/2014).

Table 2 Questions for women participants

1. What follow up care has been arranged for you e.g. doctor's visits, tests, medication reviews?
2. What sort of ongoing problems or symptoms are you experiencing and how do you manage these?
3. What are the long term effects of the cancer/medications/treatment?
4. Were you given a survivorship care plan- what does it contain? Do you have a copy of it? How has it been used?
5. Has your life returned to the way it was previously? If not, how have your roles and responsibilities changed since finishing your cancer treatment?
6. Have your relationships with others (partner, family members) changed since the treatment finished? How?
7. What might be some potential positives to come out of the cancer experience?
8. Have you had any problems with resuming work? If not working, how do you spend your days currently?
9. Can you describe any resources or services that you are currently using and are these successful? Do you participate in a support group- what is this/is it effective for your needs? Are you satisfied with the resources and supports you are currently using- why/why not?
10. Do you feel that your partner is experiencing any issues following the completion of treatment? What are these?
11. What would your recommendations be for other cancer survivors?
12. Do you think that having cancer has changed you as a person and in what way?
13. How have your future plans and goals changed as a result of the cancer and or treatment?

Questions for partners

1. Now that treatment has finished for your partner, what's your daily routine? How have your roles and responsibilities changed? Are you currently working? If not working, how do you currently spend your days?
2. Does your partner experience any ongoing problems or symptoms? Do these problems impact you and have you experienced any changes in your relationships with others (partner, family members) since the treatment finished?
3. Was your partner given a survivorship care plan- what does it contain? Do you have a copy of it?
4. Can you describe how the SCP has been used during this period? Was it utilised to identify any issues for you personally as well as your partner?
5. What might be some potential positives to come out of the cancer experience?
6. Has your life returned to the way it was previously, if not how has it changed?
7. Can you describe any supports that you are currently using (with or without your partner) and are these successful? Are you satisfied with the resources and supports you and your partner are currently using- why/why not?
8. Can you identify any needs that you personally feel have not been met?
9. Can you recommend any changes/improvements in services for the partners of cancer survivors?
10. Do you think that being the partner of a cancer survivor has changed you in any way? Have your future plans and goals changed as a result of the cancer and/or treatment?

Data analysis

Each transcript of the interviews was imported into NVivo © and this software was used to organise and categorise information from the participants. Thematic analysis was used to analyse the content of interviews using a six step process devised by Braun and Clark [82] and widely used in the qualitative literature. The first author read each of the transcripts line by line repeatedly to understand what was being stated by each of the respondents. The next step of the thematic analysis involved assigning a 'description' for each idea, event, reflection or phenomena discussed by the participant using an inductive approach [83]. These descriptions were then reviewed and further categorised into preliminary 'themes'. Preliminary themes were refined across the three authors, provided with a defined title and finalised. Saturation of data was determined by the authors following this process as no new or emerging themes were discovered [74].

Trustworthiness

Trustworthiness of the research was achieved using multiple methods. Peer review was utilised to discuss the development and progress of the research following interviews and during data analysis [84]. Member checking was used to confirm the authenticity of each transcript. Several participants made adjustments to the transcript following this opportunity. Memos and field notes were completed following each interview and contributed to the development of an audit trail [85].

Results

A range of demographic similarities was evident among the group of participants. The mean age of women was 47 years (ranging from 38 to 52 years) and their partners 48 years (ranging from 34 to 53 years). All couples were married. Most women had secondary schooling and/or a university degree ($n = 7$). Similarly, six of the eight male participants had completed secondary schooling and/or a university degree. All women and their partners were currently working in paid employment. The mean time since completion of treatment was two years and two months, with a range of one year to five years.

Participant women and their partners spoke openly and in-depth about their experiences and challenges during survivorship, with three distinct themes established following analysis: (1) a disconnection within the relationship - this was expressed as the woman survivor of breast cancer needing to prioritise her own needs, sometimes at the expense of her partner and the relationship; (2) reformulating the relationship - this reflects the strategies used by couples to negotiate changes within the relationship; and (3) support is needed to negotiate the future of the relationship - couples emphasised the need for additional support and resources to assist them in maintaining their relationship during early survivorship.

The findings from this study support the extensive published literature regarding the physical and cognitive challenges experienced by women survivors of breast cancer. These included: changes to body image and identity, fatigue, sleep difficulties, pain, loss of range of movement in the affected limb, as well as a variety of cognitive symptoms including short term memory loss, concentration difficulties and poor motivation [86–91]. However, the use of a dyadic interviewing strategy presented a range of further issues impacting the relationships between women and their partners during early survivorship. The themes arising from these findings offer a unique 'shared' perspective of a couple's experience during this time.

A disconnection within the relationship

The first theme identified a range of personal and relationship changes experienced between couples during early survivorship. Most women reported that the experience of surviving breast cancer resulted in a need to always think of oneself and prioritise personal needs, before anyone else's. They felt this changed the way they responded to others, especially their partner, which was often detrimental to the relationship. Describing this as a form of 'selfishness', coupled with her need for privacy, Fran (one year and three months post-treatment) describes her thoughts:

> *I just want my space, I want a good night's sleep ...it's just so important. I found that with breast cancer in one aspect it's made me more selfish. I'm looking after myself rather than looking at whether he's OK or not... I don't really care whether you're OK...I just want to take care that I'm OK.*

The period of early survivorship created a sense of disempowerment and women felt a need to regain control in the new environment of 'survivorship'. Women stated that this resulted in a need to suppress their thoughts and feelings, as a strategy for coping with lost 'control'. This might be explained as a form of 'self-protection' and resulted in an emotional disconnection with their partner and the relationship. Danielle (one year and ten months post-treatment) discusses further:

> *I was so upset I would just yell at him and it was easy to throw my hands in the air...it's not what I want to do but I'm not thinking straight, I'm not thinking like me...Our relationship has changed, it's hard to know how to respond, it takes time to become yourself again, the expectation that things should be back to normal and it's not. Learning to live afterwards is not as easy as what people presume it's going to be. And trying to know what I want... every day was different. Poor David would never really have a clue... or what mood I'd wake up in or what I wanted or what I needed because it was different from yesterday.*

Partners also reported a range of difficulties when asked about their own experiences during early survivorship. Many stated that whilst they recognised and understood the many changes affecting their spouse, they felt that all they could do was observe and try not to react negatively to the situation. Some partners managed these difficulties by disregarding their own emotional needs, with an acceptance that the experience of breast cancer was continuing to impact their relationship long after cessation of treatment. It was also recognised that this sometimes meant a withdrawal from each other and resulted in the partner feeling rejected and isolated. A sense of detachment occurred creating further communication issues and limited opportunities for intimacy. Christopher (Carla's partner) explains:

> *We've had a lot of tough periods and I'm a caring person...I think the relationship issues that we've had in the last couple of years post cancer has sort of been around me being a bit detached... maybe that detachment is almost like that trauma kind of*

> *response... I've got to keep my distance here a little bit because there's just so much going on and I don't know how much more I can manage or deal with.*

When prompted to discuss the changes in their relationship during this period, many women recognised that their partner was withdrawing, but that were ill-prepared to provide support, due to their own adjustment difficulties. Partners also confirmed that they needed support during this time; however, they were unaware of where or how to obtain assistance. Marg (one year and six months post-treatment) describes the difficulties she experienced with her partner:

> *My husband doesn't talk about those sort of things and he deals with it by just doing practical things. He was very good that way but he didn't share with me his concerns or what that could mean for the family. He was going through a difficult time at his work and I don't think he felt supported well himself. People knew what was going on with me, I don't think he really felt very well supported and it did affect him.*

Couples were very open with regard to the consequences of these communication difficulties and how their relationship was affected. It meant that they felt 'stuck' in their attempts to connect with each other, sometimes leading to conflict and stress. Some couples discussed many barriers regarding intimacy and resumption of sexual activity, a situation with which neither individual was satisfied. David (Danielle's partner) and then Lara (two years and two months post-treatment) discuss further:

> *We've been sort of non-intimate, I think it's been once in two years. It messes with your brain because you start getting this thought that your partner doesn't love you. Obviously you have different ideas about it and one of the doctors explained how it works with the female body...and to the point they sort of push you away.*
>
> *They're just a couple of lumps there...and I could have nipples put on but what would be the point? It's not that there's no point it's just they still wouldn't respond the way mine did ... I want to feel the way I felt before but my body just isn't the same and I felt a bit let down by my body... I am very hopeful that at some point I'll feel more like me again. You know I haven't totally written off our physical relationship.*

Changes to their communication with each other, continued stress, and a loss of intimacy during survivorship sometimes meant that couples' future plans were very different to what they had anticipated prior to diagnosis. Christopher reflects on how the breast cancer experience impacted his relationship, resulting in changes to his thoughts about the future:

> *The last couple of years have sort of been this rollercoaster of events... our way of coping and reactions and responses and that sort of thing... and it's still going ... I think it's still going along in a way that's sort of thrown us on a path that we wouldn't have ordinarily been on perhaps. It's led to us sort of drifting...drifting apart quite a bit...towards Carla's kind of recovery phase and that led to a lot of questioning of where the relationship was at.*

Reformulating the relationship

This theme reflects the opinions of women and partners regarding their attempts to accommodate changes in the relationship and the strategies they felt assisted them during early survivorship. Many women stated that their priority during early survivorship was to reclaim a sense of 'self' and that meant needing time and space for themselves before they could focus on the maintenance of their relationship. Women reported that a concentrated effort was required by their partners to understand and respect these needs, utilising open communication and empathy skills. Also recognised was that there were no clear answers about how long it would take to negotiate and adjust to the changes during this period. Marg explains her thoughts:

> *You do feel like there's some things I didn't want to talk to or couldn't talk to Matt about... It's just, it's happening to me and just have to sort it out and I knew that there was support all around me but there was just some things that I had to just do on my own and I thought at the end of the day yes it's affecting everybody else but, I felt like it was happening just to me.*

When asked about their suggestions for managing the communication challenges in the relationship, many couples recognised that alternative solutions were needed. Communication styles that had worked previously were not always successful during early survivorship. Partners also commented on their role and capacity to support their spouse, given their own personal and emotional difficulties. Some partners stated that they were not always the first person that their spouse sought out for support, resulting in further frustration. David and Danielle describe how David's usual actions and responses to his wife created problems for them:

> *I'm one of those people who love people to death you know what I mean? Like the big saying is love can fix anything, if it doesn't work just increase the dose sort*

> *of thing... So that's me in a nutshell and Danielle was sort of.... I need my space... and felt even though I'm away half the time from *FIFO (fly-in fly-out) she felt a bit smothered by it because I was always coming to her and so that's my homework is for me to stay away and for her to come to me instead of the other way around.*
>
> *[Danielle interjects]: I think one of the biggest things, is that guys have to be very careful that they're not doing things that benefit them. You know with the closeness thing, David would give me hugs, that's what he actually needed at the time, it wasn't what I needed... so it's a very tough thing to learn.*
> **FIFO- is the term coined to describe the work routine of individuals who need to be transported from their city of residence by aeroplane to place of work, often every 2–4 weeks throughout the year.*

Women and their partners agreed that there were many challenges during this time; however, offered suggestions regarding potential ways to assist them in negotiating this new phase of their relationship. Couples agreed that they needed to acknowledge the communication issues, address their concerns together, and try to resolve these. A determined commitment to remain in the relationship was also articulated by women and partners with the view that progress would take time and patience from both parties. Lester (Lara's partner) and Lara discuss their thoughts:

> *It is a massive thing and that'll be the show stopper for I'd say 60 – 70 % of marriages. It's just that non-information and communication...can't say more than stop the arguing side of things and talk and communicate what you're actually trying to say. Don't turn it into an argument, don't storm out, just don't.*
>
> *I think it's always been a big thing for us that we'd be there for each other no matter what... If you know that your partner's going to be there no matter what, 'cause there's no one, there's not a lot of people in this world for you.*

Many women reported that they were able to access a range of informal supports (friends, work colleagues, female family members) which greatly assisted them during early survivorship. These people were vital supports and offered women the opportunity to talk with someone other than their partner about their thoughts and feelings during this unpredictable period. This was in stark contrast to their partners' experiences, and it was generally recognised that their partners often did not utilise their friends or family to discuss issues or concerns regarding the relationship. Couples agreed that both women and their partners needed someone to talk to away from each other and that this was very useful; offering another resource or just some time to listen to them during stressful periods. Glenda (five years post-treatment) and Gary (Glenda's partner) share their experience:

> *I used to say to Gary... he was in a club, building a hot rod at the time and I knew when the hammer got louder, he was taking his anger out on it and all the guys used to turn up and say 'what do you want a hand with?'... I actually thought when they were all down the shed they'd be saying 'how you going Gary?' you know?*
> *(Gary interjects) Blokes don't talk to blokes like that you know... I mean you see these blokes' sheds they've got if you're depressed and things like that you know... Blokes... well blokes don't talk about things like that.*

Support is needed to negotiate the future of the relationship

Whereas the previous theme explored strategies that were used in an unplanned and ad hoc manner, the final theme identified the lack of a concrete plan which would enable the couples to move forward in a direct and co-ordinated manner. Women and their partners felt vulnerable and unprepared for this next stage in the breast cancer experience and were concerned about the future. The lack of a defined transition strategy, education and information about survivorship meant that many couples felt unprepared for this period, which also impacted their relationship with their partner. Danielle explains how this uncertainty affected her:

> I *spoke to one of my doctors and he said to me when you were going through chemo and your treatment you wouldn't have wanted me to say to you 'you're going to crash and burn afterwards'. He said 'you wouldn't want to hear that and you would have said no, I'm not'..... 'So all we can do is wait for you to get to that and when you do we're here'... But I think maybe, even if it was just information, even written, that you read in your own time when you've finished or maybe let you know that it is ok to feel like that. You know you may feel lost. No one really even said that. They're just like oh... last treatment 'See ya...'*

When asked about the supports and services accessed during early survivorship, women confirmed that these were more difficult to obtain compared with those sourced during treatment. None of the women interviewed were offered a survivorship care plan or written information following completion of treatment. Some women reiterated that often it was not until treatment had concluded, that many new fears and concerns emerged, especially regarding the resumption of previous roles and responsibilities. Also noted was the distinct lack of awareness regarding the potential for relationship difficulties. Ingrid (one year post-treatment), reported that she would have benefitted from ongoing support from the breast cancer nurse when her medical treatment was completed:

> *That's where I think the breast care nurse would have come in handier for me at the end of treatment... Not before and not during, at the end. Even if it was just a phone call or maybe you know... a visit or you can go there and see her.*

Couples were united in their suggestions about the potential value of formal support from health professionals to assist them in negotiating improvements in communication within their relationship. Some women stated that they had sought support to assist them with a range of personal and shared issues. Women and their partners recognised that ongoing communication difficulties could lead to long-term issues, including irreparable changes in the nature of their relationship and that professional assistance was needed to manage this. Marg discussed her strategy for addressing concerns:

> *If you don't recognise what's happening and everything's really, really hard then I think you need someone to help set you in the right direction. But if you're aware enough, if things are pretty tough....go and see someone... which I was able to do. But I don't know if everyone can do that and that was very difficult but it was very good in the long run.*

There was recognition that the partners of women were largely ignored with regard to requiring targeted support during the early survivorship period. Partners stated that they could have benefitted from a range of formal supports, but that they were not made aware of any potential resources during this period. Partners identified that access to support during this period was an initial step towards adjustment and gave hope for the future. Gary emphasises his desire for timely support to build a foundation towards a positive outcome following the cessation of treatment.

> *I don't think there's enough for the guys, there's more information for the women. But as far as information for guys...what to expect and how to cope with your wife ... I mean fair enough because she's the one going through it ...but they don't sort of scope on what happens around them... you really had no one to talk to. But it may be a few phone calls and a human face to face in private or whatever... then they might give you something and then that builds momentum. So something along those lines.*

Discussion

The findings of this study support previously published literature regarding the experience of survivorship for women and raises many additional concerns about how the partners of women are also significantly impacted during this time. The physical and cognitive consequences of breast cancer and its treatments that continue during treatment and survivorship are well established and supported by many qualitative and quantitative studies [17, 59, 86, 92, 93]. Recent research focussing on the early transition from treatment to survivorship identifies further issues including loneliness and an inability to cope, as well as anxiety and emotional distress sometimes leading to depression [5, 11, 26, 92]. Our study's findings raise additional concerns for women and their partners during survivorship, many of which have not been previously reported.

The women in this study expressed many psychological concerns relating to the early period following cessation of treatment. Women felt their physical, psychological and emotional needs were largely undervalued by their usual medical supports, with a sense that the psychological and emotional difficulties experienced during early survivorship were not considered a priority during this period. Women reported that the period immediately following cessation of treatment was the most problematic, with many emerging difficulties relating to the resumption of previous roles and responsibilities. A desire to 'put themselves first', a need for privacy, suppression of thoughts and feelings and being able to maintain control over their lives were frequently discussed as having a profound impact on daily function and maintenance of the relationship with their partner.

The resultant stress of coping with the diagnosis and treatment of breast cancer may be superseded by the problems experienced during survivorship [19, 47, 94–101]. There is some evidence to suggest that resources provided during this time including information, education, peer support/mentoring and self-management tools may assist women in preventing further issues including depression and other psychological sequelae [16, 102–104]. The literature reports that most women experience improvements in quality of life beyond the five year period (long–term survivorship) [105, 106]. However, some women do not; those with a previous history of depression and women who completed chemotherapy are thought to be at greater risk of long term problems [107, 108].

This study found the partners of women reported many unmet needs and were unaware of where they could obtain assistance to help them manage the many challenges experienced during survivorship, also citing that there was a lack of recognition for the important role they played in supporting their partner during this time. Common issues reported by participant partners of this study included; difficulty understanding and accommodating their partner's needs during survivorship, communication issues, problems with intimacy and resumption of sexual activity as well as feeling isolated and detached from their relationship with their spouse. These findings add weight to the existing evidence that many partners feel largely unsupported during the breast cancer experience generally [21, 42, 92, 109]. While the supportive care efforts to meet partners' needs appear to be improving, these are concentrated during the treatment period. Significant distress may continue beyond this the treatment period, resulting in further adjustment difficulties, anxiety and depression [21, 42, 51, 110, 111].

Results of this study reflect the complex interaction between women and their partners during survivorship and support the view that the breast cancer experience must be considered as 'shared'. The literature describes this concept as a form of 'dyadic coping' and it explains the method for which women and partners learn the skills required to accommodate the stress experienced as a result of illness [39, 54]. This perspective is supported by several studies indicating that the psychological distress experienced by cancer survivors and their partners is interdependent with the recognition that cancer is a 'family' disease [27, 44, 54, 112, 113]. However, there are few Australian studies that highlight the unique needs of partners during breast cancer survivorship [114–116].

Changes to intimate relationships were also recognised by participants. Women reported that the physical and emotional changes experienced during survivorship resulted in them being unsure about if, and when, they would feel comfortable to resume a sexual relationship with their partner. Thematic findings of this research offer many examples of women needing to remain distanced from their partner, physically, emotionally and sexually. Treatment for breast cancer (chemotherapy, surgery and radiation) as well as the use of adjuvant (hormone) therapy are noted to potentially contribute to the physical and psychological consequences of breast cancer and may offer some explanation towards the complex relationship problems experienced at this time [32, 33, 117–119].

The findings of this study support the view that the experience of breast cancer for women with partners is profound. While the period of diagnosis and treatment is identified as creating significant stress for both partners regarding their relationship, emotional, financial and spiritual concerns [39], our findings indicate that the early survivorship period may continue to create many additional difficulties for couples. There is an expectation that women and their partners resume their previous activities and relationships with ease following cessation of treatment; however, the themes explored in this paper indicate that couples may experience a range of ongoing issues and partners themselves may have unique problems that are often overlooked.

There have been some efforts to date aimed at improving couples' communication, coping skills and adjustment during survivorship. A systematic review conducted in 2013 [50] concluded that a range of psychological interventions completed with couples experiencing breast and gynaecological cancer were effective; however, the majority of the studies reviewed were focussed on the treatment stage [120–124]. Additional research has been completed examining a range of interventions applicable during survivorship including: adjustment to illness and the development of coping strategies [125]; addressing cancer related stress and improving marital communication [48]; and addressing body image concerns, intimacy and sexuality [126–128]. The findings of this study support the need for further development, application and evaluation of cost effective supports for couples affected by breast cancer, particularly during early survivorship.

Recommendations regarding the development, utilisation and efficacy of supportive care must be viewed within the context of that care. Models of cancer care vary considerably across the world, with a range of underpinning philosophies including a traditional medicalised approach, a biopsychosocial framework and the wellness model [65, 129–131]. To date, there is no consensus on which model/approach is most appropriate for the provision of support during breast cancer survivorship. It is widely recommended that these models of care must provide timely, cost effective services and supports according to the preferences of consumers [17]. Evidence from our study demonstrates that the experience of early survivorship for couples is complex, with many psychological, social and sexual issues, suggesting that a biopsychosocial framework is appropriate in addressing couples' ongoing needs.

Researchers concur that there is an urgent need to further explore the efficacy of these approaches while observing the recommendations made by the Institute of Medicine (IOM), these being: the prevention of recurrent and new cancers; surveillance for cancer recurrence and medical and psychosocial late effects; strategies to manage the consequences of cancer; and co-ordination of specialists and primary providers [132]. The IOM also made key recommendations including the use of SCP's to address many of the concerns raised by the current study's participants [58]. There is a volume of literature suggesting that SCP's may assist women to identify and address many of the ongoing issues and concerns relating to breast cancer survivorship [22, 25, 99, 133–135].

While participants of this study were not offered a SCP as a strategy for managing the consequences of breast cancer, the strongest recommendation of women and their partners was that they needed a formal plan to manage this new phase of their lives and to help them adjust to the many personal challenges being experienced during survivorship. Women and their partners interviewed in this study were left to negotiate this time on their own without the recommended supports and services needed to meet their varied and complex needs. Survivorship Care Plans may be an essential, yet underused resource that offers great potential to assist both women survivors and their partners to document, direct and facilitate the required supports and services in early survivorship. Our study suggests that any plan should also include the concerns of partners.

Limitations

There are limitations to this research and some of these are common to the methodology of dyadic interviewing. Most women were interviewed with their partner present, which may have created a situation where a participant might not have offered information that could create difficulties or discomfort for the other person. Interestingly, the data gathered from the two couples interviewed separately from their partners were not dissimilar to that divulged by partners interviewed together. This may be because couples who agreed to be interviewed together felt comfortable in discussing their concerns with one another. It may be that the concerns of couples experiencing extreme distress may not be captured by this research project. All couples were heterosexual, limiting the unique perspectives that may have been provided regarding same sex couples. Inclusion criteria did not preclude same sex couples; however, no same sex couples volunteered for interviews.

Participants were asked about the support services utilised during survivorship; however, were not asked for their suggestions regarding potential recommendations, accessibility or the applicability of shared services and this is recognised as a limitation, warranting further investigation. Participant demographics indicate that the socio-economic status of couples was comparatively high and that the particular needs of individuals from low socio-economic groups were not represented in the findings. All participants were recruited from a large city and therefore may have been able to access services and supports if required. All participant women interviewed were married and therefore the findings may not be generalised to single/divorced women. However, it is reasonable to conclude that the findings may be transferrable to women residing in developed countries, where health and community services are comparable to existing Australian services.

Conclusion

Results of this research support a shift from the traditional medicalised approach to a 'biopsychosocial' framework incorporating comprehensive multi-disciplinary care which targets women's and their partner's complex physical, psychological, communication and emotional needs, especially during early survivorship . Further development of this framework must complement the existing resources and be targeted towards the shared needs and preferences of women and their partners. Women survivors of breast cancer are recognised as a significant, yet distinct group of health care recipients requiring specialised and targeted services to manage their health care during survivorship. This paper provides additional evidence that the partners of women also experience a range of psychological, emotional and relationship consequences during survivorship. Women and their partners want increased awareness of, and support for, the important role partners provide during treatment and survivorship.

Acknowledgements
The authors wish to acknowledge the many women survivors of breast cancer and their partners who provided valuable time and contributions to this research and the Breast Cancer Network of Australia who assisted with recruitment of participants.

Funding
The authors declare that funding was not obtained to complete the research.

Availability of data and material
The datasets generated during and/or analysed during the current study are not publicly available as individual privacy may be compromised but are available from the corresponding author on reasonable request.

Authors' contributions
SK: conceptualisation and development of research design, recruitment of participants, interviews with participants, acquisition of data, analysis and interpretation of data, drafting and revising the manuscript. LR: research design, data analysis and interpretation of data, drafting and revising the manuscript. BM: research design, data analysis and interpretation of data, drafting and approving the manuscript. All authors read and approved the final manuscript. All authors agree to be accountable for all aspects of the work in ensuring that the accuracy and integrity of any part of the work are appropriately investigated and resolved.

Competing interests
The authors declare that they have no competing interests.

Consent for publication
The authors declare that written consent for publication was obtained from all study participants.

Ethics approval and consent to participate
The authors declare that the study has been approved by the Curtin University Human Research Ethics Committee (approval number HR 51/2014). Written consent to participate was obtained from all study participants.

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Received: 30 January 2016 Accepted: 18 August 2016

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Chapter 5 Publication Three ‘A call to action: the need for improved service co-ordination during early survivorship for women with breast cancer’

The publication represents stages one and two findings. In stage one, in-depth interviews were completed with women survivors of breast cancer and their partners and addresses the first objective of the research; ‘identify the met and unmet occupational needs of women and their partners during the early survivorship period’.

During stage two, a cross-sectional questionnaire was completed by a range of health services identified as providing support for women survivors of breast cancer. Results collected from this questionnaire addressed the second objective of the research ‘identify and describe the range and type of current supports available to women survivors of breast cancer and their partners, from the perspective of the support organisations providing these services.’

The publication outlines the background literature, research methods, and findings with a discussion of results. Results of both research activities were triangulated to determine if supports provided by health services were adequate in meeting the expressed needs of women and their partners during survivorship. Findings of this publication indicated many barriers relating to the delivery of services, poor co-ordination of services and the need for refinement of formal survivorship planning. The findings obtained during this stage assisted to inform the subsequent stages of the research, including the development of key questions used in the focus groups completed during stage three.

The manuscript was accepted for publication with Women and Health Journal on May 1st, 2018 (in press). An email confirming acceptance for publication can be found in Appendix M.

Inclusion in the thesis as a manuscript has been approved by the Publisher according to the copyright agreement. Details of this arrangement can be found in Appendix L Copyright declaration three.

Title: A call to action: the need for improved service co-ordination during early survivorship for women with breast cancer and partners.

Aim: Survivorship is an under-recognized period in the care of women with breast cancer. This paper aimed to determine if supports provided by health services were adequate in meeting the expressed needs of women and partners during survivorship.

Methods: A mixed method study consisted of: (1) in-depth interviews with women (n=18) and partners (n=8), (completed June 2014-November 2014) and (2) a questionnaire with health providers (n=34) (completed April 2015) regarding services offered, needs addressed and barriers to service delivery. Both were completed in Perth, Western Australia. Findings were determined using thematic analysis and descriptive statistics.

Results: Many unmet needs were identified by women and partners, including: pain; fatigue; fear of recurrence; employment, leisure, social and intimacy difficulties. Participants did not receive a formal plan to assist them. Health providers reported a range of supports, including cancer surveillance and management of physical, psychological, emotional and relationship concerns. However, many barriers concerning service delivery were identified.

Conclusion: Despite services reporting that they provided various supports, interview participants did not appear to use and benefit from these. Coordination of service delivery was identified as requiring improvement. The use of survivorship care plans also needs refinement to determine suitability for use during survivorship.

Key words: breast cancer survivor, health service needs, patient care planning, co-ordination, partners

Introduction

Breast cancer is currently the most frequently occurring cancer affecting women worldwide, with 1.67 million new cases diagnosed in 2012 (Ferlay et al., 2012). However, those diagnosed with breast cancer also have a very high proportion of survivors; between 60- 89% of women living in middle- to high-income countries achieve a five-year survival rate, largely as a result of the well-established screening and treatment advances accomplished over the last 30 years (American Cancer Society, 2016; Coleman et al., 2008; World Health Organisation, 2015). Contrary to the widely-held belief, completion of active treatment (surgery, chemotherapy and radiotherapy) does not always mean the end of the breast cancer experience, with many women continuing to experience significant difficulties affecting their daily function (Fallowfield & Jenkins, 2015). The transition to ‘survivorship’ is fraught with uncertainties regarding the resumption of usual activities, including return to employment, hobbies and interests as well as maintaining valued relationships and roles with a partner, family members, colleagues and friends.

The type and range of issues affecting women varies considerably, yet fatigue, cognitive problems, pain, lymphoedema, fear of disease recurrence, poor body image, premature menopause, mood disturbance and sexual dysfunction are widely reported as causing distress in the longer term (Foster & Fenlon, 2011; Gil et al., 2004; Keesing, McNamara, & Rosenwax, 2015; Pelusi, 2006; Player, Mackenzie, Willis, & Loh, 2014). Evidence suggests that unmet needs during survivorship may contribute to the development of complex physical, psychological and emotional consequences in the longer term (Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005). The impact of breast cancer may also extend to the individual’s partner and family with varying psychological and emotional repercussions. This phenomena is comparatively underexplored but extremely relevant to successful transition for women survivors and their partners (Badger, Segrin, Torros, Meek, & Lopez, 2007; Holmberg, Scott, Alexy, & Fife, 2001; Oktay, Bellin, Scarvolone, Appling, & Helzlsouer, 2011; Segrin & Badger, 2014).

The support available to women during survivorship varies immensely according to a complex range of variables, including the model and context of care, timely identification and assessment of needs, preferences of the treating medical practitioner, referral to suitably qualified and experienced health professionals as well as access to education and information (Brennan, Butow, Marven, Spillane, & Boyle, 2011; Hewitt, Greenfield, & Stovall, 2006). In 2005, the United States’ Institute of Medicine (IOM) formally recognized the many disparities pertaining to the care of all cancer survivors and issued a range of recommendations designed to improve survivorship care (Institute of Medicine and National Research Council of the National Academies, 2005).

These recommendations included: the development of guidelines to assist in the prevention, screening and surveillance of breast cancer recurrence and other cancers; assessment and management of the long term effects of breast cancer; implementation of coordinated interdisciplinary care and the use of health promotion strategies (Runowicz et al., 2015). The IOM recommendations have been widely accepted internationally as 'best practice' in survivorship care; however, their delivery and applicability vary considerably and may not target individual needs and preferences across many different care contexts.

Many other resources are used by health providers including treatment summaries and survivorship care plans (SCPs) (Chubak et al., 2014; Jefford et al., 2015; Kenyon, Mayer, & Owens, 2014; Todd, Feuerstein, Gehrke, Hydeman, & Beaupin, 2015). While the IOM mandated that all cancer survivors should receive a SCP and treatment summary, in Australia these are used inconsistently, with no universally accepted standard or template dictating the format, structure, timing or person responsible for their development (Brennan, Gormally, Butow, Boyle, & Spillane, 2014).

The care of women survivors of breast cancer and their partners during survivorship varies considerably and is emerging as an essential consideration in the comprehensive management of women diagnosed with breast cancer. It is timely, therefore, to consider the views of women and partners regarding their needs during early survivorship as well as the perspectives of health providers currently offering services to these individuals.

The aims of this study were: 1) Determine the physical, psychological and emotional needs of women survivors of breast cancer and their partners and their relation to a return to previous levels of function, 2) Identify the type and range of current supports provided from the perspective of health providers, and 3) Determine whether the needs of women and partners are adequately met by the existing services provided.

Methods

A mixed method approach was implemented to meet the research aims (Creswell, Plano Clark, Gutmann, & Hanson, 2003). During stage one, in-depth interviews were conducted with women survivors of breast cancer (n= 18) and some of their partners (n= 8) living in Perth, Western Australia (WA) between June and December 2014. Stage two consisted of the distribution of a questionnaire to known providers of breast cancer survivorship support in WA between March and April 2015. Ethics approval for the study protocol was obtained from Curtin University (Approval number HR 51/2014). All participants and questionnaire respondents were provided with information about the research, an assurance of confidentiality and anonymity, and informed written consent was obtained prior to data collection.

Stage one-participants

Stage one used an extensive literature review to inform the development of an interview guide, which was further refined following a pilot. Participants were recruited using purposive sampling methods, with a flyer developed for inclusion in a community newspaper, university intranet web-page and distributed to non-government organizations (NGOs) known to provide services to women during breast cancer survivorship. The researcher was also interviewed on community radio in an effort to recruit participants. These recruitment strategies aimed to reach women and their partners living locally who felt they had a contribution to make to the study and were prepared to volunteer their time and share their experiences following cessation of treatment for breast cancer. Women who made initial contact with the researcher were screened using telephone or email contact to discuss their eligibility using a series of standard criteria about their breast cancer experience.

Women were eligible to participate if they were aged 35-70 years, had received a diagnosis of breast cancer, and completed active treatment (including surgery, chemotherapy, radiotherapy or a combination of these treatments) between six months and five years previously. Women were asked about the type of treatment they had received, current employment status and if they were available to meet with the researcher for up to two hours on one occasion to discuss their experiences. Women were also asked if they currently had a partner and if he would be willing to participate in the study. Women who were still currently receiving chemotherapy, radiotherapy, surgery or palliative care were excluded. The eligibility rate for women was 18/18 as this was the total number of women who met the inclusion criteria. All of the women who agreed to participate initially were interviewed (no women withdrew after providing initial consent) indicating a participation rate of 18/18.

A single criterion was applied to screen for eligibility of partners. Partners were eligible to participate if they identified as having a significant and ongoing relationship (married or defacto) with an eligible participant, were available for an interview and willing to share their experiences of breast cancer with the interviewer. The eligibility rate for partners was 15/18, as one woman was a widow and two others were separated, with all other women being married. The participation rate for partners was 8/15. No partners withdrew from the study following their initial intention to contribute.

Stage one-data collection

The first author completed all interviews of women and partners. Women were asked a range of questions about their daily function with a focus on the management of ongoing symptoms, mood, engagement in leisure and social interests, employment and management of relationships. Current roles and responsibilities were explored as well as the awareness and use of supports during survivorship. Partners were asked about their experiences of survivorship, how they supported their partner, management of relationships, use of resources and supports, and their ability to manage their own commitments.

Stage one- data analysis

Each interview, lasting approximately 45-90 minutes, was recorded and transcribed. NVivo© was used to organize the data prior to implementation of thematic analysis using the six-step approach described by Braun and Clark (2006). Using an inductive approach, step one commenced with the first author reading each transcript several times, noting initial thoughts regarding overall content. Authors two and three independently reviewed approximately one third of all transcripts (a random sample) to obtain an overview of content and to develop their own independent analysis of the information. In step two, the first author generated initial 'codes'- groups of content representing the range of data organised into separate ideas. During step three, all authors independently reviewed these codes and compared them to step one findings to generate potential themes. Step four required authors to collaborate and review initial themes, determine links between the themes and further reworking of relationships between and within the themes. Naming and clarifying themes in stage five was undertaken by all authors to achieve saturation, followed by finalisation of themes (stage six) (Liamputtong & Serry, 2013). Further strategies for ensuring credibility and trustworthiness included; forwarding of themes to all participants for member checking, regular peer review and documentation (memos) following completion of interviews and the development of an audit trail (Noble & Smith, 2015).

Stage two-participants

Stage two consisted of the development of a 22-item cross-sectional questionnaire for providers of health services. Data collected in stage one and the literature review were used to inform and develop questions. These were presented using a questionnaire hosting template (Qualtrics). The questionnaire was piloted with a health professional working in a health service and modified before the unique link was emailed to known providers of breast cancer care services (n=56) situated in Perth, WA. Known providers of breast cancer services were identified by contacting several key organizations and service directories; the Australian Cancer Services Directory, Cancer Council Western Australia, Breast Cancer Network Australia (BCNA) and the West Australian Survivorship Collaboration (a local community of practice organization). Providers included organizations and individuals specializing in breast cancer care, eg., breast cancer clinics in public and private hospitals, oncologists and surgeons specialising in breast cancer, breast cancer nurses and allied health professionals, relevant NGO's; health and wellness clinics, and cancer support agencies.

Stage two-data collection

Providers were asked to nominate a suitable person to complete the questionnaire. These organizations offered a variety of services ranging from medical surveillance and the management of ongoing physical issues to a focus on psychological, emotional and relationship concerns. Several agencies provided preventative care and health and wellness strategies to women. A variety of question formats (20 closed and two open) were used to obtain information regarding the type and scope of the service, format, delivery, cost, target audience, staffing and the use and content of SCPs.

Stage two- data analysis

Analysis using univariate descriptive statistics as well as content analysis of open-ended questions was completed by the first author. Triangulation of data from stages one and two ensured validity of results (Grbich, 2017).

Results

Stage one

Of the 18 women interviewed, 77% were married, 61% had completed a university degree and 72% were working in paid employment. The mean age was 52 years (range 38-69 years) with mean time since active treatment cessation being one year and eight months (range 1-5 years). Of the eight male partners, all were married; 50% had completed a university degree and all were working in paid employment. The mean age for partners was 48 years (range 34-53 years). Three themes were identified as a result of the stage one interviews with women and partners.

The first theme identified highlighted the overwhelming physical, psychological and emotional issues experienced by many women during early survivorship. These included pain, fatigue, memory and concentration problems, anxiety and emotional distress, difficulty sleeping, spiritual distress and problems engaging with their daily habits and routines (Table 5.1). Returning to employment, resuming friendships, engaging in previous hobbies and interests, parenting and maintaining relationships was challenging. Although women had completed their treatment, many felt unprepared for this period stating that they had expected to resume their previous roles and responsibilities without difficulty. They felt ambivalent about seeking help stating that the societal expectation was that they should ‘just get on with it’, but being unsure about where and how to seek assistance during this critical period of transition.

Most women reported feeling overwhelmed by the many changes occurring during this time. Adjusting to their new sense of ‘self’, trying to manage the side effects of hormone medication, pain and lymphedema, as well as a fear of recurrence, all contributed to a sense of turmoil. For some women, this period was reported to be the most difficult in the breast cancer experience’ many felt abandoned by the previous medical supports available during treatment and were unprepared for the resultant distress. Danielle (participant W4) described the problems she experienced attempting to manage her work demands while negotiating many personal difficulties during this time:

> *I really just felt broken … I didn’t know where to start to try and get the pieces back together. I should be thankful that I’ve got boobs, I’ve survived and I am those things but I’m also really sad and pissed off and a little bit annoyed that my body let me down. It was just an effort every day; nothing was making me happy.*

Common needs identified by women (n=18) and their partners (n=8) during early survivorship	
Physical needs	
	Assistance for cancer surveillance e.g. follow up tests, appointments for review of surgery, chemotherapy and radiotherapy
	Monitoring of medication and side effects
	Lymphoedema, loss of range of motion in affected limb, postural problems
	Pain
	Needing advice regarding consequences of surgery, reconstruction and alternatives, preventative hysterectomy
	Managing the long term effects of breast cancer/medications/treatment, unpredictability of the disease course, health and wellness information, weight management, nutrition and exercise
	Fatigue
	Sleep difficulties
Psychological/emotional needs	
	Cognitive problems- memory and concentration problems
	Sadness, depression, anxiety, mood swings, anger, helplessness, loss of control, frustration and guilt
	Fear of breast cancer recurring and development of other cancers
	Impaired body image, disfigurement, feeling less feminine, loss of sensation in breast/s
Psychosocial needs	
	Relationship difficulties, including; communication, intimacy, resuming a sexual relationship with partner
	Difficulty resuming daily routines, coping with work demands, leisure interests and ongoing responsibilities and roles
	Spiritual concerns; sense of identity, sense of failure, loneliness, feeling guilty and responsible for cancer
	Resuming friendships and social life, being part of a social group/situation
	Partners communication issues; partners feelings of detachment and isolation, internalising feelings and difficulty expressing thoughts and feelings

Table 5. 1 Common needs identified by women and their partners during early survivorship

The second theme identified significant problems regarding the relationship between women and their partners, with particular focus on the shared impact of the breast cancer survivorship experience. Problems reported by most couples included poor communication, difficulty expressing their needs, and having unclear expectations of each other. Partners also reported feeling alone and detached, not understanding how to support their spouse, as well as being unable to access supports for themselves. Many partners felt that they continued to assume the role of 'carer' for their partner as she continued to experience problems long after completion of treatment. Resuming an intimate and sexual relationship was also problematic.

Many partners described a state of liminality as they struggled to understand their experiences during this period. Others continued to fear a recurrence of the cancer for their spouse and many stated that they simply did not know where or how to seek support or what available resources might assist them during survivorship. Christopher (participant M3) explains the dearth of resources available to him:

> *So I went pretty deep … pathways that I could have gone down which were escaping from all of that stuff … I think it's really important and perhaps the system could promote partners going to these information sessions and meeting other people, just like your wife. A lot of partners perhaps didn't go because there wasn't enough promotion them attending. Its imperative I reckon.*

The third theme identified the need for timely, holistic support for women and partners to assist them in navigating a way forward following treatment cessation. Many physical, psychological and emotional difficulties continued to be experienced during this period, with women reporting a lack of awareness regarding where and how to obtain suitable supports, as well as the absence of a formal strategy to plan for the future. A SCP was not offered to any of the participants, and women felt this would have greatly improved the identification and co-ordination of available services. Women stated that while they were required to attend regular follow-up appointments to review their physical health status, they had little opportunity to discuss their psychological, emotional or psychosocial concerns. Many were experiencing problems resuming employment, exercise routines and social opportunities as well as difficulties coping with changes to their relationship with their spouse.

The contrast between supports offered during diagnosis and treatment with survivorship was extreme, with women stating that the concept of 'survivorship' needed to be identified early in the disease trajectory and considered as a critical stage in their care. Supports needed to be formalized and arranged using a coordinated strategy, rather than women themselves trying to navigate the maze of options available after treatment completion. They felt unsure about who was the most suitable health professional to approach and discuss their concerns with. Hannah (participant W8) discussed her experiences following treatment, regarding the need for a formal plan to assist her and her partner during this time:

> *One of the things I struggled with afterwards was … you go through all this intensive treatment, you've been scarred and disfigured and all these things that happen to your body and you're just left … you know … boobless … with a scar and that's it and no one says anything … well are you leaving me like this, what's the plan? What's the plan?*

Stage two

The questionnaire was emailed to 56 health providers, with 34 questionnaires completed (response rate of 61%). Eleven questionnaires were not completed as the service stated it did not offer support to women during survivorship. Of the eleven remaining services invited to participate, no reasons were provided for non-completion. Providers reported that women could find out about the service in a variety of ways including their current health providers (88%), other breast cancer survivors (65%), internet (50%), friends or colleagues (44%), media (51%) and NGO's (18%). The format of supports varied from individual meetings (85%), telephone support (68%), fact sheets (59%), group meetings and guest speakers (44%), and internet sources (26%), to email support, newsletters, DVD's and CD's (12%). Most services were free or low cost (97%).

Health providers employed a range of medical and nursing professionals (82%), administrative staff and volunteers (82%), allied health professionals (65%), complementary therapists (15%) and breast cancer survivors (12%). Support was also available to women and their partners from culturally and linguistically diverse (CALD) backgrounds (88%), with translation services (53%) and resources available in multiple languages (47%). The type of support offered to partners also varied but included the management of relationships (91%), long term implications of diagnosis (64%), practical (resuming daily routines, return to work (56%), financial/legal (36%) and the management of anxiety/distress (27%) (Table 5.2).

Health providers were mostly satisfied that their services met the needs of women and partners with 61% indicating a score between 7-10 on a sliding scale (with a score of 1 being low satisfaction and 10 being high satisfaction). However, health providers identified many barriers regarding the provision of care. These included the availability of suitably qualified and experienced professionals (56%), financial resources (53%), physical resources (38%), limited awareness of the service (32%) and poor co-ordination/transition between tertiary and primary setting (15%).

The number of health providers using SCPs was 29%. For those providers using SCPs, the content was relatively consistent and included psychological support (90%), resources for ongoing support (90%), referrals to other providers (80%), healthy lifestyle information (80%), diagnosis and treatment summary (70%), follow-up schedule (70%) links to other services (70%) and identification of possible late side effects of breast cancer treatment (60%).

Provision and frequency of services offered by health providers (n=34) during early survivorship	**Frequency (%) of service provision**			
Services to address physical needs	Not provided	Occasionally provided	Frequently provided	Always provided
Medical surveillance including follow-up appointments and tests with health professionals	32	6	21	41
Medication prescription and support	37	12	21	30
Lymphoedema management	30	12	26	32
Management of the long-term effects of breast cancer e.g. pain, co-morbidities	18	24	29	29
Management of surgical complications E.g. scarring, disfigurement.	27	18	27	28
Advice for making decisions regarding breast reconstruction and other surgery	24	11	24	41
Weight management support	21	44	21	14
Nutrition advice	12	44	23	21
Advice regarding exercise	3	26	41	30
Development of self-management skills	6	35	32	27
Strategies to manage fatigue	8	25	37	30
Sleep hygiene	18	24	40	18
Services to address psychological/emotional needs				
Strategies to manage cognitive changes e.g. memory loss, concentration difficulties	18	35	41	6
Management of anxiety and depression, relaxation and stress management	3	21	47	29
Support for fear of cancer recurrence	9	15	44	32
Strategies to address problems with body image	8	21	56	15
Services to address psychosocial needs				
Support for relationship and family issues	3	32	41	24
Assistance regarding sexual functioning and intimacy	8	44	24	24
Support for resuming employment	26	50	18	6
Advice for spiritual concerns	21	41	30	8
Assistance to resume social interests and hobbies	21	32	44	3
Support to address partners' concerns	0	23	56	21
Smoking cessation	32	41	21	6
Legal advice/support	50	29	21	0
Financial support	24	38	24	14
Additional services provided				
Complementary therapies	26	32	21	21
Peer support	10	32	29	29
Allied health referrals	3	6	47	44
General advice regarding resources available	0	9	41	50

Table 5. 2 Service provision and frequency of services offered across all health providers

Discussion

The findings of this study identified the many physical, psychological and emotional needs of women and their partners during the critical transition from breast cancer treatment to survivorship. Women also continued to experience ongoing problems regarding resumption of previous roles, return to employment, hobbies and interests as well as communication and intimacy problems with their partner. Also of concern was the perspectives of partners, with reports that they felt overwhelmed during the survivorship period, were unsure about how to assist their spouses and did not know how or where to seek support for a range of psychological, emotional and relationship concerns.

Literature suggests that if these issues are not addressed early during this transition, quality of life for some women may be impaired with resultant long term physical and mental health consequences (Brennan, Butow, Spillane, & Boyle, 2014; Keesing, Rosenwax, & McNamara, 2016; Shi, Michonski, Stein, Kaw, & Cleeland, 2011). Results of this study also supports the findings of others regarding the increased risk of psychological difficulties for partners, as well as the shared concerns of couples, including communication, intimacy and relationship issues (Hodgkinson et al., 2007; Schmid-Buchi, Halfens, Dassen, & van den Borne, 2011; Segrin & Badger, 2010; Talley, Molix, Schlegel, & Betencourt, 2010).

Questionnaire results indicated that while a wide range of services are available to address the needs of women and partners, health providers noted several barriers which may offer an explanation concerning the potential difficulties regarding access and uptake of these supports. These included: poor identification and referral to appropriate supports by treating health professionals; limited awareness of the service, unclear referral pathways and poor co-ordination between tertiary and primary services. Some of these barriers are reported elsewhere with an urgent call for survivorship to be recognised as a distinct period in the care of women with breast cancer, together with improved efforts to co-ordinate services utilising suitable models of survivorship care (Brennan, Butow, et al., 2014; Easley & Miedema, 2012; Jefford et al., 2015; McCann, Illingworth, Wengstrom, Hubbard, & Kearney, 2010).

The women and partners interviewed in this study also stated many difficulties concerning the transition from treatment to survivorship; they were not adequately prepared for this period, were overwhelmed by the volume of information available, experienced a lack of continuity of care and were not offered a formal plan following cessation of treatment. Recommendations to facilitate improvements during this period are numerous and supported by recent literature. These include the identification of a model of service delivery that meets a woman's individual concerns as well as the use of a suitable survivorship care plan. In addition, assessment of unmet needs, improved co-ordination of various health and wellness supports, timely review of ongoing concerns, dissemination of suitable education resources and regular evaluation of progress is also vital (Clinical Oncology Society of Australia, 2016; Runowicz et al., 2015).

The type of service delivery models currently used to direct available support services are varied, including specialist-led, primary care practitioner-led, nurse-led and patient-led. In addition, many women had very little experience with the post-cancer treatment health system and supports, which may potentially contribute to feelings of confusion and uncertainty. Further guidance from suitable health professionals is clearly required to determine the best model to suit their individual preferences for future care (Bessen et al., 2014; Grant, De Rossi, & Sussman, 2015; Jefford, Mann, Nolte, Russell, & Brennan, 2014; Muktar, Thiruchelvum, & Hadjimanus, 2015; Railton et al., 2015; Weaver et al., 2014). It is suggested that the use of a dedicated 'patient navigator' or nominated care co-ordinator together with the use of a formal plan (SCP), would assist to identify needs, facilitate referral to suitable supports, provide targeted information and improved co-ordination of services (Ruddy et al., 2015).

None of the women interviewed in this research recalled receiving a SCP to assist them during the transition from treatment to survivorship. They did report, however, that they were provided with a range of other information, including test results and written and online resources, which at times, felt overwhelming. For this reason, the validity of self-report was a potential limitation during stage one. At the time of the research, SCPs had only recently been introduced to clinicians and were not a mandatory resource in breast cancer survivorship care. This may explain the low use of SCPs by the health providers included in this study. Several previously identified issues included the inconsistent use of SCPs which may explain potential reasons for poor uptake. Variability of content, format, availability and time taken to develop, reduced focus on the psychological and emotional consequences of breast cancer and a lack of consensus regarding which health care professional should be nominated to develop and coordinate the plan are noted (Ashing-Giwa et al., 2013; Birken, Mayer, & Weiner, 2013; Daudt et al., 2014).

In Australia, the use of SCPs is sporadic and uncoordinated (Lawler, Spathonis, Masters, Adams, & Eakin, 2011). However, the timely and consistent use of SCPs in this context offers a sound foundation to assist health providers in meeting the needs of women and their partners during survivorship. A SCP should include a summary of treatment, scheduled reviews, assessment of current physical, psychological and emotional needs and assist to facilitate the co-ordination of a diverse range of required health supports. The use of a SCP may assist in improving the co-ordination of timely, holistic and targeted supports to women and their partners during this period.

Limitations

Some limitations to the research were identified. Most couples participated in shared interviews, potentially creating discomfort or withholding of information. All couples were heterosexual, well-educated and from a high socio-economic background. Most women interviewed were married; so the findings may not be transferable to single/divorced women, those from lower socio-economic or culturally-linguistically diverse backgrounds Respondents were not asked to comment on the existing barriers regarding support for partners and families; however, this is a topic worthy of further exploration. The limitations of qualitative research are also recognised. For stage one, only 26 participants were interviewed, and it was not possible to determine if the issues discussed were representative of all individuals' experiences, therefore limiting generalizability of the findings. Additionally, only women and partners who were prepared to share their stories of survivorship volunteered to participate. Therefore, women and partners who did not have problems during survivorship may not have come forward to join the study, further potentially reducing the generalizability of findings. For stage two, the sample size was small, with a response rate of 61%, and it is, therefore, probable that this was not a representative sample of all health providers, limiting the generalizability of findings. Questionnaire respondents were de-identified to protect the privacy of individuals and organizations, limiting further analysis linking health providers to specific service delivery.

Conclusion

This study reflects a range of unmet physical, psychological, psychosocial and relationship needs for women and their partners during breast cancer survivorship. Health providers purported to meet these needs using a range of supports and resources delivered using various tools, resources and formats including some use of SCPs. However, the findings of this study highlighted many inconsistencies across the various contexts of care regarding women's preparation for survivorship, awareness of supports, access and co-ordination of services, contributing to the range of unmet needs reported by women and their partners.

Further investigations are required to determine how to best to facilitate improved survivorship practices including a focus on improved care co-ordination and the development and use of a suitable SCP to assist in meeting individual needs. As the number of Australian women diagnosed and surviving breast cancer is predicted to increase in the future, services must be person-centred, cost effective and targeted to meet the expressed needs of individuals (Australian Institute of Health and Welfare, 2012).

Acknowledgements

Gratitude is expressed to the many women and their partners who participated in interviews and service providers who completed questionnaires. Thanks also to BCNA for their assistance with recruitment of participants in stage one and Dr Elinda Lee for her assistance with the literature review.

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Chapter 6 Publication Four ‘The implications of women’s activity limitations and role disruptions during breast cancer survivorship’

This publication represents the findings of stages one and three of the research. In stage one, in-depth interviews were completed with women survivors of breast cancer and their partners and addresses the first objective of the research; ‘identify the met and unmet occupational needs of women and their partners during the early survivorship period’. Questions used in the interviews can be found in Appendix C.

Stage three consisted of the delivery of focus groups with two essential aims. The first aim was to explore the activity limitations and role restrictions of women, their partners and couples during the early survivorship period. The second aim was to recommend a suitable framework to assist women and their partners to resume valued activities and roles during early survivorship. Topics and key questions used during the focus groups can be referred to in Appendix G. The publication outlines the background literature, qualitative research methods, triangulation of stages one and two findings and provides a discussion of results, presented as themes. These are comprehensively discussed with the conclusion that many women and their partners continue to experience disruption to valued activities and roles following the completion of treatment for breast cancer. Key recommendations include access to rehabilitation as well as the availability of multi-disciplinary services and supports.

The findings of this publication assisted to develop the key questions utilised in the Delphi process implemented in stage four of the research and discussed in Chapter seven.

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Primary

WOMEN'S HEALTH

The implications of women's activity limitations and role disruptions during breast cancer survivorship

Women's Health
Volume 14: 1–11

DOI: 10.1177/1745505718756381
journals.sagepub.com/home/whe
SAGE

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Abstract

Early survivorship is a time of critical transition for women survivors of breast cancer as they attempt to resume functional activities and important life roles. This study aimed to explore the challenges of women and their partners as they attempted to resume activities and roles, identify unmet needs and make recommendations regarding a suitable framework to support women and partners to recommence valued activities and important roles during early survivorship.

Qualitative methods utilising in-depth interviews of women (n = 18) and their partners (n = 8), and two focus groups (n = 10) were completed in Perth, Western Australia, between June 2014 and April 2015. These methods were used to facilitate women and partners' views regarding the resumption of previously meaningful activities and important life roles during early survivorship. Questions addressed their individual and shared experiences concerning self-care, leisure, social and productive activities and important roles. Thematic analysis was employed to determine themes.

Women and partners reported significant impact on their ability to engage in valued activities, resulting in changes to participation in meaningful roles. Three themes were determined: (1) ambiguity regarding survivorship prevents resumption of activities and previous roles, (2) breast cancer continues to impact a couples' relationship during survivorship, and (3) support is needed to assist women and partners to resume activities and important roles.

This research provides evidence suggesting that the ongoing symptoms of breast cancer treatment continue to impact many women and their partners, as they attempt to resume functional activities and important life roles during early survivorship. Disruption to these valued activities and roles may influence women and their partner's health and well-being during early survivorship and extend beyond this period. Rehabilitation following cessation of treatment could be offered as required to facilitate access to multi-disciplinary services and supports for both individuals and couples.

Keywords
activities, breast cancer, partners, rehabilitation, roles, survivors

Date received: 6 June 2017; revised: 30 November 2017; accepted: 8 January 2018

Introduction

Survivorship is a crucially important period that follows active treatment for breast cancer.[1] The term 'survivorship' is used in many different ways to describe a variety of post-treatment time periods. These include the period immediately following cessation of treatment, following completion of adjuvant hormonal therapies (up to 5 years following diagnosis) and even the time extending to the end of life. However, the critical period impacting women considerably is termed 'early survivorship' and this is recognised as being the time following cessation of active treatment to 5 years.[2] During this transition, women attempt to resume their usual functional activities and important life roles.[3,4] Functional activities include the physical, psychological and social

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components of a person's life and are essential to their well-being, allowing them to participate successfully in society.[5]

Successful functional activity engagement refers to an individual's capacity to complete desired activities – those tasks that they need to do or want to do during everyday life.[6] These activities include the relatively mundane daily tasks of showering and dressing, to more complex tasks including homemaking, childcare and those associated with leisure, social participation and employment. These activities require the successful interaction of physical, psychological, emotional and social systems of the person in order to complete them. Roles are associated with socially and culturally prescribed activities where certain rights, obligations and behaviours are expected.[6] Examples of roles include parent, friend, carer, worker, partner and homemaker.

While many women survivors experience minimal disruption to activities and roles during survivorship, others report that they are unable to complete functional activities and participate in roles in a satisfactory manner.[7,8] Their ability to resume these previously important activities and roles is impacted by a range of ongoing physical, psychological, social, relationship and emotional difficulties. There are a myriad of factors that contribute to the way that women survivors of breast cancer resume their lives following treatment including resilience, coping skills, social networks and support, age, co-morbidities and pre-existing medical history.[1,9,10] Furthermore, for some women, treatment for breast cancer may result in a variety of complications consisting of infection, treatment-induced early menopause and complex psychosocial issues including anxiety and depression. The resultant consequences of these well-documented problems include chronic pain, lymphoedema, fatigue, depression, cognitive impairment, poor body image, intimacy and sexual functioning difficulties, as well as fear of recurrence of cancer.[11–14]

For some women, the problems associated with treatment have significant consequences on their ability to complete self-care, home management and leisure, as well as social and productive activities, resulting in long-term disruption to their daily lives. Previous social supports may no longer be available and, for some, returning to their previous work responsibilities may be difficult. Completing important functional activities and participation in meaningful roles within an individual's environment is linked to societal and cultural practices.[6] Following treatment cessation, women are expected to balance the roles of parenting, family life, employment and taking care of their own health.[15] Engagement in desired activities and roles is considered to be an important enabler contributing to an individual's sense of personal competence, identity and health, as well as assisting to meet societal and others' expectations regarding successful participation in daily life.[16,17]

The breast cancer survivorship literature affords little attention to the links between successful functional activity engagement and role participation with improved health and well-being.[18] However, the value of successful participation in meaningful activities and roles is known to have significant health benefits including improved self-esteem and motivation, decreased stress and anxiety, improved physical capacity and intellectual challenge, meaning and purpose.[19,20] The long-term consequences of activity limitations and role restrictions have been associated with serious health concerns including stress-related illnesses, physiological changes, depression, anxiety and social isolation leading to chronic disease and decreased quality of life.[21,22]

Women survivors of breast cancer who have partners have unique needs as their daily interaction and relationship as a couple are interdependent. Some partners may experience psychological distress, further disruption to their own routines and activities and there is potential for complex adjustment problems for these individuals.[23] Partners may become withdrawn, detached or feel abandoned by their spouse and have difficulty discussing their thoughts and feelings.[24] Although they each have individual needs at this time, the dyadic nature of the relationship between women and their partners also suggests that they may experience challenges to shared activities and roles including parenting, homemaking and family responsibilities, community engagement and social commitments.[25] This disruption to shared activities and roles indicates that increased attention is required to the shared needs of couples as they attempt to negotiate and accommodate changes during survivorship.[26,27]

Given that more research is needed to fully understand how women, together with their partners, resume valued activities and important roles during early survivorship, this study aims to (1) explore the challenges of women and their partners as they attempt to resume their usual functional activities and roles in the early survivorship period, (2) identify the unmet needs and recommendations of women and their partners in relation to resumption of these activities and roles, and (3) propose recommendations to assist women and their partners to recommence valued activities and important roles during early survivorship.

Methods

Qualitative methods, in the form of in-depth interviews and focus groups, were used to elicit women and their partners' views regarding the resumption of activities and roles during survivorship. A phenomenological approach was employed to guide the research process and was suited to this study as it allowed researchers to understand the 'lived experience' of the participants.[28] Purposive sampling was used to recruit participants for the study including newspaper advertisements in the community newspaper, Breast Cancer Network Australia (BCNA) and a community radio station. Women were eligible to participate if they met the following inclusion criteria: age 35–70 years, treatment for breast cancer was completed between 6 months and 5 years previously (excluding adjuvant hormone therapy) and spoke English. Potential participants were excluded if they were currently undertaking 'active' treatment (surgery, chemotherapy or radiotherapy) or were receiving palliative care. Partners were invited to join the study during initial contact with their spouse, if they identified as having a significant relationship with their partner (married or de facto) and spoke English.

In total, 21 women who made contact using the various recruitment strategies were screened for eligibility. Two women did not meet the criteria of having completed treatment within the previous 5 years, and one participant withdrew due to scheduling difficulties. Of the 18 women interviewed, 14 were married or in de facto relationships, with all of these partners eligible to participate in interviews. However, only eight partners were willing to participate in interviews. Review of the literature was completed to develop an interview guide consisting of a series of questions and prompts and was used to direct the interviews of women participants and their partners. A pilot was conducted resulting in minor modifications to questions. Interviews (duration of 60–90 min) commenced with the collection of demographic information (Table 1). Women were asked to describe their experiences regarding survivorship with particular emphasis on their usual daily activities and roles undertaken since cessation of treatment as well as the services and supports utilised.[29] Partners were then asked the same questions. All interview participants were invited to attend the two subsequent focus groups.

The two focus groups (duration of 2 h each) provided an opportunity for participants to explore issues relating to survivorship and to share personal insights with others who had also experienced breast cancer. Further opportunity was provided for participants to verify the findings of the interviews and to expand upon experiences common to individuals and couples. Each focus group included the first author (S.K.) as facilitator with second and third authors (L.R. and B.M.) assuming roles as cofacilitator/notetaker. Questions explored the needs of women and their partners following completion of treatment, the key supports needed or utilised and their suggestions for further strategies for support. Of the initial 26 participants, 10 people agreed to attend the focus groups: 4 couples and 2 women (1 woman who was recently separated and 1 woman whose partner was unavailable to attend).

Information was provided at the commencement of each interview and focus group outlining; time commitment, purpose of the interview or focus group, assurance of confidentiality, potential risks, ability to withdraw at any time and follow-up support services were available. Interviews and focus groups were conducted by S.K. at the participants' home or workplace and the researchers' workplace. The study was approved by the Human Research Ethics Committee of Curtin University (approval number: HR 51/2014). All participants provided written informed consent prior to each activity. Pseudonyms and age ranges have been used to protect the privacy of all participants for quoting information cited throughout this article.

Interviews and focus groups were audio recorded, transcribed and imported into NVivo©. Each transcript was read line by line by S.K. to obtain a preliminary overview. Thematic analysis using the six-step process described by Braun and Clarke[30] was used to review the content before assigning preliminary codes. These codes were reviewed by all three authors, further refined and assigned a final label. Saturation of the data was achieved by independent review of the themes when no new themes were identified. In order to ensure integrity and neutrality regarding the interpretation of the data, extensive peer review was completed between all three authors.[31] Interviews were undertaken by S.K., transcribed and subjected to thematic analysis. To ensure that S.K. remained objective concerning the developing themes, all three authors reviewed the initial findings, groups of coded data and preliminary themes. The final themes are the result of independent analysis, consultation and modification to best represent thematic findings. Memos were made by S.K. following each interview, again as a method of reflecting on thoughts about the information collected and ensuring that subjective responses were removed from data analysis. These methods were also used throughout the focus groups and contributed to the overall trustworthiness of the research findings.[32] Transcripts of interviews and focus groups were also forwarded to each participant to ensure accuracy, with minor corrections completed. Each stage of the research was documented, with actions reviewed representing an audit trail.

Results

The mean age of the 18 women interviewed was 52 years (range 38–69 years), most were married (n = 14), well educated with a university degree (n = 11) and working in paid employment (n = 13). Their partners' mean age was 48 years (range 34–53 years), were married (n = 8), some held a university degree (n = 4) and all were working in paid employment. The mean time since treatment completion for all women was 2 years and 8 months. Focus group demographics were similar (age, marital status, education and employment status) with a small difference in mean time since treatment completion being 2 years and 1 month. The contributions shared offer new insights into the difficulties experienced during survivorship, with three themes identified.

Table 1. Demographics of women and men participants.

Participant	Current age range (years)	Education	Marital status	Partner interviewed	Time since treatment completed	Treatment	Service type
1	61–65	University degree	Separated	No	1 year, 9 months	Bilateral mastectomy, radiotherapy, hormone therapy	Public
2	56–60	Year 11	Married	No	1 year, 7 months	Bilateral mastectomy	Private
3	46–50	University degree	Married	Yes	3 years	Bilateral mastectomy, chemotherapy, hormone therapy, preventive hysterectomy, breast reconstruction	Private
4	46–50	University degree	Married	Yes			
5	36–40	Year 12	Married	Yes	1 year, 10 months	Bilateral mastectomy, chemotherapy, radiotherapy, hormone therapy, breast reconstruction	Private
6	30–35	Year 12	Married	Yes			
7	51–55	University degree	Married	No	3 years, 10 months	Unilateral lumpectomy, chemotherapy, radiotherapy, hormone therapy	Private
8	41–45	University degree	Married	Yes	1 year, 3 months	Unilateral lumpectomy, chemotherapy, radiotherapy, hormone therapy	Private
9	46–50	University degree	Married	Yes			
10	46–50	Year 10	Married	Yes	5 years	Unilateral lumpectomy, chemotherapy, radiotherapy, hormone therapy	Public
11	46–50	Not known	Married	Yes			
12	41–45	Master's degree	Married	No	8 months	Unilateral mastectomy, chemotherapy, radiotherapy, hormone therapy	Public
13	51–55	Diploma	Married	Yes	1 year	Unilateral lumpectomy, chemotherapy, radiotherapy, hormone therapy	Mix
14	51–55	University degree	Married	Yes			
15	51–55	University degree	Married	Yes	2 years	Unilateral lumpectomy, radiotherapy	Public
16	51–55	Not known	Married	Yes			
17	51–55	Year 11	Separated	No	3 years, 9 months	Bilateral mastectomy, breast reconstruction	Public
18	46–50	Year 12	Married	Yes	2 years, 2 months	Bilateral lumpectomy, chemotherapy, mastectomy, hormone therapy	Private
19	46–50	Year 12	Married	Yes			
20	51–55	University degree	Married	Yes	1 year, 6 months	Unilateral lumpectomy, chemotherapy, unilateral mastectomy, hormone therapy	Mix
21	51–55	University degree	Married	Yes			
22	41–45	Master's degree	Married	No	2 years, 5 months	Unilateral lumpectomy, chemotherapy, radiotherapy, hormone therapy	Mix
23	66–70	Year 10	Widow	No	3 years	Unilateral lumpectomy, chemotherapy, radiotherapy, hormone therapy	Mix
24	61–65	University degree	Married	No	4 years, 10 months	Unilateral lumpectomy, chemotherapy, radiotherapy, hormone therapy	Mix
25	66–70	University degree	De facto	No	3 years, 1 month	Unilateral mastectomy, chemotherapy, radiation, hormone therapy	Private
26	36–40	University degree	Married	No	4 years, 5 months	Bilateral mastectomy, chemotherapy, radiotherapy, hormone therapy, breast reconstruction, preventive hysterectomy	Private

Theme 1: ambiguity regarding survivorship prevents resumption of functional activities and previous roles

A sense of ambiguity was evident during survivorship as women tried to reclaim a sense of 'self' and resume their previous activities and roles. All women participants agreed that while they felt grateful having survived the immediate threat of cancer; they also felt unsure about how and when to resume previous activities and roles. The majority of women stated that they experienced a conflict between their previous identity of cancer 'patient' versus 'survivor', with the weight of societal expectation being that they were now cured and had to simply get on with their lives. This indeterminate state meant that it was a challenge to easily resume their previous routines and commitments. Ongoing symptoms and adjuvant hormonal medication affected all of the women's engagement in their usual activities, with the range and severity of symptoms varying. However, pain, fatigue, poor sleep, lack of concentration and low motivation, hot flushes, anxiety, depression and poor self-esteem sometimes meant that women reported some difficulty maintaining interests and social commitments. Importantly, all women agreed that the experience of breast cancer had changed them as a person and two participants reported ongoing mental health consequences of depression and anxiety following treatment. This sense of liminality was described by Marg:

> There's a kind of a dichotomy between the anxiety of it [cancer] returning and the perception that you've got the 'new normal' and you're going back to life as normal as it can ever be…. So you're busy focussing on getting back to work, and getting back to being normal, but at the same time your life's been irrevocably changed. (Marg)

The resumption of women's usual activities and routines, including home management tasks, employment, caring for children, and enjoying hobbies and leisure, was disrupted. The majority of participants vacillated between wanting to resume these meaningful activities while trying to manage the physical and mental health challenges that persisted. These women reported that the survivorship period was the most challenging period of their breast cancer experience, stating that they needed privacy, avoided social situations and did not maintain contact with family and friends, as a way of coping with their post-treatment life. They felt conflicted during this time and were unsure whether and how to resume their usual (pre-cancer) responsibilities. Danielle discussed how this conflict impacted her usual social activities and friendships:

> We just had a few friends. They were all there in the beginning but not now … I became very reclusive, I was very cautious. I didn't let people see me when I was having a bad day, I didn't want to carry on friendships at that point so I just had probably two really close friends that know me very well and know what I need when I needed it. (Danielle)

Over half of the participants reported that resuming exercise and other physical activities were also affected. This group of women felt uncertain about their capacity as a result of ongoing symptoms including cording, lymphoedema, pain and loss of range of motion in their arm/s. Several women reported that they were not directed to appropriate supports, while others stated that they preferred not to join an exercise or support group for other women survivors of breast cancer. They did not want to be identified as having particular physical needs relating to their diagnosis and were reluctant to join adapted exercise programmes. This meant that they were unable to achieve their previous level of fitness, creating further dissatisfaction with their changed body. All participants believed that the benefits of exercise for improving fitness, relieving stress, health, wellness and weight management were impacted and this was another important activity they had to restrict, creating further frustration about how this valued activity changed. Sandra discusses her angst:

> I know how to exercise but it feels totally different and I don't want to do some light weight exercise, I thought I'd get back into boxing and all the things I used to do … it's dealing with disappointments around that and accepting it. (Sandra)

The majority of women agreed that there appeared to be ambiguity surrounding survivorship and this was further perpetuated by societal expectations, attitudes of the wider community, the media and treating health professionals. They also agreed that women who had completed treatment for breast cancer were regarded by others as a 'good news' story, having 'beaten' breast cancer. All participants lamented that the lived experience of breast cancer survivorship appeared to be hidden from others, which created an ongoing struggle as they attempted to adjust to life following treatment. Two women also commented that they did not want to identify with the breast cancer 'culture', remarking that although they recognised the excellent support that could be offered by support groups and others women who had experienced the disease; they preferred to keep their experiences private. Glenda reported difficulties managing others' expectations:

> People are telling the positive story and obviously that's good but I feel like there's another story to be told … yes I'm through it and I'm incredibly grateful but I'm now living with a different set of circumstances which are actually really difficult. I think that's the general population's view as well … you should just get on with it … but it's like grief, it doesn't go away. (Glenda)

Theme 2: breast cancer continues to impact a couples' relationship during early survivorship

A level of relationship distress during and following breast cancer was reported by the majority of couples. There were a range of difficulties identified: poor communication, loneliness, being unable to resume previously shared interests and responsibilities and feeling overwhelmed when attempting to renegotiate their previously healthy relationship. Several women stated a need to be 'selfish' and to prioritise their own needs over that of their partner. The need for privacy, time alone to understand and process the transition from treatment to survivorship, was reported as detachment from the relationship, resulting in changes to communication and less opportunity for shared activities and roles. All women participants reported significant changes regarding their important role as an intimate partner. Concern was raised about changes to their bodies as a result of treatment, lack of desire for intimacy and reduced sexual response. A total of 10 women participants completed mastectomies as part of their treatment and these women reported extensive physical and psychological changes. The surgery, coupled with persistent symptoms resulting from previous treatment and medication, contributed to ongoing relationship problems. While not all of these women required professional help to manage the resultant body image problems, two women stated that they sought further assistance from a counsellor to support them for these problems. The remaining women commented that they were still concerned about the way their bodies looked. Lara discusses how this resulted in changes to her role as a sexual partner:

> I know that I'm not quite right and it's the acceptance of this body that's not mine. It's just not who I am and I just haven't quite accepted that … How do we renegotiate this, how do we restart this [sexual relationship?] and you realise that it's really important … it does change things … and I think it changes it permanently … this is not my body anymore. (Lara)

The impact of breast cancer on fertility and childbearing was a concern for just one couple. Of the 18 women participants, all but one stated that they did not want to have more children in the future. For this woman and her partner, the breast cancer diagnosis coincided with a recent miscarriage and they were struggling to manage both of these health issues at the same time. The consequent treatment for breast cancer (bilateral mastectomy, chemotherapy, radiotherapy, hormone therapy and breast reconstruction) meant that she commenced menopause during the treatment period and this removed any opportunity to become pregnant in the future. For this couple, the emotional difficulties created by breast cancer had a serious and significant consequence on their individual roles not only as intimate partners but also as parents.

For the eight male partners who participated in interviews or focus groups, all but one reported personal changes during this time as they attempted to maintain their own roles, continuing as the primary support person for their spouse as well as juggling practical tasks including home management and childcare, paid employment and managing most of the social and emotional labour with family and friends. Their spouses also reported that their partner did not seek out help to resume their usual daily activities, roles and important relationships and that there did not appear to be any agencies or supports that offered targeted services for partners. For these individuals, the experience of 'carer' continued from the treatment period and they felt stressed, anxious, a loss of control over their lives and a conflict between caring for their spouse and family while trying to maintain their own psychological and emotional health. The majority of partners felt a sense of rejection and disconnection, resulting in intimacy problems between the couple. Furthermore, one couple questioned their commitment to each other and their future together. Chris was unprepared for how these changes would impact his relationship:

> It's a traumatic experience, it's obviously led me into an element of depression. There's a lot of things to work through which they don't kind of tell you about. So that sort of led to us sort of drifting apart quite a bit, towards Carla's recovery phase and that led to a lot of questioning of where the relationship was at. (Chris)

Theme 3: support is needed to assist women and partners to resume functional activities and valued roles

The final theme relates to a lack of recognition of survivorship being considered by health professionals as a distinct period in the comprehensive care of women with breast cancer. All of the participant women described a sense of abandonment by the supports and services that assisted them during treatment and they were unprepared for other important issues that might be encountered during survivorship. While all agreed that they were generally satisfied with the level of care regarding surveillance and prevention of cancer and agreed that their medical needs were met, the majority reported reduced availability of psychosocial supports during this time. Several women indicated that they were unclear about how to manage ongoing concerns relating to their self-image due to scarring, lymphoedema, fatigue and the side effects of medication that continued to plague them. Others were uncertain about how to seek support for the persistent psychological consequences of treatment and adjuvant medication including anxiety, mood swings, depression, poor concentration and lack of motivation. These problems impacted their success in resuming previous daily routines and activities including employment, leisure, exercise and social interests as well as their significant roles as a parent, partner, friend and/or worker. Sandra reflected on her needs:

> The biggest thing for me is the psychological support, this has been far more difficult than the physical … getting through chemo, whatever, and a lot of that is because you know no matter what public campaigns are done it's still very difficult to talk about and it's just so … intangible. (Sandra)

Information was also needed regarding reliable resources and supports to assist women and their partners with preparation for survivorship. All participants agreed that they required information regarding health and wellness, managing intimacy and sexual difficulties and coping with menopausal symptoms before treatment was completed. Importantly, all participants stated that apart from their regular annual review with their oncologist, no other follow-up care was offered. All of the women and their partners who participated in the focus groups agreed that they felt overwhelmed by the need to seek out and co-ordinate their own care due to a lack of knowledge and experience in determining what expert assistance would be most beneficial. They felt that while they may not need everything that is available, it was reassuring to know that this assistance was available if and when required. These participants also discussed the need for a formal transition following treatment cessation, offered by their general practitioner (GP), including an individualised and co-ordinated health care plan and funding for support.

Ingrid reflected these ideas:

> You need to be contacted by your GP surgery and for them to say … 'Ok now I know you've got through all of that [breast cancer treatment], so now's the time to come back and let's talk about getting a care plan or a health care plan together, which are available … You know they're well-funded, but you don't know that they're available … (Ingrid)

Our study highlights the needs of women as well as the unique needs of couples. All but one couple indicated that they required supports to assist them with managing shared concerns including relationships with children, family and friends, resuming leisure and social interests, managing the home, adjusting to the resumption of employment as well as communication, intimacy and sexual needs. These couples assumed that life would resume as usual after treatment but were overwhelmed when they recognised that they needed support to help them with resumption of their own activities and roles. Lester reiterates the need for partners to also access suitable supports:

> It's like somebody's just given you permission for delayed shock and grief and trauma … that really took me by surprise and I don't know what that means and I don't know what resources are available and I was blown out of the water a year after, not at the time. (Lester)

Discussion

The findings of this study concur with previously reported literature regarding the physical and psychological consequences experienced by many women survivors of breast cancer.[33] What our study also found was that many participants experienced difficulties resuming their meaningful activities and roles. The complex nature of these difficulties, varied models of care, inconsistent provision of information and limited access to psychosocial support all contributed to these women feeling overwhelmed and concerned for their future.[34,35] All participant women agreed that while they understood that priority was given to medical surveillance for disease recurrence and physical symptoms, they also stated an urgent need for support that considered the broader and ongoing impact of treatment for breast cancer. Their confidence, motivation and ability to complete self-care, work, leisure, exercise, social interests and homemaking tasks were impaired due to the range of complex symptoms associated with the disease and its treatments. They also sensed the weight of societal, health professionals' and others' expectations of them being a 'survivor' and most stated they felt guilty and conflicted as they were unable to simply recommence their pre-cancer lives. Consequently, the valued roles of parent, partner, friend and worker were significantly disrupted. However, five women were not in paid employment at the time of diagnosis and these individuals commented that they did not experience all of the challenges discussed by others, regarding balancing a range of roles, including that of 'worker' during this period. Similarly, only one couple did not have children and therefore did not concur with other's descriptions of managing the role of parent during this time.

Limited research is available regarding activity limitations and role disruption during breast cancer survivorship.[36] While there is a focus placed on limitations to physical activity, this is only one consideration of an individual's capacity to complete functional activities. Many other physiological and psychological factors are known to negatively influence activity performance including pain, fatigue, lymphoedema, cognitive impairment, anxiety, depression, poor body image and negative self-concept.[37,38] The majority of women participants described some difficulty with many of these issues with the resultant consequences being reduced activity engagement, disruption to daily routines, communication and relationship problems as a couple and restricted participation in leisure, social and work commitments. The findings of our study indicate that the social, cultural and health care environments also contributed to ongoing difficulties in returning to pre-cancer activities and roles.

A range of unmet needs were noted by the majority of women in this study. While some were able to resume their usual activities and roles with minimal difficulty, others experienced ongoing problems due to the physical, psychological, social, emotional and relationship problems created by the diagnosis and treatment of breast cancer. These women and their partners would greatly benefit from targeted supportive care to address their unmet needs regarding completion of functional activities and role participation. The type and composition of supportive care offered for women and their partners during survivorship varies considerably across a range of international care contexts. However, there is currently an emphasis on physical dysfunction, with little consideration of women's broader needs including psychosocial, cognitive, occupational and lifestyle concerns.[39] The results of our study reflect many of these needs, with further insights being that comprehensive survivorship care is not offered routinely and does not always consider the significant concerns noted by partners or the needs of couples.

While acknowledging that not all individuals require support or only need this for a limited period, being able to access supportive care services targeted towards the diverse and sometimes, complex problems experienced by women, could assist to address the many identified needs during survivorship. A suggested strategy for this supportive care could be identified as a form of 'cancer rehabilitation' and should be made available for those women who identify difficulties during survivorship. The term 'cancer rehabilitation' is established within the survivorship literature, with several studies indicating that rehabilitation may improve outcomes for cancer survivors, including addressing pain and musculoskeletal issues, improving endurance, a reduction in fatigue as well as addressing the symptoms of lymphoedema.[38,40] Cancer rehabilitation may take many forms, based on the models of service delivery, the availability of supportive care and the varied needs of women requiring this care.

Also noted is the great variation regarding the format that rehabilitation may be delivered, with a vast range of options including individual or group sessions, online delivery via web-based platforms, telehealth or structured programmes delivered as part of outpatient hospital or community-based care.[39,41] Further evidence supporting the use of a rehabilitation framework to improve the psychological symptoms of breast cancer is discussed by Palmadottir.[8] Other researchers have previously raised concerns regarding the lack of support for women to address activity and role restrictions, suggesting that difficulty accessing rehabilitation may contribute to these ongoing and unmet needs.[42]

Results of this study indicate that supportive care may be required by some women survivors of breast cancer and their partners. Access to rehabilitation services at the completion of treatment could facilitate the following actions: identification of unmet needs, assessment of function, determination of achievable goals, provision of information and improvement of the individual's personal resources in order to facilitate engagement in desired activities and roles.[43] Breast cancer can be considered as a chronic condition requiring well co-ordinated care, surveillance for further disease as well as strategies to minimise the long-term effects of treatment and co-morbidities. The concept of a rehabilitation approach is supported by the chronic disease literature and may be a suitable strategy for addressing the multiple, enduring and multifarious consequences of breast cancer, according to the many different contexts of care.[44]

Historically, survivorship support has focussed on surveillance of physical symptoms and prevention of further cancer and consequently guided by a medical model of care.[45] More recently, however, there has been a greater recognition that women survivors also experience many psychosocial, emotional and relationship issues requiring the consideration of alternative models of care. The findings of this study offer support towards the provision of rehabilitation (as required) during survivorship in order to facilitate access to multi-disciplinary health supports including occupational therapy, physiotherapy, psychology and social work. These health professionals complement the existing medical and nursing services and offer holistic, comprehensive supports targeting the day-to-day performance of functional activities and roles.[46–49]

For the majority of women contributing to this study, there was an expressed need to improve their awareness of suitable and easily accessible supportive services, using an individualised approach and capacity to be adapted across the various contexts of care. Assessment of need, education strategies and interventions will vary according to current limitations and personal preferences. Some women may require the assistance of a variety of health professionals to manage their ongoing symptoms: adapting self-care, leisure and work tasks, providing pain and fatigue management strategies or constructing an alternative daily routine and exercise schedule. Other supports may include developing self-management or cognitive strategies to address the psychological challenges associated with mastectomy, including poor body image or reduced self-esteem. Many side effects of treatment and hormonal therapies, including anxiety and menopausal symptoms, may respond to relaxation and stress management with many women benefitting from these interventions. In addition to the personal, social and relationship benefits associated with improvement of activity and role participation, this approach may serve to assist towards prevention of many of the long-term health consequences associated with breast cancer and its treatment.

A lack of supportive efforts directed towards partners was identified by several women participants as a significant concern and they felt that any supportive efforts offered must include partners. It has been suggested by others that the experience of survivorship is interdependent for women and partners and consideration should be given to carers/partners being 'co-users' of cancer supportive services.[50,51] In addition to partners' previously reported issues of distress, poor coping, managing family members and managing core functions, our study suggests that partner's daily participation in their usual activities and roles may be disrupted. This contributed to a range of ongoing personal, social and relationship problems as partners attempt to appraise the relationship, adapt to changes and move forward with their lives.[52]

All participant couples stated that their relationships were impacted by a range of factors as a result of diagnosis and treatment, and the lack of preparedness for survivorship as well as changes to shared roles including parenting, home management, social commitments and intimacy. Importantly, the survivorship literature also notes that for some women and their partners, the breast cancer experience may include some positive consequences relating to their relationship. Couples who shared the treatment experience by attending appointments, sharing strategies for coping and acting as each other's 'confidant' identified the cancer experience as a period of growth in their relationship.[53] Other studies comment on the extensive identity changes and dyadic coping required to successfully maintain the relationship during this period.[54,55] While our study participants did not comment that the experience contributed to positive relationship changes, several acknowledged that it created many tensions and one woman participant felt that her experience was the catalyst for separation from her husband.

For couples, the consequences of breast cancer must be considered as shared concerns and therefore any supportive approach that considers these shared needs is essential. The benefits of psychosocial interventions for couples coping with breast cancer have been reported, with recent efforts concentrating on a psycho-educative strategy for improving coping skills, problem-solving, communication and sexual functioning.[56] The results of our study further emphasise the need to broaden these efforts to address the shared concerns regarding activity and role participation of couples during survivorship, using high-quality, effective and timely supports.[57]

All participants of this study reported that they were not offered a formal plan to assist them in identifying unmet needs or direct referral to appropriate supports. The Institute of Medicine (IOM) recommends that a survivorship care plan (SCP) is implemented to facilitate survivorship care; however, the participants of this study were not offered this following cessation of treatment.[58] In Australia, SCPs are not used consistently, with many barriers identified regarding the implementation of SCPs including a lack of agreement regarding format and content, who is responsible for development, and minimal empirical evidence to support its efficacy.[35,59] With further investigation and research, an SCP used as part of ongoing care efforts may offer a timely opportunity to identify ongoing needs and co-ordinate valuable supports during survivorship.

Limitations

There are some limitations to this research; interviewing women and their partners together may have prevented either of the participants from fully disclosing information that may have been viewed as creating difficulties for their partner/spouse. However, dyadic interviews serve a specific purpose for this research, to meet the study aim of investigating the needs of couples during early survivorship. All participants were well educated, heterosexual and recruited from a large city so may have been able to access supportive services if required. Nevertheless, none of the participants appeared aware of the presence of the services and this was an important finding of the study.

The participant women and partners had similar demographic characteristics, age, marital status, education and employment status, representing a reasonably homogeneous group. However, one participant was the only individual (as well as her partner) to discuss how breast cancer impacted her fertility and prevented the couple from being able to have more children. This also meant that all women with children (with this exception) were at a period in their lives where their children were either teenagers or were not living with them. The research aim and scope prevented further exploration of issues relating to fertility, childcare and parenting and this is considered as a limitation and a topic worthy of further research.

Most participants were working in paid employment and therefore a comparison relating to individuals who were not working was not possible, with this being recognised as limitation of the research. The themes determined in this article reflect important findings relevant to this group of women and their partners and it is acknowledged that they agreed to participate because they may have been experiencing difficulties. Therefore, there the opinions of women and partners who did not experience issues may not have been captured during this research. While it may not be possible to generalise the findings of this research, the authors believe sufficient information has been provided for readers to determine the applicability of the research over different contexts of care.

Conclusion

This research provides evidence to suggest that the ongoing symptoms of breast cancer treatment continue to impact many women and their partners on a daily basis, as they attempt to resume functional activities and important life roles in the period of early survivorship. An individual's lack of engagement in functional activities and participation in valued roles may influence their health and well-being during early survivorship and extend beyond this period. The long-term consequences of breast cancer not only impacts women as individuals, but for those with partners, these are inextricably related. Rehabilitation following cessation of treatment could be offered as required, as part of ongoing supportive care in order to facilitate access to multi-disciplinary services and supports for both individuals and couples during survivorship.

Acknowledgements

The authors would like to thank women and their partners who participated in the research and to BCNA who assisted with recruitment. The authors declare that they all meet the terms of contributorship (authorship) for the work. Sharon Keesing declares that she is assigned as the Guarantor for the work.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

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Chapter 7 Publication Five ‘Identifying the contribution of occupational therapy in meeting the needs of women survivors of breast cancer’

This publication represents the findings of stage four of the research. Results of the previous three stages indicate that women survivors of breast cancer and their partners continue to experience activity limitations and role restrictions during survivorship. There appears to be gaps in the provision of care, particularly around access to rehabilitation and multi-disciplinary health supports. It is postulated that occupational therapy may have a potential role to contribute to addressing many unmet needs during this time. However, there is very limited research available to determine the value and contribution of occupational therapy for survivors of breast cancer and their partners.

This final stage aims to address the fourth objective of the research; determine the views of occupational therapists regarding the enablers and barriers impacting the provision of occupational therapy services for women survivors of breast cancer and their partners, as they attempt to resume previously valued roles and activities during the period of early survivorship.

This publication outlines the Delphi process, including the participants recruited, the research methods, key findings and discussion. The publication concludes that occupational therapy is well-positioned to address many of the barriers identified by women during survivorship, as well as recommendations for future development.

This paper represents these findings. Inclusion in the thesis as a PDF copy has been approved by the Publisher’s archiving policy. Details of this arrangement can be found in Appendix L Copyright declaration five.

British Journal of
Occupational
Therapy

Research Paper

British Journal of Occupational Therapy
1–11

DOI: 10.1177/0308022618762080
journals.sagepub.com/home/bjot
SAGE

Identifying the contribution of occupational therapy in meeting the needs of women survivors of breast cancer

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Abstract

Introduction: Little is known about how occupational therapy could assist women survivors of breast cancer and their partners who experience activity and role limitations during survivorship. This study sought to obtain views and consensus among occupational therapists regarding their potential role and the barriers and enablers to this potential service.

Method: We used a three-round classical Delphi process to determine the views of occupational therapists (*n* — 40), and sought consensus (70%) for 49 statements concerning barriers and enablers affecting occupational therapy service provision during survivorship. Thematic analysis was used to determine themes and descriptive statistics to determine consensus level and median for statements.

Findings: Forty-six statements showed consensus. Themes identified were: (a) women and partners experience unmet needs; (b) gaps exist regarding supportive care; (c) access to comprehensive survivorship support is required; (d) barriers to occupational therapy exist; and (e) occupational therapists offer many supports to improve activity and role engagement for women and partners.

Conclusion: Occupational therapy is well-positioned to affect improvements in occupational engagement and role participation for women survivors of breast cancer and their partners. However, many barriers are identified. Occupational therapists must advocate the value of occupational therapy during survivorship to facilitate women's engagement in meaningful activities and roles.

Keywords
Breast cancer, survivorship, partners

Received: 18 September 2017; accepted: 19 January 2018

Introduction

In developed countries, an increased number of women are surviving breast cancer as a result of regular screening, early diagnosis and advances in treatment, with a 5-year survival rate of between 80% and 90% (Ferlay et al., 2012). However, diagnosis and treatment for breast cancer is associated with a vast range of physical, psychological, emotional, social and existential problems (Runowicz et al., 2015). Historically, supports to address these issues during the treatment period have been provided by specialised medical and nursing services; however, recent studies have identified the benefits of a multi-disciplinary approach, resulting in a greater awareness and access to other healthcare professionals, including occupational therapy, (Silver and Gilchrist, 2011).

Many of the issues identified during treatment for breast cancer continue to affect women during the period of early survivorship (defined as up to 5 years following cessation of active treatment) and contribute to ongoing health challenges. These include chronic pain, restricted upper limb range of motion, lymphoedema, cognitive dysfunction and a fear of recurrence (Jefford et al., 2014). Other reported problems include treatment-induced early menopause as well as anxiety, depression and sexual dysfunction (Lemoignan et al., 2010). Many women also experience challenges pertaining to their self-esteem, identity and personal expectations (Fobair, 2007). Breast cancer treatment can cause chronic health problems for women that significantly affects their ability to resume previous activities, roles and relationships (Phillips and Currow, 2010). Women survivors of breast cancer report that they have some difficulty completing previously valued personal care, leisure and productive occupations (Lyons et al., 2015b).

The literature raises many questions regarding the unmet needs of women following breast cancer treatment,

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as well as the potential for holistic services and supports designed to meet these needs. Occupational therapy, offered as part of comprehensive rehabilitation, has the potential to have a significant effect on the quality of life of women surviving breast cancer, due to its focus on activity engagement and participation in meaningful roles (Hwang et al., 2015). Although there is a growing literature briefly reviewed below, the range and type of occupational therapy services for women survivors of breast cancer in Australia is underexplored, with limited knowledge regarding the potential explanation for this. The aims of this exploratory study were to establish what occupational therapists view as their potential role in supporting women survivors of breast cancer and their partners during early survivorship, and to obtain consensus regarding the barriers and enablers to occupational therapy service delivery in this field of healthcare.

Literature review

There is some evidence to support the value of occupational therapy during early cancer survivorship, although much of the published research is not specific to breast cancer. Occupational therapists provide interventions to improve cognitive dysfunction, persistent fatigue, lymphoedema and psychosocial difficulties including emotional concerns (Polo and Smith, 2017). Assistance for returning to employment and resumption of sexual activity have also been discussed (Hunter et al., 2017b). Other studies discuss the value of various physical treatment modalities to improve shoulder movement, arm function and strength (Lattanzi et al., 2010). Although these papers provide some support regarding the value of occupational therapy during the early survivorship period, several authors have identified their concerns about the lack of a holistic, occupation-focussed framework used during the rehabilitation of cancer survivors (Baxter et al., 2017).

As a result of the many physical, psychological, emotional and social issues affecting them, women survivors of breast cancer experience deficits relating to occupational performance and participation (Palmadottir, 2009). As referred to within the broader occupational therapy literature, this concept refers to an individual's engagement in activities of daily living (ADL), play, leisure or work according to their sociocultural context (Kielhofner, 2008). Using this concept as a basis for discussion, it can be concluded that the consequences of activity and role restrictions during survivorship are likely to have a significant effect on the wellbeing and overall participation of these women in the longer term (Sleight, 2017). Cancer survivors' ability to complete their usual activities including self-care, home-making and work-related tasks is often impaired and meaningful roles may also be disrupted. Fleischer and Howell (2017) concluded that women survivors of breast cancer were also often unable to resume important leisure and social activities following treatment. In a recent systematic review, researchers called for further studies examining the use of occupation-based strategies and their effect on function and participation, in an effort to address the gaps in cancer survivorship care (Hunter et al., 2017a).

Research has also identified that many ongoing issues are also experienced by family members and significant others, particularly spouses and children, during survivorship (Bowman et al., 2006). Family members may even appraise the cancer experience as more stressful than the cancer survivor, with the recognition that family members could be considered as 'secondary survivors' (Bowman et al., 2006). The resultant problems affecting couples include changes in communication and intimacy, as well as feelings of detachment and isolation during early survivorship, with a call to improve and develop the use of targeted resources during this critical period of transition (Keesing et al., 2016).

There is great variation regarding the delivery of survivorship care in Australia, including the shared care model, specialist nursing model, peer support model offered by community organisations (including non-government organisations) and various telehealth platforms (Bessen et al., 2014). Services may also be varied according to public or private healthcare funding arrangements. Women survivors of breast cancer may require a wide range of supports and services during the post-treatment period to assist them with the many occupational difficulties experienced. The traditional medical follow-up currently offered may not meet survivors' full needs due to its focus on cancer recurrence and not on psychosocial concerns, as well as the anticipated shortage of expert medical specialists available to service this group of cancer survivors in the future (Brennan et al., 2011a). This research aims to address the gaps in the literature regarding the availability of suitable supportive care for women survivors of breast cancer; further, will the type and composition of current services address women's needs in the future? Should occupational therapy be considered as an essential service in supporting women survivors of breast cancer during this period?

Method

The Delphi is a multi-stage research technique used to generate opinions and consensus on matters relating to a subject where limited data exists, develop policy and practice information or to rank priorities (Keeney et al., 2011a). Often using a mixed method approach, the Delphi facilitates the collection of data from 'expert' participants with a guarantee of anonymity, allowing for the expression of a wide range of views. The Delphi is an effective tool for obtaining information from participants located across multiple geographical areas, due to its flexibility regarding the form and type of delivery used to meet the research aims (Hasson et al., 2000).

A classical Delphi approach was used in this study over three rounds to obtain information from occupational therapist participants. As limited information was available to support the research aims, it was determined that in-depth, current knowledge relevant to the context was only available from participants who had recent experience in oncology care. Therefore, the first round was obtained from participants and used a case scenario and a series of structured questions to generate qualitative data regarding participants' views and experiences pertaining to the research aims.

The subsequent two rounds utilised the qualitative data collected previously to develop a structured questionnaire consisting of a series of statements, for the purpose of obtaining consensus regarding relevant areas of interest. The purpose of attempting to achieve consensus in a Delphi study is to represent the broad range of participant views and to determine when the research should be terminated (Diamond et al., 2014). A priori consensus of 70% agreement was determined prior to commencement of the study (Keeney et al., 2011a). Details of the study were provided, informed consent was obtained prior to commencement of the survey and participants were assured of their anonymity to each other and were de-identified using a numeric code. Efforts to achieve consensus during rounds two and three was to determine the level of agreement regarding the statements developed from round one, rather than rank the most important issues. As there is limited research regarding occupational therapy service delivery in this field of healthcare service delivery, the opportunity to obtain further text feedback in the third round offered additional data to support the overall aims of the study.

Participant recruitment and sampling

Identification and recruitment of suitable expert participants were critical components of the study design. This research used a purposive strategy to ensure that participants with relevant experience and interest in the field of study were recruited, as well as the time available to complete three rounds of surveys. Invitations were extended to potential participants using the researcher's clinical and research oncology networks and special interest groups (occupational therapists who meet to share their ideas regarding a particular area of practice).

Following initial identification, the snowballing method was also used to target potential participants (Keeney et al., 2011a). Registered occupational therapists with at least 1 year's experience (within the previous 5 years) working with people who have a cancer diagnosis, living in Australia, were approached via email. In total, 83 occupational therapists from all Australian states were identified, with 48 individuals agreeing to participate in the study, which was conducted between April and July of 2017.

Round one

Following review of the existing literature, the first round survey was constructed using a Qualtrics survey platform and consisted of six demographic questions (Table 1), a fictitious case scenario (Figure 1) and 10 corresponding open-ended questions (Table 2) relevant to address the research aims. This draft survey was piloted with three occupational therapists, with modifications made to improve clarity and comprehension. The fictitious case scenario (Figure 1) was created for this study and used to describe a variety of potential issues experienced by women survivors of breast cancer. The scenario reflects many of the concerns described by women survivors and documented in the research literature.

Table 1. Demographic characteristics of Australian occupational therapist participants.

Demographic characteristic	Number of participants ($n = 40$)	Percentage
Gender		
Male	2	5
Female	38	95
Age range (years)		
20–29	4	10
30–39	19	47.5
40–49	16	40
50–59	0	0
60+	1	2.5
Highest level of qualification		
Bachelor's degree	23	57.5
Honours degree	6	15
Postgraduate certificate/diploma	7	17.5
PhD	0	0
Number of years' experience working with people with cancer		
1–5 years	9	22.5
5–10 years	16	40
10+ years	15	37.5
Service type		
Community clinic	3	7.5
Hospital, private	3	7.5
Hospital, public	26	65
Non-government organisation	0	0
Private practice	2	5
Other (community palliative care team, not-for-profit organisation, combination, residential aged care facility, rural team, private partnership)	6	15
Service location		
Northern Territory	1	2.5
New South Wales/Australian Capital Territory	8	20
Queensland	5	12.5
South Australia	1	2.5
Tasmania	1	2.5
Victoria	14	35
Western Australia	10	25

The software program NVivo^{TM} was used to organise and collate all of the qualitative responses, with thematic analysis used to interpret the data and develop preliminary themes and statements used in round two (Braun and Clarke, 2006). This method of thematic analysis requires a six-step process to determine themes from the data, Tracey was diagnosed with breast cancer 2 years ago and had a bilateral mastectomy, chemotherapy, radiotherapy, breast reconstruction and preventative hysterectomy. Her reconstruction was complicated by repeated infections as well as lymphoedema, chronic pain and significant scarring over the surgery sites. She is currently taking tamoxifen, is reviewed by her oncologist every 6 months and anticipates further surgery to modify her breast reconstruction. Tracey previously worked as an office manager and has been married to Tom for 12 years, the couple have two children aged 8 and 11 years. Her interests include home renovations, attending the gym (has competed in triathlons), boxing classes, travel, enjoying meals with friends, gardening and attending her children's sporting activities.

Tracey returned to her previous position as an office manager approximately 6 months ago, but is experiencing difficulties due to fatigue, poor sleep and poor concentration. She is feeling anxious and concerned that she is not managing her work responsibilities as well as she hoped she would following her illness. She is concerned about the financial ramifications of reducing her work hours. Tracey is also having difficulties with gardening and resuming exercise due to pain and decreased range of motion in her right shoulder and is frustrated with her reduced fitness. She also experiences hot flushes and mood swings. She feels guilty because she is not the active, confident mum and wife she was previously.

Tracey is currently upset with her perception of her body, stating that she still feels 'broken', with a 'concave chest and a big tummy'. She has loss of sensation in her breasts and feels like 'her body isn't hers', she has gained approximately 15 kg since diagnosis, and has no interest in intimacy or sexual activity with her husband. She has trouble finding clothes to fit and avoids her previous friends and social occasions, stating that other people 'don't seem to understand why I'm not the same person any more'.

Tom is also feeling concerned about his wife's current difficulties, and reports that he thought everything would 'go back to the way it was before the surgery'. He is anxious about their lack of intimacy and sexual relationship. He finds it hard to discuss his concerns with her (or anyone else) and is worried about what the future holds for their relationship and the family. Tracey and Tom are both concerned about the cancer recurring and poor results from the breast reconstruction. Tom continues to take on a lot of the commitments relating to the children (school and sporting pick-ups and drop-offs) and is feeling overwhelmed with his day-to-day responsibilities, including full-time work and assisting with home management tasks.

Both are concerned about the future of their relationship and caring for the children.

Figure 1. Case scenario, Tracey (46 years old) and Tom (48 years old).

including reading of transcripts, determining key phrases, assigning descriptions to groups of similar concepts, discussion between all authors regarding preliminary themes, refinement and establishment of final themes and sub-themes.

Round two

The themes and sub-themes from round one were developed into 49 statements and informed the round two survey. These statements were sent to eligible participants, with an opportunity to decide their level of agreement with each statement, using a Likert scale with four options: strongly disagree, disagree, agree and strongly agree. SPSS version 23 was used to analyse the percentage of agreement for each statement, with a level of agreement of 70% determined as the minimum required for consensus. According to the literature, there is no definitive level of consensus accepted as a minimum for use in Delphi surveys, with options ranging from 51% to 80% (Diamond et al., 2014; Keeney et al., 2011a). A priori consensus of 70% was agreed upon following review of recent occupational therapy publications that used the Delphi technique, including Aguilar et al. (2013).

Round three

The round three survey consisted of the four items that did not achieve consensus in round two, with free-text options for participants to explain the reasoning for their rating. Round two statements were presented to participants: level of consensus for all of the statements, the cohort's median response and the participant's previous response. Provision of the median enabled participants to know where their individual response fell in relation to others. SPSS version 23 was used to analyse the level of consensus and median scores for the remaining statements. Thematic analysis, as described by Braun and Clarke (2006), was used to interpret the text responses from this round.

Trustworthiness

Methodological rigour was achieved using a variety of strategies over the course of the study. Member checking was completed as a result of presenting each round's summary statistics to all participants (percentage agreement and median for each statement). Round one data analysis was completed by the first author, with preliminary themes, sub-themes and statements developed, agreed and finalised by all authors. A detailed summary of each stage was

Table 2. Round one survey questions.

Q1. From your experience, which of the problems reported in the case study could be experienced by women and their partners following completion of treatment? Please provide as many as you can.
Q2. Referring to the problems identified in Q1, what kind of supports and services are needed to address these problems? Please provide as many as you can.
Q3. In your opinion, who should provide these supports and services? Please provide as many as applicable.
Q4. Does your current service offer any supports that would help Tracey and Tom with the problems reported in the case study? If so, please describe them.
Q5. If not offered at your service, where could they obtain these supports? Who would provide them?
Q6. What are the barriers or concerns regarding the provision of ongoing care for people like Tracey and Tom?
Q7. Would you refer Tracey and Tom to any other health professionals? For what reason/purpose?
Q8. What resources or tools would you use to support people like Tracey and Tom?
Q9. In your opinion how could OTs establish a role in this area of service delivery (survivorship) and promote their role?
Q10. Do you have any other comments or suggestions regarding Tracey and Tom's care?

prepared and discussed using peer review, contributing to an audit trail. Participant identities were known only to the first author and successive iterations facilitated feedback and comments from participants, contributing to overall credibility of the research findings (Keeney et al., 2011b).

Results

Round one

Of the 48 occupational therapists who agreed to participate, 40 completed the first round (83% completion). The other eight therapists were excluded from all future rounds. Occupational therapists provided free-text responses based on the case scenario. A total of five themes and related sub-themes were used to develop round two statements as follows: (a) women and partners experience a range of unmet needs during survivorship; (b) gaps exist for supportive care during survivorship for women and their partners; (c) access to comprehensive cancer survivorship support, including multi-disciplinary services, is required to meet the needs of women survivors and their partners; (d) many barriers exist that prevent access to occupational therapy services during breast cancer survivorship and (e) occupational therapists could offer a range of supports and services to improve activity engagement and role participation for women and partners during survivorship.

Round two

Thirty-seven participants completed round two (response rate of 92.5%). A priori level of 70% agreement (agree/strongly agree) yielded consensus for 45 out of 49 statements (Table 3). Four statements did not achieve consensus: 'most women experience difficulties completing ADL' (68%), 'engaging partners is difficult' (54%), 'supportive care for survivorship is unnecessarily complex' (46%) and 'a common public perception is that women who have survived breast cancer should just get on with life' (68%).

Round three

A total of 33 participants completed round three (response rate of 89%). Consensus of 76% was achieved for one additional statement: 'a common public perception is that women who have survived breast cancer should just get on with life'. Three statements did not achieve the required 70% consensus. Participants provided additional text feedback regarding these statements and these responses were further analysed and are presented as part of the following Discussion (Braun and Clarke, 2006).

Discussion and implications for occupational therapy

Findings of this study will be discussed in the context of previous research and our round three findings. These findings offer substantial insight regarding the potential contribution and barriers to service delivery regarding the role of occupational therapy in assisting women and their partners during the survivorship period following breast cancer.

Women and partners experience a range of unmet needs during survivorship

The participants agreed that most women were affected by the physical and psychosocial consequences of breast cancer affecting engagement in activities and disruption to roles and relationships, as well as the risk of developing long term physical and mental health issues. The findings of this study are consistent with the literature, which has established similar concerns across a variety of care contexts (Mols et al., 2005; Palmadottir, 2009).

One statement that did not receive consensus over two rounds was 'most women experience difficulties completing ADL'. Participant comments relating to this statement in round three were explored further, with explanations offered being that the term ADL is very broad and can encompass self-care, housework, shopping, driving and a range of other occupations, so not all women will be affected. However, participants agreed that *some* women experience difficulties with ADL, with variations between individuals due to the ongoing symptoms experienced and the amount of time passed since treatment.

Participants stated that the type and extent activity and role disruption affecting women survivors varied considerably, with women's personal attributes including attitude, motivation and previous levels of activity all contributing to successful adjustment. These findings are supported by recent literature identifying the effect

Table 3. Level of consensus and median achieved for statements in round two and three.

	Round two (*n* = 37)		Round three (*n* = 33)	
Statement	% Agreement	Median	% Agreement	Median
Theme: Women and partners experience a range of individual and shared unmet needs during survivorship				
Most women are overwhelmed by the physical health challenges experienced	81	Agree		
Most women are overwhelmed by the psychosocial challenges experienced	81	Agree		
Most women experience difficulties completing ADL	68	Agree	64	Agree
Most women experience difficulties completing leisure occupations	87	Agree		
Most women experience difficulties completing productive occupations	84	Agree		
Most women experience disruption to their roles	97	Strongly agree		
Activity engagement and role participation are affected by the use of hormonal therapies	95	Agree		
Women have an expectation that their lives will return to normal once treatment is finished	92	Agree		
Women are at risk of developing mental health issues as a result of breast cancer	92	Agree		
Support is needed for partners and children	100	Strongly agree		
Engaging partners is difficult	54	Agree	54	Agree
Partners continue to carry a 'burden of care' relating to their role as the primary support person	89	Agree		
Women experience relationship and intimacy difficulties	100	Agree		
Women experience sexual function difficulties	89	Agree		
Theme: Gaps exist for supportive care during survivorship for women and their partners				
The primary reason survivorship care is not prioritised is due to funding limitations	86	Agree		
Waiting lists for public services in survivorship care are prohibitive	78	Agree		
Supportive care for survivorship is unnecessarily complex	46	Disagree	45	Disagree
Supportive care for survivorship is poorly coordinated	87	Agree		
Support for psychosocial issues affecting women and their partners is under-resourced	92	Agree		
Women and their partners have limited awareness of available community supports	92	Agree		
Health professionals should have a high level of skill and experience to work in survivorship care	95	Strongly agree		
Women are 'lost' to non-medical supportive care services following completion of treatment	92	Agree		
Women and their partners who are located in rural settings are disadvantaged regarding access to survivorship care	97	Strongly agree		
There is a lack of standardised tools to assist health professionals who provide services to women survivors of breast cancer	81	Agree		
A common public perception is that women who have survived breast cancer should just 'get on with life'	68	Agree	76	Agree
Women and their partners are poorly informed about what to expect when treatment finishes	97	Agree		
Theme: Access to comprehensive cancer survivorship support, including multi-disciplinary services, is required to meet the needs of women survivors and their partners				
Provision of oncology rehabilitation would improve the range and type of support available to women during survivorship	100	Agree		
A survivorship care plan would assist women survivors and partners to identify needs and direct supportive services	100	Strongly agree		
A Medicare healthcare plan provided by a general practitioner would assist women survivors and their partners to access supportive services	97	Strongly agree		
A multi-disciplinary team of health professionals is required to provide services to women survivors of breast cancer and their partners	100	Strongly agree		
Health professionals should direct women survivors and their partners to the range of educational and supportive care resources available	100	Strongly agree		
Partners and families of women survivors would benefit from supports provided by community-based services and organisations	100	Strongly agree		

(continued)

Table 3. Continued.

	Round two (*n* = 37)		Round three (*n* = 33)	
Statement	% Agreement	Median	% Agreement	Median
The community would benefit from increased awareness regarding the long-term implications of breast cancer treatment	95	Strongly agree		
Theme: Many barriers exist that prevent access to occupational therapy services duringbreast cancer survivorship				
It is difficult for occupational therapists to establish a role in survivorship due to funding limitations	95	Strongly agree		
It is difficult for occupational therapists to establish a role in survivorship care as it is primarily a medical/nursing model of care	87	Agree		
Women survivors of breast cancer and their partners are unaware of the potential role of occupational therapy in survivorship care	97	Strongly agree		
Referral for occupational therapy relies on other health professionals to recognise the potential services and skills that can be provided	100	Strongly agree		
The number of community-based occupational therapy services are insufficient to support the needs of women and their partners during survivorship	95	Strongly agree		
Hospital-based occupational therapists are not able to offer sufficient services during survivorship due to workload limitations	95	Strongly agree		
Occupational therapists need to establish the effectiveness of interventions for women survivors and their partners with further research	100	Strongly agree		
Occupational therapists need to raise awareness of their role to the community, other health professionals and consumers of cancer services	100	Strongly agree		
Improved focus is needed regarding cancer and survivorship care in the education of occupational therapy students	100	Strongly agree		
Theme: Occupational therapists could offer a range of supports and services to improve activity engagement and role participation for women and partners during survivorship				
Occupational therapists are able to assist women and their partners to improve ADL, leisure and productive occupations	100	Strongly agree		
Occupational therapists are able to assist women and their partners to improve role engagement	100	Strongly agree		
Occupational therapists can assist women survivors during survivorship as they offer a holistic approach to care	100	Strongly agree		
Occupational therapy should be engaged as an essential service, supporting women throughout all phases of breast cancer care, including survivorship care	95	Strongly agree		
Regular occupational therapy assessment and intervention would assist in meeting the needs of women and their partners	100	Strongly agree		
Goal-setting is a useful tool for working with women survivors of breast care and their partners	100	Strongly agree		
Increasing the number of occupational therapists working within community-based organisations and non-government organisations could improve women survivors' access to occupational therapy services	97	Strongly agree		

ADL: activities of daily living.

of diagnosis and treatment, with ongoing difficulties regarding the performance of meaningful activities often referred to as functional deficits. Baxter et al. (2017) and Pergolotti et al. (2017) concurred that these issues were often overlooked as part of rehabilitation services and were considered as significant gaps in survivorship care.

The effect of breast cancer on family members and partners was also an important finding, with the recognition that support was needed for significant others, including partners, who continued to carry a burden of care during survivorship. Participants suggested that although most partners were usually keen to be involved, they were also coping with many challenges and juggling multiple roles. A study by Oktay et al. (2011) is consistent with our findings, reporting that although often commencing during the treatment period, partners continued to manage the responsibilities of paid employment, child care and home management tasks, all while continuing to support their spouse during this critical period. The study's participants reported that a further contributory factor was the nature of the couple's preexisting relationship; any relationship difficulties experienced prior to diagnosis affected the partner's response to ongoing issues during survivorship (Oktay et al., 2011). Participants reported that in their experience working with partners and women survivors of breast cancer, the dyadic nature of relationships, role dynamics and communication styles all influenced the level of engagement by partners during survivorship. They were less inclined to be engaged with supportive services, believing that the worst was over and life would resume as usual.

According to Segrin and Badger (2014), partners may also experience a range of difficulties affecting participation in chosen activities, roles and responsibilities, potentially creating individual and shared issues affecting long-term adjustment. The occupational disruption caused by breast cancer for both women and partners as individuals, as well as couples, may create serious disturbance to daily routines and relationships and affect couples in the longer term. There is a paucity of literature to support the value of occupational therapy to assist partners during breast cancer survivorship. This is identified as a key gap in the research and worthy of further exploration.

Gaps exist for supportive care during survivorship for women and their partners

Participants reported that there were many gaps in supportive care during survivorship with the focus of this period being medical surveillance and prevention of cancer recurrence. Although these issues were viewed as essential considerations, it was noted that psychosocial supports were often not available in the community or were under-resourced, attracted limited funding and were associated with long waiting lists. A novel finding of this study was the view of occupational therapists who felt that rehabilitation during the survivorship period was not consistently available in Australia. Existing supportive care was fragmented, with poor communication between acute care and community-based organisations. Participants also noted that for many women, an absence of information limited preparation for survivorship and the lack of follow-up for psychosocial difficulties meant that they were often ‘lost’ to services.

The statement ‘supportive care for survivorship is unnecessarily complex’, did not achieve consensus. An explanation offered by occupational therapists was that the statement could be viewed from two perspectives: first, from that of an experienced healthcare professional working within the supportive care ‘system’, and second, from what they believed to be the experiences of women themselves attempting to negotiate suitable supportive care. The participants of this study were experienced health professionals with a sound knowledge of the many variables affecting survivorship care. As such, they may not find the system complex, but one in which they can assist their clients negotiate a complex trajectory.

In contrast, participants also reflected on their work with women survivors and noted that often, women had very poor knowledge of the supportive care services available and that the individual needs of women varied considerably. These issues, coupled with limited opportunities for rehabilitation, waiting lists, ad hoc referral processes, poor coordination and communication between providers meant that many women felt overwhelmed during this time. Participants noted that the volume of information and complex care pathways to obtain support, including many variations between public and private services and availability of targeted care, was also noted to create angst for women. The participants reflected that many women and their partners would find the processes within the supportive care system unnecessarily complex to navigate independently. These barriers are also noted in the literature by others (Brennan et al., 2011b; Palmadottir, 2009; Porter-Steele et al., 2017).

Access to comprehensive cancer survivorship support, including multi-disciplinary services, is required to meet the needs of women survivors and their partners

The provision of oncology rehabilitation is varied across the many contexts of care in Australia as well as internationally. A recent Australian article by Porter-Steele et al. (2017) discussed this as a critical concern with the need for improvements regarding the availability of accessible and coordinated supportive care for women survivors of breast cancer. Participants also shared many insights regarding their experiences of working in oncology, stating that historically, survivorship care has utilised the medical model as a foundation for providing support to women. For example, a medical practitioner or nurse delivering supportive care screening, assessment or care coordination will be primarily concerned about acute surgical or treatment-related side effects (scarring, infection, medication adherence) and may not prioritise other important aspects of supportive care (cancer fatigue management, lifestyle modification, returning to work concerns, fear of cancer recurrence, mental health concerns and even relationship concerns). Working within a multi-disciplinary team, participants suggested that occupational therapists could offer targeted assessment and interventions that supplement the existing methods of supportive care, take responsibility as case managers or even take a lead role in survivorship clinics.

Use of a survivorship plan to assist in the identification of unmet needs and coordinate services achieved 100% agreement amongst participants in this study. According to Brennan et al. (2014), the use of survivorship care plans in Australia are inconsistent, due to a lack of accepted standard or template regarding the format/structure and lack of individual responsibility for their development. Participants noted many other resources and actions that could improve access to psychosocial supports, including the use of a healthcare plan developed in consultation with the woman’s general practitioner and the provision of financial support for women to receive supportive services including community-based occupational therapy.

Many barriers exist that prevent access to occupational therapy services during breast cancer survivorship

Many barriers affecting the delivery of occupational therapy services during breast cancer survivorship were identified. Participants agreed that women survivors of breast cancer and their partners were often unaware of the potential role of occupational therapy in survivorship care, noting the reliance on other health professionals for referral. Hospital-based occupational therapists were unable to offer suitable services during survivorship because of workload limitations, and the number of community-based occupational therapists were inadequate to support the needs of women and their partners during survivorship.

Participants noted that while they had some opportunities for supporting women and partners during survivorship, it was often difficult because of the 'medical focus' of care, varied models of survivorship support, poor coordination of services and others' lack of knowledge concerning the value of occupational therapy in this area of healthcare. Participants agreed that a lack of evidence regarding the benefits of occupational therapy for women survivors of breast cancer was also concerning, with an urgent need to establish the effectiveness of interventions with further research. In a recent Australian study, Buckland and McKenzie (2017) reiterated these findings, with additional recommendations to improve cancer survivorship care. These included improved care pathways that provide access to occupational therapy, greater promotion of the role to healthcare professionals and dedicated survivorship content in the education of occupational therapy students.

Occupational therapists could offer a range of supports and services to improve activity engagement and role participation for women and their partners during survivorship

The findings of this study support the view that occupational therapy should be engaged as an essential service, supporting women throughout all phases of breast cancer care, including survivorship care. Participants described many daily challenges affecting women survivors of breast cancer, completing day-to-day activities and routines as well as communication and relationship challenges affecting their important roles of spouse, parent, friend and worker.

Occupational therapy has an emerging role in the acute care context during the diagnosis and treatment phase for individuals with cancer (Fleischer and Howell, 2017; Hunter et al., 2017b). Participants suggested that this could be used as a basis for which to develop the occupational therapy role during survivorship. Advocating for the value of occupational therapy with members of the wider community, the media, other health professionals and women survivors must occur using an evidence-based philosophy, comprehensive assessment, effective interventions and established outcomes. Although there is some evidence that occupational therapy is able to improve many of the physical symptoms experienced during breast cancer survivorship, the benefits of increasing occupational participation is not as well articulated (Palmadottir, 2009). Using this holistic approach, it is likely that occupational therapists could facilitate resumption of valued activities and roles in a timely fashion, resulting in less reliance on health services and consequent financial costs in the future. The benefits of occupational participation include women being able to maintain their self-worth and to achieve stability and control in daily life, contributing to recovery and improved health, wellbeing and quality of life (Baxter et al., 2017).

Participants agreed that increasing the number of occupational therapists working within community-based organisations and non-government organisations could improve women survivors' access to occupational therapy services. These organisations could offer an additional opportunity to work as part of the healthcare team, which often utilises a psychosocial model of care to support women. This would require an innovative approach to service delivery, as funding for these services often rely on fund-raising activities or access to charity-based contributions. Further suggestions could include the development of occupational therapy private practices focussed on cancer survivorship care, with reimbursement utilising the resources provided by the Australian Government's Medicare scheme (Australian Government, 2014). Occupational therapists are also able to offer 'specialty' services within supportive care that aim to address specific concerns, including interventions targeted at intimacy and sexuality, return-to-work services and group-based interventions providing education for fatigue and stress management.

Evidence to support the occupational therapy role during breast cancer survivorship is growing. Newman (2013) reported women who addressed daily challenges relating to cognitive dysfunction using a program of self-management, action planning and problem-solving strategies was effective. The use of self-management as part of routine interventions is also suggested as a way of managing the many functional, emotional and psychosocial difficulties experienced during survivorship (Baxter et al., 2017).

Occupational therapy was considered essential to assist women to re-engage in leisure and social activities (Fleischer and Howell, 2017). The value of goal-setting facilitated by a telephone-based intervention assisted women to achieve their goals relating to personal recovery and promotion of function (Lyons et al., 2015a). In their 2015 study, Hwang et al. (2015) suggested that cancer survivors (of which 53% were breast cancer survivors) could improve their symptoms of pain, fatigue, poor sleep, reduced mobility and strength using the strategies of energy conservation, relaxation, and adapted leisure and exercise programs. Further improvements to ADL and productive roles as a result of cognitive dysfunction could be achieved with the implementation of activity adaptation, cognitive strategies and the use of assistive technology (Pergolotti et al., 2016).

Limitations

Limitations are recognised as part of this research. The predetermined level of consensus being 70% was within the mid-range of previously published studies; however, it is recognised that there is considerable variability regarding consensus, with no agreed 'minimum' standard (Aguilar et al., 2013; Diamond et al., 2014). The number of participants retained between rounds was considered as high (83% between round one and round three). Participants were recruited from all Australian states; however, the proportion from each state was varied because of the number of services available in each state as well as the geographical location of these services. Selection bias was not evident as the number of participants was considered as a representative sample of potential occupational therapists across all Australian states and used strict inclusion and exclusion criteria. The views of other health professionals and women survivors of cancer were not sought, and this is recognised as a limitation. The findings of this study may not be transferrable to other locations where policies, cancer survivorship care and models of service delivery may be different to that of Australia.

Conclusion

Occupational therapy is well positioned to improve occupational engagement and role participation for women survivors of breast cancer and their partners. The limitations of the current service delivery model and barriers relating to survivorship care mean that most women survivors of breast cancer and their partners currently do not have access to occupational therapy during this period. Occupational therapists must advocate and promote the value of occupational therapy using the existing platforms available in the acute care context, and extending these to community-based contexts in order to provide services to women and partners during survivorship. Timely referral for occupational therapy may contribute to reduced reliance on traditional medical and nursing services, reduce the overall cost of care and enable women and their partners to effectively resume valued activities and meaningful roles in the future. Occupational therapists should also conduct research to evaluate their interventions to provide further evidence of value.

Key findings

Consensus across a range of issues affecting the role of occupational therapy for women survivors of breast cancer and their partners was achieved. Several barriers relating to service delivery were identified, including; the unmet needs of individuals and couples, gaps in existing models of supportive care and occupational therapy is not currently recognised or accessed as a key provider of supportive care during survivorship.

What the study has added

The study demonstrates that occupational therapists believe they have the skills and expertise to assist women and their partners to resume important activities and roles during early survivorship. Recommendations regarding opportunities to develop the occupational therapy role using further research are suggested.

Acknowledgements

We sincerely thank the occupational therapists who committed their time and expertise over a 4-month period to contribute to the study.

Research ethics

Ethics approval for the study was obtained from Curtin University on 7 April 2014 (approval no. HR51/2014). All participants received a participant information form outlining the purpose, time commitment, opportunity to withdraw at any stage, privacy and benefits of the study. All participants provided informed written informed consent to be part of the study at the beginning of each survey round.

Declaration of conflicting interests

The authors declare that there is no conflict of interest.

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

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Chapter 8 Discussion

This research aimed to explore several important issues pertaining to the survivorship period following treatment for breast cancer. These included an in-depth understanding of the occupational experiences of women and their partners following treatment, and the supports and resources accessed by women and their partners. As a result of the findings in stages one and two, further information was sought from healthcare providers, including occupational therapists, regarding the type and range of supports available and to determine whether the supports provided were sufficient to address the occupational needs of women and their partners following breast cancer treatment. Mixed methods research strategies were implemented to meet the objectives associated with each of the four stages of the research. This chapter provides a comprehensive interpretation and discussion regarding the overall findings of these four stages as well as recommendations for the development, planning and implementation of strategic services to women survivors of breast cancer and their partners.

This thesis considers the lives of women during survivorship from a perspective that is unique to occupational therapy. Where previous studies that explore cancer survivorship have considered resumption of usual activities from a medicalised or symptom-focussed approach, this thesis has focused on participation in activities and meaningful roles. This approach was taken as review of current studies indicated a dearth of information that examined the lives of women from an occupational viewpoint.

This research has identified a critical issue concerning women survivors of breast cancer and their partners, offering a unique contribution to the knowledge base in this area. The women who participated in this research experienced occupational disruption during early survivorship and this impacted directly upon their partners. During the early survivorship period, these women were unable to resume their usual activities and important roles as they had expected. Throughout treatment, partners undertook a number of activities and roles previously performed by their spouses. When treatment finished they expected to resume their previous lives, but this was not the case. They too continued to experience significant occupational disruption. Other women survivors of breast cancer and their partners in similar circumstances may also experience the same kind of disruption to desired activities and roles.

While supporting the findings of other studies that describe how women survivors of breast cancer experience a number of debilitating symptoms and concerns following treatment, this research focused specifically upon how these symptoms and concerns impacted the day to day activity engagement of both women and their partners. This research used an occupational lens to view the problem. This approach is a unique perspective which has not been identified in the survivorship literature to date. The research provided evidence to indicate that occupational therapists should take an explicit role in multidisciplinary approaches to breast cancer rehabilitation.

Research participants were not prepared for the survivorship period and were unable to obtain suitable supports to address occupational disruption. They were conflicted due to the various messages they were given about 'moving on with their lives'. They believed the messages perpetuated within society that women survivors of breast cancer were stoic and resilient and that once treatment was completed, they would be able to simply resume life as it was prior to their diagnosis. However, their own stories did not reflect this and they felt guilty and worried that they were unable to progress towards recovery.

Although the cancer literature discusses the many physical, psychological and emotional consequences experienced during survivorship, very little is known about how breast cancer impacts the manner in which women and their partners attempt to re-engage with their previous activities and roles during this critical period. This research aimed to address these gaps in knowledge and to determine recommendations for improving care during survivorship.

The research findings presented in this chapter are discussed in light of the current literature and offer recommendations to assist women survivors and their partners during survivorship. This chapter discusses the following key findings: the occupational experiences and consequences of breast cancer for women; the resultant impact of breast cancer for partners; challenges directly related to occupational disruption; and the unmet needs of couples. Recommendations to address these occupational and other needs, including evidence for the use of survivorship care plans and rehabilitation, are also discussed. Finally, a rationale regarding the value and efficacy for the inclusion of occupational therapy as part of usual care during survivorship is presented and explored, supported by the overall findings of this thesis.

8.1 Women's disrupted lives following cessation of active treatment

An important finding of this research was that women were highly unprepared for the period of survivorship. Understandably, their focus during treatment was on surviving the disease as opposed to thinking about what their lives would be like following cessation of treatment. As their active treatment was completed, women were no longer required to attend regular appointments and had minimal contact with their treatment team. They felt extremely unprepared for what to expect during this time but stated they anticipated being able to resume their usual routines and responsibilities without difficulty. The lived experience of women during the survivorship period was very different to their expectations.

Many participant women reported ongoing physical, psychosocial, emotional, occupational and relationship difficulties. They were unsure how to address these concerns. The women spoke of feeling guilty that they could not simply recommence their lives prior to the breast cancer diagnosis. Publications two and three discuss these issues, with women participants describing how these concerns, combined with managing treatment-related side-effects meant that they were overwhelmed during this transition and that this state was highly unexpected. While they undertook the required medical reviews and appointments with their designated medical practitioner/s, they felt that many of their psychosocial and emotional needs were undervalued and largely unaddressed. They expressed a sense of abandonment by their previous treating health professionals, felt alone and unsupported, and raised concerns regarding their future health.

These findings are supported by other studies describing this period of transition as critical to long-term health outcomes. Diagnosis and treatment for breast cancer usually represent a considerable disruption in women's lives (Ben-Zur, Gilbar, & Lev, 2001; Bodai, 2015). This disruption varies according to the prescribed treatment regime, but often requires some time away from usual employment, interruption of family responsibilities, the absence of leisure and hobbies as well as modifications to an individual's social and recreational life. The literature dedicated to women's experiences during diagnosis and treatment is voluminous and consistently reports the overwhelming impact of breast cancer on women's lives during this period.

Of note, the literature is considerably varied concerning the impact of breast cancer on women following treatment cessation. While some women report minimal disruption following the treatment period, many others experience overwhelming problems during this time. Important factors contributing to these transitional difficulties include a previous history of anxiety or depression, having completed extensive/extended treatment including mastectomy, and younger age (being less than 50 years) (Arndt et al., 2004; Costanzo, Lutgendorf, & Mattes, 2007). The impact of transitioning from a tertiary-based treatment environment to primary care, with poorly co-ordinated follow-up care and limited survivorship care choices are also noted as concerns (Kantsiper et al., 2009; R. Miller, 2008).

The research findings support previous literature that documents the ongoing distress experienced by women as they struggled to re-establish their usual activities, roles and responsibilities. The majority of participants stated that the time following treatment cessation was the most difficult time of their breast cancer experience. The evidence provided by the study offers an additional incentive to address the needs of women during survivorship with appropriate services.

8.1.1 The competing expectations of survivorship

A key finding of this research was the competing expectations experienced by women during survivorship. Women struggled with conflicting stories about breast cancer survivorship as their own experience did not match what they believed was portrayed in the wider community. This appears to relate to the different interpretations of surviving breast cancer. One viewpoint conveys the dominant myth in society that once a person has completed treatment for breast cancer they have ‘beaten’ the disease, heralding a happy and positive outcome. This myth is perpetuated by the media and popular culture.

Conversely very little, if any, attention is given to women survivors who struggle in their daily lives as they continue to live with debilitating symptoms and treatment side-effects. Publication four discusses how women participants attempted to manage these competing expectations during survivorship. Women stated that they felt enormous pressure to identify as being strong, resilient and empowered, having completed treatment, yet they felt guilty as they did not feel this way. They reported being conflicted about this state and consequently did not seek help for important concerns, thus contributing to resultant difficulties in the longer term. Although feeling grateful for having survived breast cancer, they continued to experience many complex symptoms and side-effects of previous and current (adjuvant hormonal) treatment, resulting in an inability to complete many of their usual activities and roles, including taking care of their home, employment, parenting, exercise routines and social obligations. They continued to be affected by breast cancer, long after active treatment had finished.

Ironically, many women participants felt that the breast cancer ‘culture’ created concerns for them and as a survivor, they did not wish to be identified as part of the wider breast cancer community and the associated ‘pink ribbon’ culture. They stated that this created an expectation that as they had survived the disease, they should simply get on with their lives and that they should be grateful for this positive outcome. While recognising and appreciating the valuable contribution of this community in raising awareness of breast cancer and much-needed funds for support and research, some women felt apprehensive and guilty about these personal views, creating further turmoil during this time.

There has been some research identifying women’s rejection of certain elements of the pink ribbon culture, reflecting the views of participant women of this study (Bell, 2014; King, 2004; Sulkin, 2011). In their 2014 publication, Gibson, Lee and Crabb discussed the illness culture of breast cancer including the underpinning concepts of individual responsibility and empowerment as well as optimism as the basis of this community (Gibson, Lee, & Crabb, 2014). What was highlighted in this publication, was that women were often portrayed as having control over their illness and health using a range of strategies including positive thinking, exercise and affirming beauty practices. These community perceptions of women being optimistic, resilient and actively engaged during the period of breast cancer survivorship, contributed to study participants feeling guilty and anxious, with little available support to address these concerns.

The literature also discusses the range of diverse experiences experienced by women during survivorship, including fear of cancer recurrence, (Northouse, 1981), ambiguous identity (L. Miller, 2012), appearance-related side-effects (Brunet, Sabiston, & Burke, 2013), as well as treatment-induced menopause, anxiety and depression (Lemoignan, Chasen, & Bharqava, 2010). In contrast, there is also evidence that discusses the positive outcomes following diagnosis and treatment for breast cancer, with many women able to easily resume their previous lives, while also reporting that this period can be considered as a time of immense personal growth. While this was not the case for any of the women in this project, it is acknowledged that those with ongoing concerns may have been more likely to volunteer for the study.

The continued problems experienced on a daily basis during survivorship appear to be under-reported by some women and this is often misunderstood by the general community. This study confirms other research that shows many women continue to experience difficulties after treatment, especially relating to ongoing symptoms. Women participants believed that the broader community and sometimes their health professional providers did not understand their continuing concerns. They felt that the ongoing difficulties experienced during survivorship were hidden from others, perpetuating continued distress during this time.

Another area where there are competing interpretations about cancer survivorship is that of cancer being considered as a chronic disease. Surviving cancer may result in persistent changes to health and well-being which can be likened to the consequences of experiencing a chronic disease and the findings of this study support this view. Hewitt, Greenfield and Stovall (2006), and Phillips and Currow (2010) determined that many cancer survivors continued to experience chronic physical, emotional and psychological co-morbidities, resulting in an increased potential for disability. Importantly, the Australian Government Department of Health recognises breast cancer as a chronic condition, along with other illnesses including cardiovascular, kidney, respiratory, eye, musculoskeletal and communicable diseases (Department of Health, 2017). Recommendations to address the consequences of these conditions include programs for prevention, management and long-term care in an effort to reduce the economic, social and health burden on individuals and the community. As a relatively recent initiative, it might be expected that the benefits of these programs are yet to reach women survivors of breast cancer, including the study participants.

The findings of this study indicate that women who have completed treatment were not considered to have a potentially chronic disease. This was evidenced by their reports of disengagement with their previous health professionals who appeared to be primarily concerned about the recurrence of the disease rather than the resultant consequences of the disease and its treatments. While recognising that surveillance for future cancer and monitoring of physical symptoms are essential elements of survivorship care, this medicalised approach may assist to explain why women felt their occupational and other needs were not validated and consequently were not offered adequate supports. The consequences of trying to accommodate the personal conflict between society’s views of cancer survivors and treating health professionals’ priorities as well as their own difficulties re-engaging meant that women were often ‘stuck’ during this time, with limited support and resources to assist them. It appears that improved recognition of breast cancer as a chronic disease at the societal and community level as well as by treating health professionals and significant others may assist women and their partners to have their needs addressed during the survivorship period.

The period of survivorship is also recognised as a time of significant biographical disruption due to the recognition that cancer is a potentially fatal illness. Many of the issues described by participants could be considered as barriers to successful transition from illness to survivorship, with contributory factors being fear of cancer recurrence, changes to self-identity and an inability to easily resume their previous routines and roles (McCann, Illingworth, Wengstrom, Hubbard, & Kearney, 2010). The notion of chronic illness as a form of biographical disruption was first described by Bury in 1982, with substantial further work documented in the literature supporting this conceptual framework. The disruptions to health caused by chronic diseases including HIV/AIDS, chronic fatigue syndrome and other types of cancer are discussed extensively in the literature, providing additional support for the findings presented in this thesis (Asbring, 2001; Hubbard & Forbat, 2012; Wilson, 2007).

8.1.2 Activity limitations and role restrictions during survivorship

The women participants of this study reported multiple activity limitations including completion of tasks relating to self-care, leisure and productive occupations. They required further support to address these unmet needs. Publication four discusses the important interaction between managing physical symptoms, psychological and emotional concerns, the ambiguity associated with survivorship and how these problems contributed to decreased confidence and poor motivation. Consequently, women were unable to participate in their desired social, work, leisure and community roles and often experienced ongoing relationship difficulties.

Publications two and three discuss the significant impact breast cancer has on women and their partners’ relationships with friends and family, work colleagues and other social contacts. Importantly, women also stated they experienced many changes to their previous healthcare supports as they were no longer required to complete treatment activities and consequently did not have frequent contact with these supports. Participant health service providers also acknowledged the difficult transition between active treatment and survivorship created many challenges for women and partners. Consequently, the contribution of important social and other relationships as well as the influence of healthcare supports, are noted to be critical environmental elements affecting outcomes during this time.

The impact of resultant symptoms on activity engagement and role participation are not well explored in the breast cancer survivorship literature and are often referred to as ‘functional deficits’ (Sleight & Stein- Duker, 2016). There is also an emphasis on how physical limitations impact activity engagement, with little focus on the complex interaction between physical, psychological, social, emotional and environmental factors and how these may impact women in the longer term (Loh & Musa, 2015). The results of this study offer important information regarding the consequences of ongoing symptoms and side-effects of breast cancer treatment, providing new insights regarding how women may continue to experience prolonged disruption to daily life. The findings offer an opportunity to view and understand these difficulties using occupational therapy theory which is a unique and underexplored strategy within the breast cancer survivorship literature. This is discussed at length in the next section regarding occupational disruption.

8.1.3 Occupational disruption

Women participants reported that they were having significant difficulty in resuming their previous roles and had limited capacity as productive and contributing members of their family and community. Participants described how they needed to accept a new ‘sense of self’ and their happiness was considerably impacted as a result of changes to their usual activities and roles. The consequences of activity disengagement and role restriction has been shown to be overwhelming, resulting in a range of ongoing concerns including occupational disruption. This concept is well documented in the occupational science and occupational therapy literature, but not in the breast cancer literature (Law, 2002; Polatajko, Backman, et al., 2007; Wilcock, 2007).

The findings of this study support the definition of occupational disruption as stated by Nizzero, Cote and Cramm (2017, p. 125); “Occupational disruption is a temporary state, characterised by a significant disruption of identity associated with changes in the quantity and/or quality of one’s occupations subsequent to a significant life event, transition, illness or injury. It has the potential to affect multiple areas of functioning, including social and emotional functioning”. Molyneaux-Smith, Townsend and Guernsey (2003) support this definition and add that occupational disruption may create a decreased sense of control and reduced social interaction contributing to isolation (Christiansen, Baum, & Bass, 2015; Rosenfeld, 1989).

There is an increasing recognition within the biopsychosocial literature that explicit links exist between activity engagement, participation in valued roles and overall health and well-being. The International Classification of Functioning (ICF) (World Health Organisation, 2013) utilises this philosophy as a framework to understand the dynamic interaction between illness, activity engagement, important environmental factors and how individuals may consequently experience substantial long-term challenges to health and well-being (Polatajko, Davis, et al., 2007). Implementation of this framework is suggested as a strategy to improve the understanding of the important links between occupational disruption and resultant changes to health and well-being for women survivors of breast cancer.

The breast cancer survivorship literature offers an extremely limited discussion regarding the importance of activity and role engagement and the findings of this study offer a unique contribution to this literature. A pilot study of women diagnosed with breast cancer conducted by Vrkjlan and Miller-Polgar (2001), discussed how disruption to daily routines could potentially impact an individual’s sense of identity. In their 2017 study of women with breast cancer, Fleischer and Howell noted that women did not return to their pre-diagnosis levels of social activity and recommended that targeted interventions were needed to address these deficits. Hammel (2004), suggested that women who were attempting to cope with chronic health issues, including cancer were also likely to have their usual meaningful occupations disrupted, resulting in feelings of incompetence and reduced self-worth. More recently, other authors have highlighted the importance of improving women’s engagement and participation and suggested reducing the potential for disability using a biopsychosocial framework such as the ICF (Amatya, Khan, & Galea, 2017; Khan, Amatya, Pallant, & Rajapaksa, 2012; Loh & Jonsson, 2016).

The findings presented in publications four and five of this thesis offer an original contribution to the survivorship literature, suggesting that occupational disruption must be recognised as an unmet need. In order to address this, and other unmet needs, activity engagement and role participation must be regarded as essential considerations during survivorship care, while also making an important contribution towards improving women’s quality of life. Results of this study provide evidence to support the view that the occupational disruption experienced by women during survivorship has significant implications for women at an individual, relationship, community and societal level. These findings are supported by other literature which suggests that when unaddressed, occupational disruption may also impact an individual’s sense of meaning and purpose, further contributing to chronic health concerns (Polatajko, Backman, et al., 2007;

Whiteford, 2004). An important recommendation from this study is that women must be provided with expert support and targeted strategies to address occupational disruption. Women need assistance to regain their sense of self-worth and identity by resuming a daily routine, meaningful activities and important roles.

8.1.4 Partners continue to experience a burden of care extending throughout survivorship

A significant finding of this research relates to the lived experience of partners during the survivorship period. Purposively sought for their opinions and experiences as essential stakeholders, publications two, three and four discuss partners unmet needs, together with a call for improved recognition of suitable services to address these needs. The participant partners of women survivors of breast cancer often assumed the role of ‘carer’, commencing at diagnosis and continuing throughout the period of treatment. Once treatment was completed, partners assumed they would be able to resume their previous responsibilities and roles. For the partners engaged in this study, the role of ‘carer’ continued to be relevant during the survivorship period and they felt conflicted between this role while trying to maintain their own personal, social, recreational, parenting and occupational roles. Like their spouses who had undergone treatment for breast cancer, they were also experiencing occupational disruption.

While much of the existing literature focuses on significant others (including partners) during diagnosis and treatment for breast cancer, there is an emerging recognition that partners may continue to experience additional problems during survivorship. The continued ‘burden of care’ expressed by partners has the potential to impact their psychological and emotional health and contribute to reduced quality of life (Girgis, Levesque, Smith, Durcinoska, & Gerges, 2017; Grunfeld et al., 2004). According to Kim, et al., (2008) the psychosocial needs of partners may escalate during early survivorship. Other studies have found a substantial correlation between the woman survivor of breast cancer and her caregiver’s distress during survivorship (Segrin & Badger, 2014). Harrow, Wells, Barbour and Cable (2008) described the period of survivorship for partners as a liminal stage for women and partners as they were unable to resume their usual roles due to the many changes and uncertainty experienced during this time.

Publication four discusses the experiences of partners during survivorship. They felt unprepared for what to expect following treatment cessation, reiterating their spouses’ sense of ‘abandonment’ by the usual medical supports that were previously relied upon. Most of the participant partners of this study were unaware of any suitable supports available to them and were uncertain about where to seek help. A reduced capacity to resume their own daily routines and obligations also threatened their ability to engage in personal, social and community roles, including previous and new hobbies and interests, resumption of employment, shared social groups and other relevant roles. This role disruption described by partners, and also noted previously by the participant women in this research, suggests that the health and well-being of partners contributes significantly to both individuals’ adjustment during survivorship. Partners’ reduced capacity for engagement and participation has implications for the current limited resources available, with an increased focus required to develop supports aimed at assisting partners to maintain relevant social, economic and civic responsibilities. The burden of care relevant for partners also increases the demand for the currently available health and welfare services within the community.

Study findings are consistent with other research stating that partners may be considered as co-consumers and may have even greater needs than the people they care for (Bowman, Rose, & Deimling, 2006; Pauwels, Charlier, De Bourdeadhuij, Lechner, & VanHoof, 2013). Many health and medical professionals do not recognise the ongoing needs of partners and may not provide essential information to assist them with the caring role or resources to support their own health (Girgis et al., 2017). Other studies confirm that the information needs of partners and access to healthcare professionals was often unsatisfactory, contributing to further distress as well as the potential for serious ongoing health concerns including anxiety and depression (Feldman & Broussard, 2006; Lambert, Jones, Girgis, & Lecathelinais, 2012; Segrin & Badger, 2010; Talley, Molix, Schlegel, & Betencourt, 2010).

8.1.5 The unmet needs of couples

Publication two discusses the many complex challenges experienced by couples. For women with partners, breast cancer often results in considerable impact not only from a personal perspective but also on their mutual relationship. Participant women stated a need for privacy and control, with partners explaining that they had difficulty understanding their spouse’s preferences and felt detached and isolated, creating persistent problems in accommodating each other’s needs. These problems, combined with changes to intimacy and sexuality, meant that couples experienced a disconnection with each other.

The breast cancer survivorship literature is varied regarding how couples adjust to these changes during this period. Some research states that although the shared experience of breast cancer is traumatic, for some couples this may result in positive growth, re-evaluation of the relationship and improvement in communication (Dorval et al., 2005; Kraemer, Stanton, Meyerowitz, Rowland, & Ganz, 2011). Other studies reflect on the range of complex variables that impact couples' ability to negotiate this period, including the quality of the relationship prior to diagnosis, access to ongoing support and resources, communication styles and use of effective coping strategies (Hack & Degner, 2004; Manne et al., 2006). The findings of this thesis support the view that a diagnosis of breast cancer and its' associated treatments creates significant pressure on a couples' relationship, with the need for timely, accessible support available during the survivorship period.

8.2 Breast cancer survivorship care

8.2.1 The rationale for rehabilitation

Publication three acknowledges that service provision for women and partners is complex. Participant health providers reported that their organisations offered a range of services including cancer surveillance and support to address the physical, psychological, emotional and relationship concerns. They also acknowledged many barriers concerning service delivery including others' limited awareness of the service, complex referral pathways between tertiary and primary care and poor co-ordination between services. Also noted was the lack of a formal plan to facilitate the transition from active treatment to survivorship. Despite services reporting the availability of these supports, most of the study participants were not aware of and did not appear to either use or benefit from these. Importantly, the women participants included in this study were young, well-educated and most were well-supported by their partners. Arguably, if these women had difficulty obtaining supports, then older women, those from culturally/linguistically diverse backgrounds or lower socio-economic groups and those without partners as supports, may be further challenged by the lack of suitable services. This finding is crucial to the overall contribution that this research makes to the literature, as it provides evidence to suggest that awareness of and referral to suitable services is critical to survivorship care. This is also a topic worthy of further investigation.

The provision of care to women survivors and their partners is challenging and appears to be fragmented, due to the multiple and complex symptoms resulting from breast cancer. As a consequence, there is a need for a range of individualised treatment options and access to varied healthcare supports suited to address these difficulties, while considering the different models of service delivery (Amatya et al., 2017; Kantsiper et al., 2009). Publication three summarises and acknowledges the complexity of survivorship care, together with the recognition that historically, care for women survivors of breast cancer has been provided by medical and nursing professionals. Understandably, this may be the result of a clinical focus on surveillance for further cancer, with models of care prioritising the prevention of further malignancies (Ganz, 2008; Jefford, Mann, Nolte, Russell, & Brennan, 2014). Currently, there is a distinct lack of acknowledgement regarding the occupational consequences of breast cancer treatment and targeted supports to address women and partners' occupational disruption are not offered as part of usual survivorship care.

The use of a biopsychosocial framework, such as the ICF (World Health Organisation, 2013) could assist to facilitate suitable supports as required, to women and their partners during survivorship (Amatya et al., 2017; Cheville, Beck, Petersen, Marks, & Gamble, 2009). As previously suggested, the ICF framework provides an opportunity to target ongoing breast cancer symptoms and their consequences, while considering the impact of other personal and environmental barriers and enablers on valued activities and participation in meaningful roles.

The World Health Organisation (WHO) endorses a comprehensive program of support for women affected by breast cancer during all stages of the illness; integrating prevention, early detection, diagnosis, treatment, rehabilitation and palliative care (World Health Organisation, 2015). Yet rehabilitation is not consistently offered to women as part of the transition from treatment to survivorship. Explanations for this deficit may relate to the multiple and varied models of care, geographical location, cost and different formats of service delivery. Cancer rehabilitation programs vary considerably in their fundamental philosophies and while a discussion of their respective merits is beyond the scope of this project, sound evidence exists for the use of rehabilitation with women survivors of breast cancer (Amatya et al., 2017; Egan et al., 2013; Ewerts & Jensen, 2011; Loh & Musa, 2015; Newman, 2013; Silver & Gilchrist, 2011).

Publication four discusses a key recommendation from this research, suggesting that for women and partners who experience unmet needs, including occupational disruption, role disengagement, complex physical, psychosocial, emotional and relationship difficulties during survivorship, rehabilitation would offer an opportunity to address these needs. While maintaining the core services offered by medical and nursing professionals, women and partners may benefit from the services provided by a team of multidisciplinary health professionals including occupational therapists, physiotherapists, social workers, nutritionists and others, as appropriate. Importantly, the findings presented in publication five suggests that occupational therapists could offer a significant contribution towards the rehabilitation of women and their partners. As part of a co-ordinated cancer rehabilitation program, assessment of occupational needs, assistance for developing short and long-term goals and the provision of suitable interventions would address the current activity and role deficits described by women and their partners. Access to and use of rehabilitation services may offer an important contribution to improvements in women and partners health and well-being during survivorship.

As identified by the participants of this research, there appears to be some difficulty regarding referral to and co-ordination of focused care for both women and partners during survivorship. Understanding and navigating the system of care was reportedly difficult and it was suggested by participants that a ‘case-manager’ or ‘patient navigator’ may also assist to identify and prioritise women’s concerns, co-ordinate appropriate services, advocate for the woman and her partner and facilitate communication between stakeholders. As discussed in publication three, women and partners reflected that they felt overwhelmed when attempting to identify and negotiate their own supports and services during survivorship and suggested that this was due to a lack of preparedness and awareness of suitable supports as well as the complexity of the current health system.

In 2016, the Clinical Oncology Society of Australia (COSA) published its ‘Model of Survivorship Care’ and position statement outlining the critical components of survivorship care (Clinical Oncology Society of Australia, 2016). This model does not recommend that rehabilitation is included as part of usual care, but suggests that some cancer survivors may benefit from a rehabilitation plan, access to a (medical) rehabilitation specialist and that rehabilitation may be a suitable strategy towards achieving wellness following cancer treatment. The findings of this study suggest that many women survivors of breast cancer have unmet occupational needs that could be addressed by rehabilitation. While acknowledging the substantial financial and personnel resources required to facilitate this support, international studies support the use of rehabilitation during this period (Amatya et al., 2017; Easley & Miedema, 2012; Loh & Musa, 2015). A recent publication suggested that rehabilitation may be underutilised for women survivors of breast cancer (Stubblefield, 2017). Furthermore, results of this thesis support the inclusion of partners during all stages of the post-treatment period, including rehabilitation and during survivorship.

Also recommended by COSA is the use of a 'wellness and recovery-oriented' approach to the care of all survivors of cancer. The definition of wellness used in this approach is that stated by WHO: "the optimal state of health of individuals and groups. There are two focal concerns: the realisation of the fullest potential of an individual physically, psychologically, socially, spiritually and economically, and the fulfilment of one's role expectations in the family, community, place of worship, workplace and other settings." (Smith, Tang, & Nutbeam, 2006, p. 344). This definition places a strong focus on the crucial links between health and role participation, further supporting the findings discussed in this thesis.

8.2.2 Considering the needs of individuals and couples in the provision of survivorship care

The findings of this thesis support the call for improved attention and resources offered to women and their partners to assist them with the management of the ongoing and often complex difficulties outlined throughout the thesis. Publication two discusses the interrelated needs of couples as dyadic, emphasising the significance of this interaction and this is an important consideration when determining suitable services to assist women and partners in maintaining their activities, roles and relationships during early survivorship. It is also noted in Publication three that supportive services also vary considerably according to the type of resources offered, availability of health professionals and the woman's own knowledge of these resources. Navigation of the available health 'pathways' during survivorship is recognised as complex.

Findings suggest that when a couple is dealing with a major illness such as breast cancer, the extent to which the woman adjusts to the situation plays a key role, not only in her own well-being, but is also inextricably linked to her partner's health and well-being. This research supports the view that both women and their partners should be included in continued survivorship care efforts.

As stated in the research literature, early and accurate diagnosis, as well as comprehensive medical management of breast cancer is consistently offered in developed countries; however, the provision of survivorship care varies considerably (Brennan, Butow, Spillane, & Boyle, 2014; Porter-Steele, Tjondronegoro, Seib, Young, & Andersen, 2017). Importantly, while medical surveillance for breast cancer and the management of ongoing symptoms is understandably highlighted, the social, emotional, psychological, relationship and resultant occupational needs of women are often less prioritised (Janz et al., 2014; Runowicz et al., 2015).

Recent literature supports the findings of this study and emphasises the need to make survivorship care resources available to both women and partners due to the nature and interdependence of this relationship (Dorros, Card, Segrin, & Badger, 2010; Traa, DeVries, Bodenmann, & Den Oudsten, 2015). Most interventions during survivorship are focused on the woman survivor of breast cancer and look at how her partner’s actions impact levels of stress and adjustment (Berg & Upchurch, 2007). Other studies indicate the necessity of including partners in psychosocial interventions for chronic illness (including cancer) and suggest that this approach is more effective than those provided solely to the woman (Badr & Krebs, 2013; Regan et al., 2012). Hodgkinson and colleagues (2007) also suggested the need for separate and concurrent assessment of those affected by cancer as a way of determining the unique needs of both individuals as well as couples.

8.2.3 Mandatory use of survivorship care plans

Publication one provides a comprehensive appraisal of the survivorship literature and discusses the varied opinions concerning the use of survivorship care plans (SCPs) as part of usual care. This systematic review reports a range of considerations regarding the implementation of SCPs as part of usual care due to a number of factors including the person responsible for completion, content and format, as well as varied evidence to support its use. These findings are supported by others (Daudt et al., 2014; Grunfeld et al., 2011). Additional evidence suggests that SCPs may be a valuable tool to identify and manage symptoms, offer surveillance for further disease, improve communication and co-ordination between stakeholders, and offer a formal transition from an illness-focused treatment model to a wellness model during survivorship (Burg, Lopez, Dailey, Keller, & Prendergast, 2009; Salz & Baxi, 2016). The Clinical Oncology Society of Australia recommends the development of a SCP, together with a treatment summary, comprehensive needs assessment, improved care co-ordination and stratified pathways of care to assist cancer survivors (Clinical Oncology Society of Australia, 2016).

Although mandated in many other countries as an essential component of comprehensive survivorship care, SCPs were not offered to any of the participant women in this research. As discussed in publications two, three and four, women and their partners expressed the need for a formal plan and strategy to assist them to record their treatment, document unmet needs, engage suitable supportive services and facilitate communication and co-ordination between stakeholders. Importantly, participant women also stated that the use of a SCP would offer an opportunity to establish a dialogue with health professionals concerning their unmet needs, which were currently unacknowledged. Health professionals could assist with the development of a suitable plan to determine women's future healthcare needs.

Participant health providers also stated that SCPs were not used consistently during the post-treatment period. For the 29% of services who used SCPs, the content assisted to facilitate resources for ongoing needs (including psychological support), healthy lifestyle information, treatment summary and follow-up schedule, referral for other supports and identification of possible late side effects of breast cancer treatment. The findings of stages one, two and three provide valuable support for the introduction of SCPs prior to cessation of treatment. Furthermore, they may assist to improve preparation for survivorship, offer a link between existing and future services, provide a communication tool for all stakeholders and include information and strategies to improve the many unmet needs of women and their partners. As a 'living' modifiable document, SCPs offer women and their partners an opportunity to direct and navigate their individual and shared transition from treatment to survivorship and potentially beyond this period.

8.3 Occupational therapy as an essential service during survivorship

The overall findings of this thesis indicate that occupational therapy could assist women and their partners to address their unmet occupational needs during survivorship, with publication five offering a variety of recommendations outlining how this might be effected in practice. Occupational therapists who participated in stage four of the research supported many of the findings of previous stages of the research. They suggested that women's ability to complete self-care, leisure and productive activities was influenced by diagnosis, active treatment, adjuvant hormone therapy, attitude to illness, motivation, previous levels of activity and environmental barriers. As a consequence of this occupational disruption, women's important roles and relationships may be significantly impacted, further contributing to diminished health and well-being.

To date, limited research exists regarding the use of occupational therapy for women survivors of breast cancer; however, evidence does exist regarding the value for cancer survivors more generally (Baxter, Newman, Longpre, & Polo, 2017; Buckland & Mackenzie, 2017; Hegel et al., 2011; Hunter, Gibson, Arbesman, & D'Amico, 2017a, 2017b; Pergolotti, Cutchin, Weinberger, & Meyer, 2014; Sleight & Stein- Duker, 2016). Research exploring the use of occupational therapy for women survivors of breast cancer is emerging, with some recent evidence to substantiate the role. As a member of a multidisciplinary team of health professionals, occupational therapists have the capacity to provide person-centred, holistic evaluations and interventions to target the personal, leisure, social, productive and community activities of women survivors of breast cancer during survivorship (Polo & Smith, 2017; Silver & Gilchrist, 2011).

Participation in valued activities and roles may assist women survivors of breast cancer to maintain a sense of stability, control and self-worth, contributing to recovery, wellbeing and quality of life (Baxter et al., 2017; Lambert et al., 2012). Evidence is available for specific occupational therapy interventions including goal-setting, psycho-educational support programs, mindfulness training, self-management strategies, energy conservation and cognitive-behavioural therapy (Hwang, Lokietz, Lozano, & Parke, 2015; Loh, Packer, Chinna, & Quek, 2013; Lyons, Svensborn, Kornblith, & Hegel, 2015; Newman, 2013).

This emerging evidence, together with the findings of this study, offer a unique contribution to any future rehabilitation efforts for women survivors of breast cancer and their partners. Integral to the argument previously presented regarding the need for rehabilitation using a biopsychosocial framework, examining the occupational and role difficulties from an engagement and participation perspective as opposed to a medicalised, symptom-focused approach is supported by occupational therapy philosophy. Publication five outlines the views of occupational therapy participants regarding the consequences of breast cancer for women and partners. It documents how these consequences impact engagement in activities and disruption to roles and relationships, as well as how they increase the risk of developing long-term physical and mental health issues as a result of unmet needs.

The usual roles assumed by the women participants of this study included self-maintainer, worker, volunteer, sports-person, friend, parent, partner, daughter and sister, as well as many others. The extent to which women experienced difficulties with these roles and associated activities varied within the group of participants. While some women stated they had problems resuming social roles, including that of a friend, sister or daughter due to symptoms such as pain, fatigue, weight gain or anxiety, others did not. Conversely, many participant partners attempted to engage in social roles during the survivorship period, but were concerned that their spouses were required to assume other roles in their absence (eg, home-management, shopping, child-care) and exacerbated existing symptoms. These examples and many others shared by women and partners, as well as the dearth of suitable supports, meant that the health and well-being of individuals and couples continued to be significantly impaired during survivorship.

Publication five also emphasises the previously discussed variables impacting service delivery in this healthcare field, confirming that complex and poorly co-ordinated pathways of care, as well as limited opportunities for rehabilitation, may result in gaps in service delivery, particularly for women with complex occupational needs. The occupational therapy participants included in this study identified that a multi-faceted strategy was required to introduce and facilitate an occupation-focused approach to rehabilitation as part of service delivery. Participants also recognised the important role of partners in contributing to a successful transition during survivorship as well as the potential for these individuals to experience many difficulties relating to their own occupational engagement, as a result of coping with multiple demands and roles during survivorship.

Occupational therapy participants suggested that the use of a biopsychosocial framework to address the unmet needs associated with breast cancer offers an opportunity to work in collaboration with other members of the multidisciplinary team. Yet, many barriers were noted, including: a lack of awareness shared by health professionals as well as women and their partners, regarding the potential role of occupational therapy; the historical influence of the medical model facilitating breast cancer survivorship care; and a lack of occupational therapists practising in survivorship care contexts.

The potential for the profession to contribute to improvements in suitable care for women survivors of breast cancer and their partners is supported by the overall findings of this research. Occupational therapists must practice according to the professions’ theories and philosophy as well as using an occupational therapy model to ensure the person, environment and occupation factors are considered during all stages of the occupational therapy process. This recommendation also ensures that the profession offers a strategic evidence-based approach and does not offer isolated assessments and interventions which do not offer a comprehensive approach to women's overall care during survivorship.

This potential relies on the promotion of the occupational therapy role using a multi-factorial approach, including the education of women affected by breast cancer, their partners, health professionals and the community, as well as the publication of further, high-quality evidence. It is also possible that improving women and partner's occupational engagement and role participation in the early survivorship period may assist to reduce the burden on health services and the associated cost of future health care.

The potential to examine the transferability of the findings to other cancer types is also worthy of further research. Occupational therapists could use their growing reputation in the acute care context of oncology practice to provide much-needed services during survivorship. The potential for research regarding the cost effectiveness of occupational therapy services using pilot studies are worthy of further exploration. An innovative approach to service delivery is required, particularly to develop a presence in primary care contexts including private practice, community clinics, non-government organisations (NGOs) as well as charitable breast cancer organisations. Additional contributions to the research literature could include investigating the cost-effectiveness of proposed services and interventions used as part of rehabilitation, particularly for return to work services where productivity and contribution levels could be measured. As a recent Commonwealth Government initiative, engagement of occupational therapists in Health Care Homes may offer another potential opportunity to provide services to women and partners during survivorship (Department of Health, 2018).

8.4 Strengths and limitations of the research

Methodological limitations for each stage of the research have been noted and discussed in chapter three. These include: the relatively homogenous sample of participants; use of dyadic interviewing strategies; the total number of service providers may not have been captured; and a lack of definition regarding what constitutes consensus in a Delphi study. Caution is also noted concerning the generalisability of the findings, due to the nature of the research, limited geographical location and small sample sizes for the various stages. A larger study may provide additional data to further enrich the findings, for example the recruitment of participant women, partners and health service providers from all Australian states.

Further consideration must be made regarding the limits of the research to examine women survivors of breast cancer and their partners, without considering the impact of the illness on other family members. Publication word limits, the choice of peer-reviewed journal types and the limits associated with completing this thesis in a limited period of time prevention further exploration of this topic. However, there is a recognised need to consider the impact of breast cancer for family members and other significant people in the lives of women survivors and this is suggested as a topic for future research. As the research targeted women survivors aged between 35-70 years, it was not possible to explore many issues relating to fertility, childcare and parenting and this is considered as a limitation and a topic worthy of further exploration. Importantly, the women and partners who participated in the different stages of the research were heterosexual, limiting the unique perspectives that may have been provided by same sex couples, however no same sex couples volunteered.

Demographics also indicated that the socio-economic status of couples was comparatively high and that the particular needs of individuals from low socio-economic groups were not represented. All participants were recruited from a large city and therefore may have been able to access services and supports. All participant women were married and therefore findings may not be generalised to single/divorced women.

Recommendations are articulated in a manner that may not consider the economic components of service delivery and while the implementation of rehabilitation and use of occupational therapists would be valued in this area, further research must be undertaken to examine the efficacy of these suggestions.

Some potential strengths are also noted; although the research focused on breast cancer only, the findings may be relevant to other people who experience biographical and/or occupational disruption due to a life-threatening illness, eg; other cancer diagnoses or serious life-limiting illnesses. The findings support the use of a biopsychosocial framework for breast cancer survivorship care and provide further evidence to suggest that the care of women survivors of breast cancer and their partners must be diversified to address their many physical, psychological, emotional, social and resultant occupational needs.

Also noted as an artefact of the research process is the possibility that only women who experienced difficulties volunteered to contribute their stories, whereas others who experienced fewer problems did not. Conversely, it is feasible that the women most impacted by breast cancer may not have had the motivation or confidence to contribute to this study. What is critical, is that the women participants who contributed to this research emphasised the need for others, including family, friends and treating health professionals to consider their unmet occupational needs during survivorship as having the potential to continue to disrupt their lives for extended periods.

8.5 Conclusion and recommendations for further research

The findings of this thesis indicate that many women and their partners experience difficulties adapting to the changes in valued routines, activities and roles during early survivorship. As the number of women diagnosed and surviving breast cancer continues to grow, it will become increasingly harder for existing healthcare and support systems to meet the demands for services placed upon them. An evidence-based and co-ordinated approach is essential to meet the occupational needs of these women and their partners. The research findings highlight the complex nature of breast cancer survivorship, due to the many and varied models of care and support available, the number of potential stakeholders involved, limited preparation for survivorship and failure to identify partners as individuals with their own unmet needs. Women and their partners would benefit from rehabilitation and the use of a formal care plan, with occupational therapists positioned to play an integral role in service delivery.

Survivorship following treatment for breast cancer is an extremely complex period for women and their partners. This thesis has indicated four key findings which are novel to this research area and generally underexplored in the broader survivorship literature. These are noted to be: women and their partners experience occupational disruption during survivorship, many women and partners experience difficulty resuming meaningful activities and roles and women may benefit from access to formal rehabilitation that assists to provide targeted support during this period. Occupational therapists are well equipped to address these occupational engagement and role participation needs of women and partners during early survivorship.

However, the profession is challenged to ensure that development and establishment of this role is integrated, evidence-based and financially justified. Suggestions for future research include an exploration of occupational disruption for other survivors of cancer, to determine if similar needs are identified and to justify the efficacy of occupational therapy. Pilot studies examining the contribution of occupational therapy for women survivors of breast cancer could be implemented using existing models of outpatient and community care. Opportunities for these studies currently exist in occupational therapy practice locations such as outpatient chronic disease, survivorship and lymphoedema clinics, mental health and wellness clinics, private practice and as part of medical (GP) clinics.

The addition of further robust studies are also needed to complement existing research examining the occupational therapy role in facilitating return to work, improving cognitive symptoms created by ‘chemobrain’, lymphoedema management and stress-management programs. Although survivorship care plans have historically been implemented by medical and nursing professionals, the potential contribution offered by occupational therapists to this goal-setting tool should be explored. The findings of this thesis represent a largely homogenous group of participants. For this reason, additional studies examining the transferability of key findings to single, divorced, culturally and linguistically diverse women as well as those from rural and low socio-economic locations is proposed. A significant finding of this thesis is the impact of breast cancer on partners. Further studies are suggested to explore the potential for occupational disruption for partners and the role that occupational therapy may have to address this disruption, as well as the broader implications for family and significant others.

8.6 References

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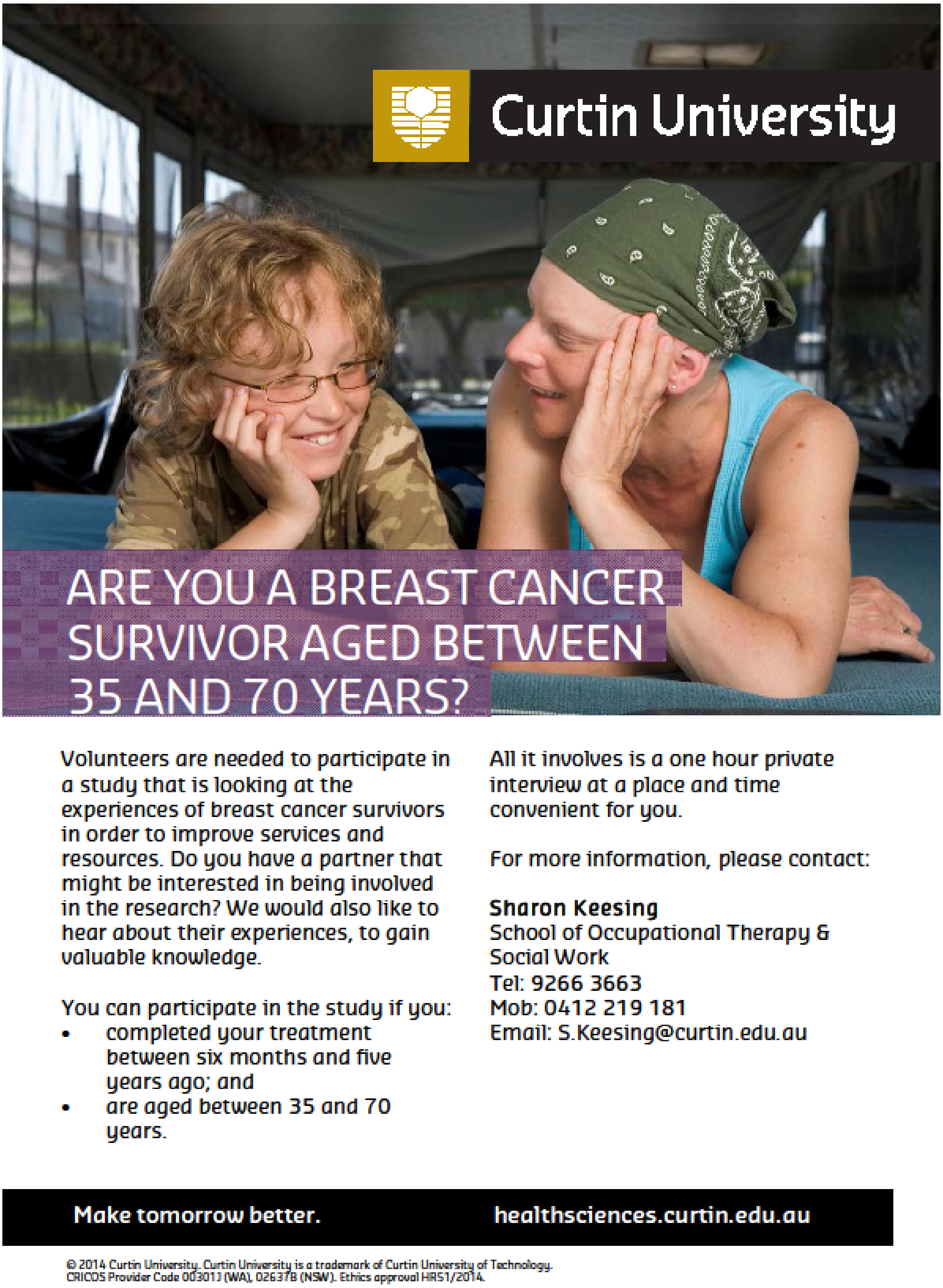
Copyright Statement

Sharon Keesing

Appendix A Stage one recruitment flyer



Curtin University

ARE YOU A BREAST CANCER SURVIVOR AGED BETWEEN 35 AND 70 YEARS?

Volunteers are needed to participate in a study that is looking at the experiences of breast cancer survivors in order to improve services and resources. Do you have a partner that might be interested in being involved in the research? We would also like to hear about their experiences, to gain valuable knowledge.

You can participate in the study if you:
- completed your treatment between six months and five years ago; and
- are aged between 35 and 70 years.

All it involves is a one hour private interview at a place and time convenient for you.

For more information, please contact:

Sharon Keesing
School of Occupational Therapy & Social Work
Tel: 9266 3663
Mob: 0412 219 181
Email: S.Keesing@curtin.edu.au

Make tomorrow better. **healthsciences.curtin.edu.au**

Ethics approval HR51/2014.

Appendix B Stage one advertisement

iSENTIA

Canning Times, Perth
13 May 2014

General News, page 13 - 287.00 cm²
Suburban - circulation 29,830 (-T-----)

Curtin University

ID 256328532

PAGE 1 of 2

BENTLEY

Tales of survival to help cancer research

CURTIN University lecturer Sharon Keesing is calling for cancer survivors to assist with a project aimed at improving the cancer journey.

The occupational therapist is seeking volunteers aged 40-70 to help with her study, 'surviving and thriving – the use of survivorship care plans for cancer survivors and their partners'.

Ms Keesing said she hoped to understand more from cancer survivors about what happened when they finished treatment and what resources and support made a difference.

"Many people survive cancer but experience a range of ongoing problems either due to the cancer itself or the treatment received," Ms Keesing said. "There isn't a lot of support available that assist people to manage these problems.

"The survivorship care plan is one option that needs further exploration."

The research is part of a larger study that considers the role of medical, nursing and allied health professionals in cancer survivorship.

"There are increasing rates of survival of many types of cancer but very little research into what happens for people when they survive; can they return to their lives the way they were previously," she said. "If not, why not?"

Ms Keesing is after volunteers who completed treatment six months to five years ago.

Call 9266 3663 or email s.keesing@curtin.edu.au.

> There are increasing rates of survival of many types of cancer but very little research into what happens for people when they survive; can they return to their lives the way they were previously?

Appendix C Stage one interview guide

Questions for women participants

1. What follow up care has been arranged for you e.g. doctor's visits, tests, medication reviews?

2. What sort of ongoing problems or symptoms are you experiencing and how do you manage these?

3. What are the long-term effects of the cancer/medications/treatment?

4. Were you given a survivorship care plan- what does it contain? Do you have a copy of it? How has it been used?

5. Has your life returned to the way it was previously? If not, how have your roles and responsibilities changed since finishing your cancer treatment?

6. Have your relationships with others (partner, family members) changed since the treatment finished? How?

7. What might be some potential positives to come out of the cancer experience?

8. Have you had any problems with resuming work? If not working, how do you spend your days currently?

9. Can you describe any resources or services that you are currently using and are these successful? Do you participate in a support group- what is this/is it effective for your needs? Are you satisfied with the resources and supports you are currently using- why/why not?

10. Do you feel that your partner is experiencing any issues following the completion of treatment? What are these?

11. What would your recommendations be for other cancer survivors?

12. Do you think that having cancer has changed you as a person and in what way?

13. How have your future plans and goals changed as a result of the cancer and or treatment?

Questions for partners

1. Now that treatment has finished for your partner, what's your daily routine? How have your roles and responsibilities changed? Are you currently working? If not working, how do you currently spend your days?

2. Does your partner experience any ongoing problems or symptoms? Do these problems impact you and have you experienced any changes in your relationships with others (partner, family members) since the treatment finished?

3. Was your partner given a survivorship care plan- what does it contain? Do you have a copy of it?

4. Can you describe how the SCP has been used during this period? Was it utilised to identify any issues for you personally as well as your partner?

5. What might be some potential positives to come out of the cancer experience?

6. Has your life returned to the way it was previously, if not how has it changed?

7. Can you describe any supports that you are currently using (with or without your partner) and are these successful? Are you satisfied with the resources and supports you and your partner are currently using- why/why not?

8. Can you identify any needs that you personally feel have not been met?

9. Can you recommend any changes/improvements in services for the partners of cancer survivors?

10. Do you think that being the partner of a cancer survivor has changed you in any way? Have your future plans and goals changed as a result of the cancer and/or treatment?

Appendix D Stage two questionnaire

Survey of services and resources available for women who survive breast cancer

Survivorship is recognised as a significant time in the breast cancer journey.
Recent research, including in-depth interviews conducted in Western Australia, provided valuable information on the range of resources and supports found to be useful by women survivors of breast cancer and their partners. This current study will scope the viewpoints of known services and resources that provide support to survivors of breast cancer in Western Australia. The survey consists of 22 questions and should take approximately 10 minutes to complete. Participation is voluntary. All responses are anonymous and respondents will not be identified in any published or unpublished results. Findings from the study will determine the range, type and availability of resources and supports available during survivorship for survivors of breast cancer and their partners living in Western Australia. If you have any questions or you would like to discuss the survey further, please contact the researcher - Sharon Keesing s.keesing@curtin.edu.au or on 9266 3663 Sharon Keesing PhD Candidate, Curtin University This study has been approved by the Curtin University Human Research Ethics Committee (approval number HR 51/2014). The committee is comprised of members of the public, academics, lawyers, doctors and pastoral care workers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Ethics Committee, c/o Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845, by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Q1. The following conditions are observed if consent is provided: 1. Participation is voluntary2. I may withdraw at any time without prejudice3. There are no known risks 4. All information will be treated in a confidential manner5. Reports published from the survey will not identify any participants
❍ Yes, I consent (1)
❍ No, I do not consent (2)
If No, I do not consent Is Selected, Then Skip to thank you for your time. You have now...

Q2 Do survivors of breast cancer use the service or resource?
❍ Yes (1)
❍ No (2)
If No Is Selected, Then Skip to Thank you for your participation, this...

Q3 What is your current role in the service/resource?
○ Health/medical professional e.g. doctor, nurse (1)
○ Allied health professional e.g. social worker, counselor, physiotherapist, occupational therapist (2)
○ Complementary therapist (3)
○ Administrative staff member (4)
○ Volunteer (5)
○ Other role not listed (Please specify) (6) ____________________

Q4 What is the postcode of the breast cancer service/resource? (enter N/A if no physical location)

Q5 Which of the following best describes the type of organisation in which the breast cancer service or resource is provided?
○ Public (1)
○ Private (2)
○ NGO/not for profit (3)
○ Other (please specify) (4) ____________________

Q6 How can survivors of breast cancer find out about the service or resource? (Click all that apply)
☐ Radio or television (1)
☐ Newspaper (2)
☐ Magazines (3)
☐ Social Media e.g. Face book (4)
☐ Other internet sources e.g. forums, online support groups, blogs (5)
☐ Medical practitioner/specialist provider/health professional (6)
☐ Friends/colleagues (7)
☐ Other breast cancer survivors (8)
☐ Other (please specify) (9) ____________________

Q7 How is the breast cancer service/resource accessed? (Click all that apply)
☐ Individual meeting/ visit (1)
☐ DVD/CD (2)
☐ Group meetings including peer support (3)
☐ Written materials e.g. Facts sheets, published articles (4)
☐ Telephone support (5)
☐ Internet based e.g. web page, online forums, blogs (6)
☐ Guest speakers (7)
☐ Information kits containing a range of materials (8)
☐ Others not listed (please specify) (9) ____________________

Q8 Is there a cost to survivors of breast cancer for the service/resource?
- ○ No (1)
- ○ Some services/resources (please specify) (2) ____________________
- ○ Yes (please specify) (3) ____________________

Q9 The breast cancer service or resource is staffed by the following people (Click all that apply)
- ☐ Health/medical professionals e.g. doctor, nurse (1)
- ☐ Allied health professionals e.g. social worker, counselor, physiotherapist, occupational therapist (2)
- ☐ Complementary therapist (3)
- ☐ Administrative staff (4)
- ☐ Volunteers (5)
- ☐ Breast cancer survivors (6)
- ☐ Others not listed, (please specify) (7) ____________________

Q10 What sources of information or evidence are used to develop the breast cancer service or resource? (Click all that apply)
- ☐ Scientific publications e.g. journal articles (1)
- ☐ Clinical guidelines (2)
- ☐ 'Grey literature'- unpublished research (3)
- ☐ Clinical experience (4)
- ☐ Surveys of the service consumers e.g. evaluations (5)
- ☐ Not applicable (6)
- ☐ Others not listed (please specify) (7) ____________________

Q11 Do survivors of breast cancer (or their partners) from non-English speaking backgrounds access the service/resource?
- ○ No (1)
- ○ Occasionally, please specify the cultural group(s) that most often access the service/resource (2) ____________________
- ○ Yes, please specify the cultural group(s) that most often access the service/resource (3) ____________________

If No Is Selected, Then Skip To Does your service utilise a 'survivor...

Q12 Which of the following does the service or resource offer to improve access for survivors of breast cancer from non-English speaking backgrounds? (Click all that apply)
- ☐ Resources in multiple languages (1)
- ☐ Access to translation services (2)
- ☐ Encourage an English speaking family member/friend to accompany the breast cancer survivor (3)
- ☐ Other (please specify) (4) ____________________

Q13 The next 2 questions are about the use of survivorship care plans. Does the service utilise a' survivorship care plan' to assist with the co-ordination of resources?

- ○ No (1)
- ○ Not applicable to the service or resource (3)
- ○ Yes, please state the name or type of survivorship care plan (if known) (4) ____________________

If No Is Selected, Then Skip To The following items were identified d...If Not applicable to my service... Is Selected, Then Skip To The following items were identified d...

Q14 What sections are included in the survivorship care plan? (Click all that apply)

- ☐ Diagnosis and treatment summary (1)
- ☐ Referrals to other providers (2)
- ☐ Possible ongoing or late side effects of breast cancer/treatment (3)
- ☐ Schedules for routine follow-up (4)
- ☐ Healthy lifestyle information e.g. nutrition, exercise, other strategies to reduce the risk of recurrence (5)
- ☐ Psychological and emotional support information (6)
- ☐ Resources for ongoing support e.g. Cancer Council, GP, support groups, complementary therapies (7)
- ☐ Assessing breast cancer risk for other family members (8)
- ☐ Links to other services/resources (9)
- ☐ Glossary of terms related to breast cancer (10)
- ☐ Others not listed (please specify) (11) ____________________

Q15 The following items were identified during recent in-depth interviews as being useful for meeting the needs of survivors of breast cancer. Please rate the Frequency that the items below are offered by the breast cancer service/resource.

	Not provided (1)	Occasionally provided (2)	Frequently provided (3)	Always provided (4)
Management of surgical complications e.g. disfigurement, scarring (1)	○	○	○	○
Medical surveillance including follow up appointments and tests with medical and health professionals (2)	○	○	○	○
Lymphoedema management (3)	○	○	○	○
Management of the long-term effects of breast cancer and/or treatment e.g. pain, co-morbid conditions (4)	○	○	○	○
Advice for making decisions regarding breast reconstruction (5)	○	○	○	○
Medication prescription and support (6)	○	○	○	○
Assistance regarding sexual functioning/intimacy (7)	○	○	○	○
Fertility advice (8)	○	○	○	○
Weight management support (9)	○	○	○	○
Nutrition advice (10)	○	○	○	○
Advice regarding exercise (11)	○	○	○	○
Strategies to manage fatigue (12)	○	○	○	○
Sleep hygiene (13)	○	○	○	○
Smoking cessation support (14)	○	○	○	○
Complementary therapies (15)	○	○	○	○
Strategies to manage cognitive changes e.g. memory loss, concentration difficulties (16)	○	○	○	○
Management of anxiety/depression (17)	○	○	○	○
Relaxation and stress management (18)	○	○	○	○
Support for fear of cancer recurrence (19)	○	○	○	○
Strategies to address problems with body image (20)	○	○	○	○
Development of self-management skills (21)	○	○	○	○
Support for relationship and family issues (22)	○	○	○	○
Support to address partners' concerns (23)	○	○	○	○
Legal advice and support (24)	○	○	○	○
Assistance with financial issues (25)	○	○	○	○
Support for resuming employment (26)	○	○	○	○
Advice for spiritual concerns (27)	○	○	○	○
Assistance to resume social interests and hobbies (28)	○	○	○	○
Referral for allied health services or other specialist services (29)	○	○	○	○
Peer support e.g. groups or individual support (30)	○	○	○	○
Referral for specialist mental health services (31)	○	○	○	○
General advice regarding resources available for survivors of breast cancer (32)	○	○	○	○

Q16 Do you have any suggestions for additional services and resources that should be made available to survivors of breast cancer?

○ No (1)
○ Yes (please describe) (2) ____________________

Q17 Please identify any barriers impacting the delivery of breast cancer services/resources (Click all that apply)

☐ Financial resources (1)
☐ Space/physical resources (2)
☐ Availability of suitably qualified/experienced people (3)
☐ Limited awareness of the service/resource among breast cancer survivors (4)
☐ None identified (5)
☐ Other (please specify) (6) ____________________

Q18 The next 3 questions focus on services and supports for partners or families of survivors of breast cancer. Does the service/resource provide support that is specifically targeted to partners or families of survivors of breast cancer?

○ No (1)
○ Yes (2)

If No Is Selected, Then Skip to how well do you think the service/res...?

Q19 What issues/concerns are typically addressed by the service/resource for partners or families of survivors of breast cancer? (Click all that apply)

☐ Relationships eg partner, children (1)
☐ Financial, legal (2)
☐ Practical eg resuming daily routine, return to work (3)
☐ Long term implications of diagnosis (4)
☐ Other (please specify) (5) ____________________

Q20 How is the breast cancer service/resource delivered to partners or families? (Click all that apply)

☐ Individual meeting/ visit (1)
☐ DVD/CD (2)
☐ Group meetings including peer support (3)
☐ Written materials e.g. Facts sheets, published articles (4)
☐ Telephone support (5)
☐ Internet based e.g. web page, online forums, blogs (6)
☐ Guest speakers (7)
☐ Information kits containing a range of materials (8)
☐ Others not listed (please specify) (9) ____________________

Q21 Almost done! Just 2 questions to go..... How well do you think the service/resource meets the needs of survivors of breast cancer? Move the slider from left to right to indicate your opinion (0=low, 10=high)
○ 0 (0)
○ 1 (1)
○ 2 (2)
○ 3 (3)
○ 4 (4)
○ 5 (5)
○ 6 (6)
○ 7 (7)
○ 8 (8)
○ 9 (9)
○ 10 (10)

Q22 What suggestions do you have regarding changes or improvements to the service/resource for survivors of breast cancer? (please list and describe below)

Answer If Does the service provide assistance to breast cancer survivors? No Is Selected
Thank you for your participation. This research is collecting information about breast cancer survivors only. You have been exited from the survey.
If this research is collecting... Is Displayed, Then Skip to End of Survey

Thank you for your participation. If you have any questions or you would like to discuss the survey further, please contact the researcher - Sharon Keesing s.keesing@curtin.edu.au or on 9266 3663
If Thank you for your participation... Is Displayed, Then Skip to End of Survey

Thank you for your time. You have now been exited from the survey.

Appendix E Stage two participant information form

The survey is part of a PhD research project being completed at the School of Occupational Therapy at Curtin University.

Survivorship is being increasingly recognised as a key period in the breast cancer journey and there are many models of care, resources and supports available to assist survivors.

This survey aims to scope the existing services, resources and supports used to support breast cancer survivors. It is being distributed to known providers of services across Australia.

The survey consists of 22 questions and should take approximately 10 minutes to complete. All responses will be collated anonymously and respondents will not be identified in any published or unpublished results.

Thank you for your consideration

Sharon Keesing

Appendix F Stage three recruitment flyer

Curtin University

ARE YOU A BREAST CANCER SURVIVOR OR PARTNER AGED BETWEEN 35 AND 70 YEARS?

Volunteers are needed to participate in a study that is looking at the preferences of breast cancer survivors for care during survivorship. Do you have a partner that might be interested in being involved in the research? We would like to hear about your experiences and ideas, to gain valuable knowledge.

You can participate in the study if you:

☐ completed your treatment between six months and five years ago

☐ are aged between 35 and 70 years

☐ OR are the partner of a woman breast cancer survivor

It involves attending (two) one hour focus groups on February 13th and 20th, 2016

For more information, please contact:

Sharon Keesing
School of Occupational Therapy & Social Work
Mob: 0412 219 181
Email: S.Keesing@curtin.edu.au

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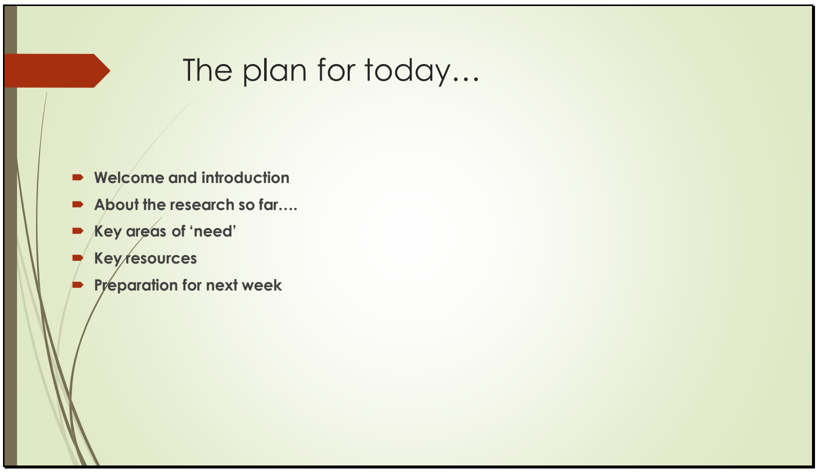
Appendix G Stage three focus group slides

WELCOME

SURVIVORSHIP CARE PLANNING FOLLOWING BREAST CANCER

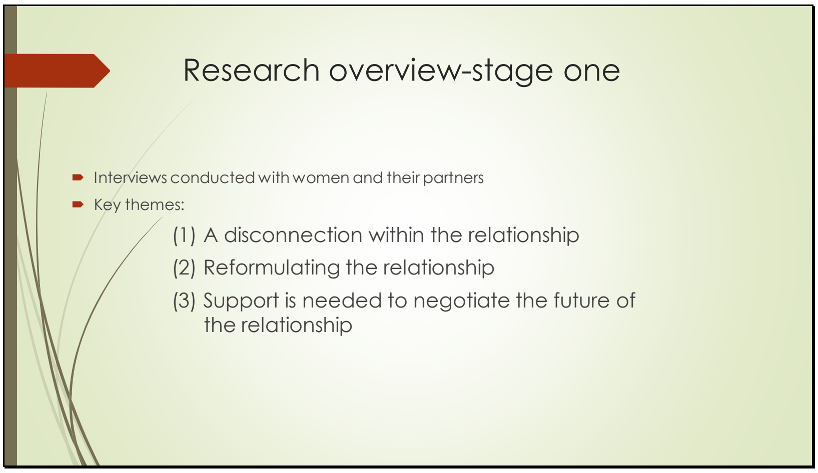
Slide 1



The plan for today…

- **Welcome and introduction**
- **About the research so far….**
- **Key areas of 'need'**
- **Key resources**
- **Preparation for next week**

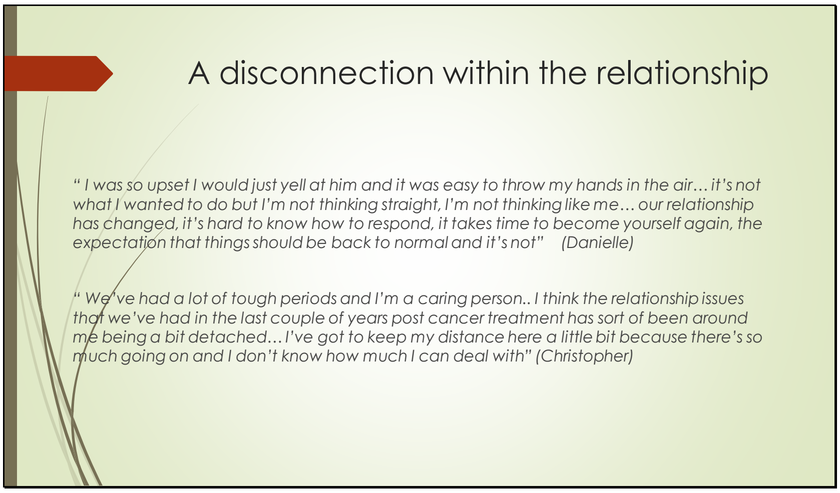
Slide 2



Research overview-stage one

- Interviews conducted with women and their partners
- Key themes:
  - (1) A disconnection within the relationship
  - (2) Reformulating the relationship
  - (3) Support is needed to negotiate the future of the relationship

Slide 3

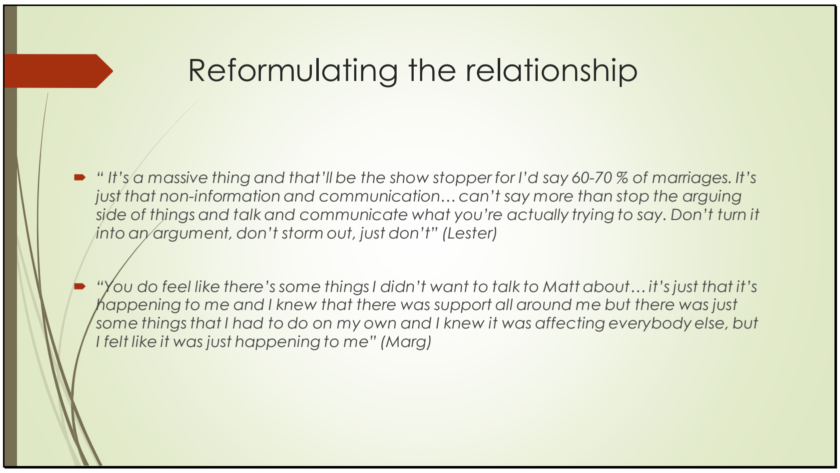


A disconnection within the relationship

“ I was so upset I would just yell at him and it was easy to throw my hands in the air… it’s not what I wanted to do but I’m not thinking straight, I’m not thinking like me… our relationship has changed, it’s hard to know how to respond, it takes time to become yourself again, the expectation that things should be back to normal and it’s not”   (Danielle)

“ We’ve had a lot of tough periods and I’m a caring person.. I think the relationship issues that we’ve had in the last couple of years post cancer treatment has sort of been around me being a bit detached… I’ve got to keep my distance here a little bit because there’s so much going on and I don’t know how much I can deal with” (Christopher)

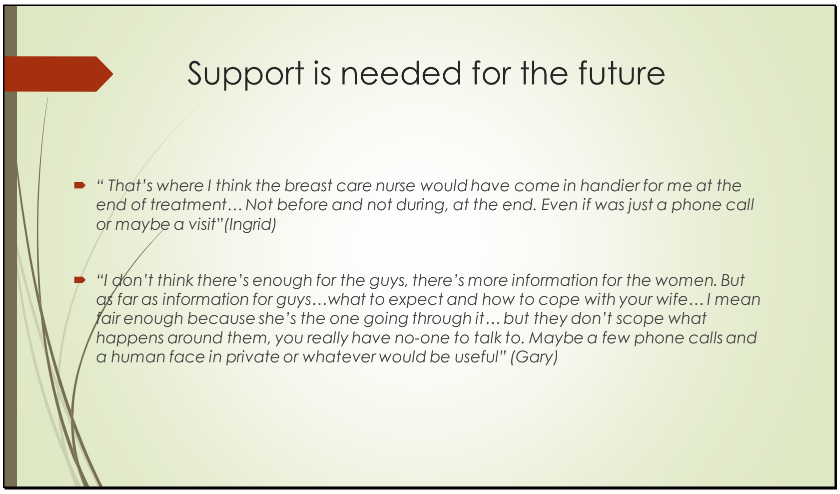
Slide 4



Reformulating the relationship

- *“ It’s a massive thing and that’ll be the show stopper for I’d say 60-70 % of marriages. It’s just that non-information and communication… can’t say more than stop the arguing side of things and talk and communicate what you’re actually trying to say. Don’t turn it into an argument, don’t storm out, just don’t” (Lester)*
- *“You do feel like there’s some things I didn’t want to talk to Matt about… it’s just that it’s happening to me and I knew that there was support all around me but there was just some things that I had to do on my own and I knew it was affecting everybody else, but I felt like it was just happening to me” (Marg)*

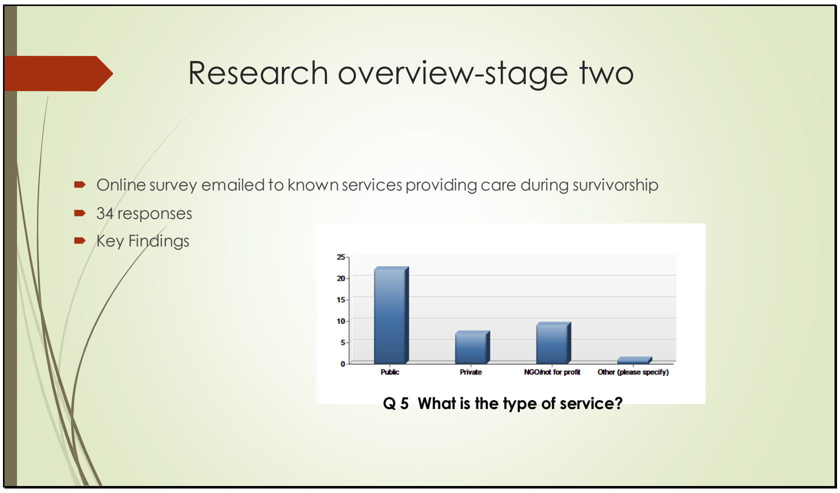
Slide 5



Support is needed for the future

- *“ That’s where I think the breast care nurse would have come in handier for me at the end of treatment… Not before and not during, at the end. Even if was just a phone call or maybe a visit”(Ingrid)*
- *“I don’t think there’s enough for the guys, there’s more information for the women. But as far as information for guys…what to expect and how to cope with your wife… I mean fair enough because she’s the one going through it… but they don’t scope what happens around them, you really have no-one to talk to. Maybe a few phone calls and a human face in private or whatever would be useful” (Gary)*

Slide 6

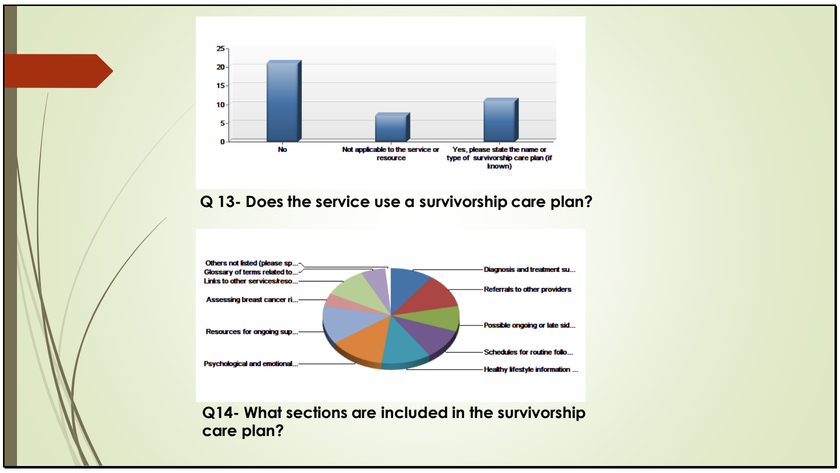


Research overview-stage two

- Online survey emailed to known services providing care during survivorship
- 34 responses
- Key Findings

Q 5 What is the type of service?

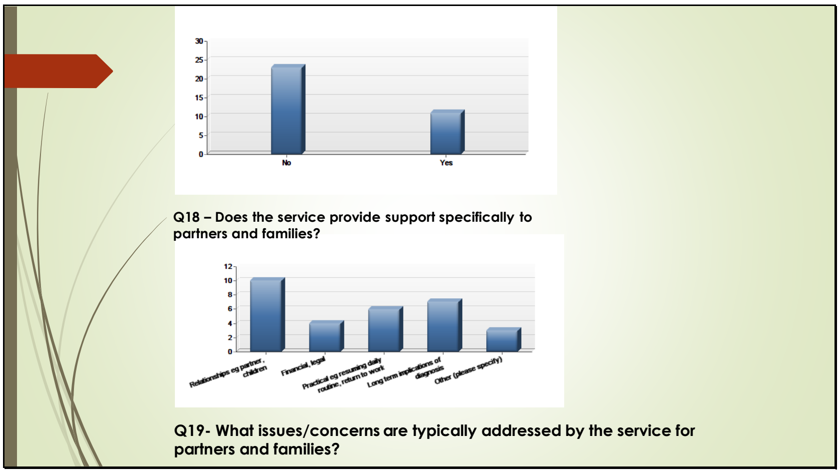
Slide 7



Q 13- Does the service use a survivorship care plan?

Q14- What sections are included in the survivorship care plan?

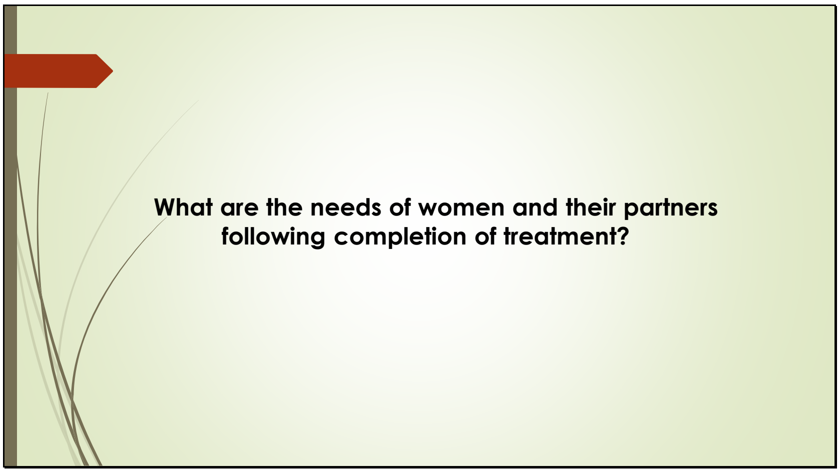
Slide 8



Q18 – Does the service provide support specifically to partners and families?

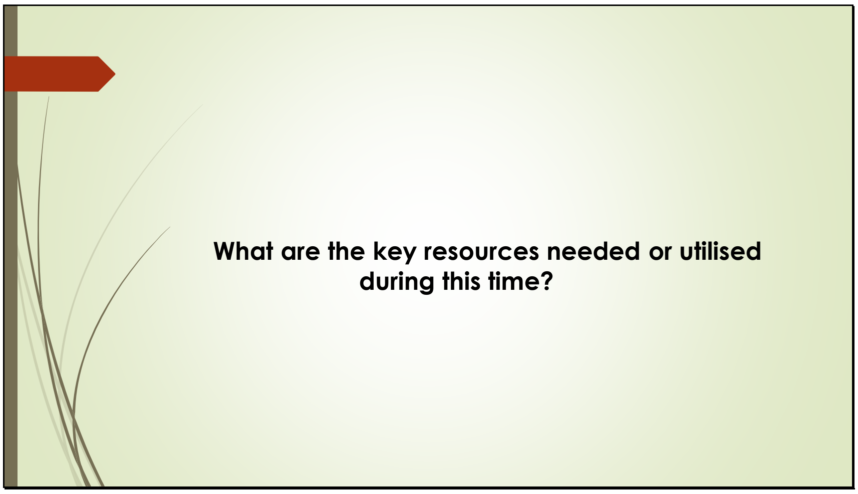
Q19- What issues/concerns are typically addressed by the service for partners and families?

Slide 9



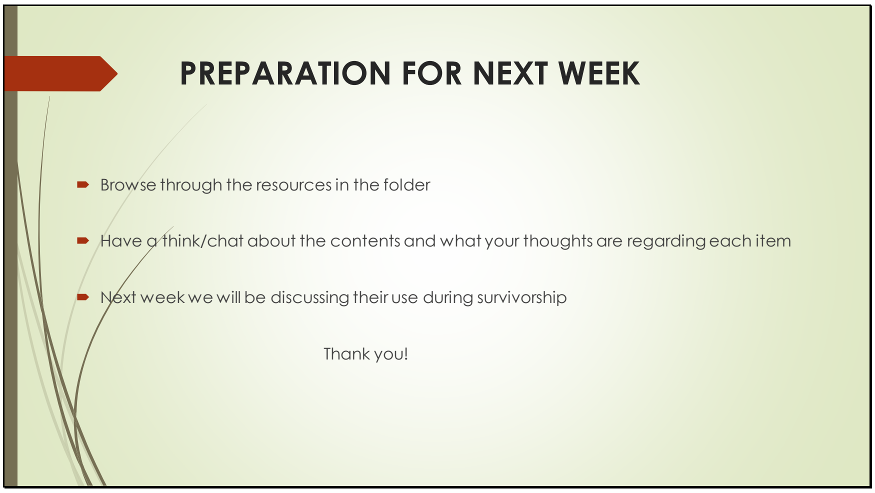
What are the needs of women and their partners following completion of treatment?

Slide 10



What are the key resources needed or utilised during this time?

Slide 11

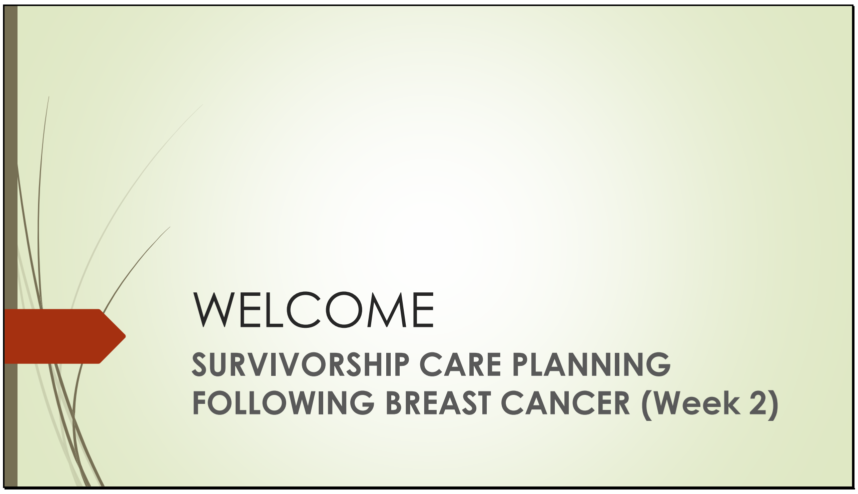


PREPARATION FOR NEXT WEEK

- Browse through the resources in the folder
- Have a think/chat about the contents and what your thoughts are regarding each item
- Next week we will be discussing their use during survivorship

Thank you!

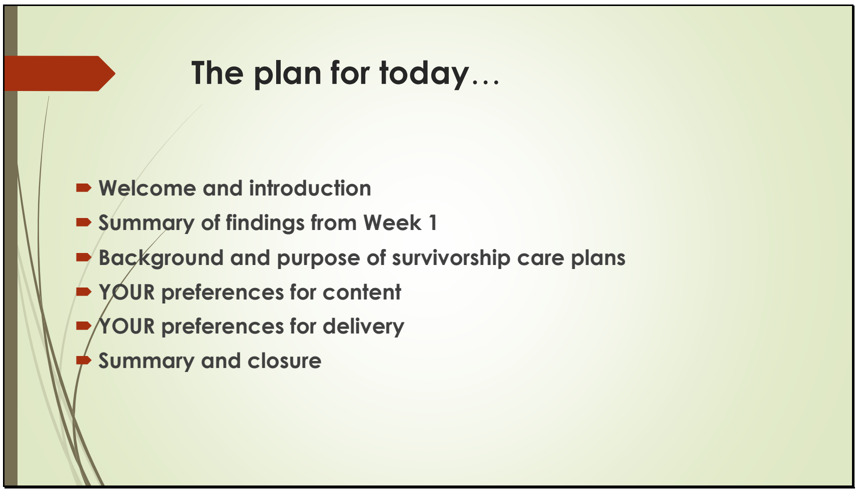
Slide 12



WELCOME

SURVIVORSHIP CARE PLANNING FOLLOWING BREAST CANCER (Week 2)

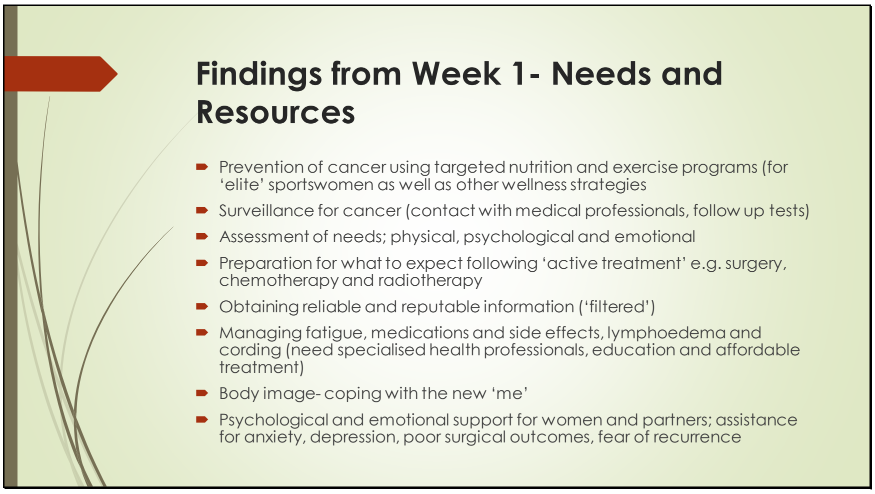
Slide 13



The plan for today…

- Welcome and introduction
- Summary of findings from Week 1
- Background and purpose of survivorship care plans
- YOUR preferences for content
- YOUR preferences for delivery
- Summary and closure

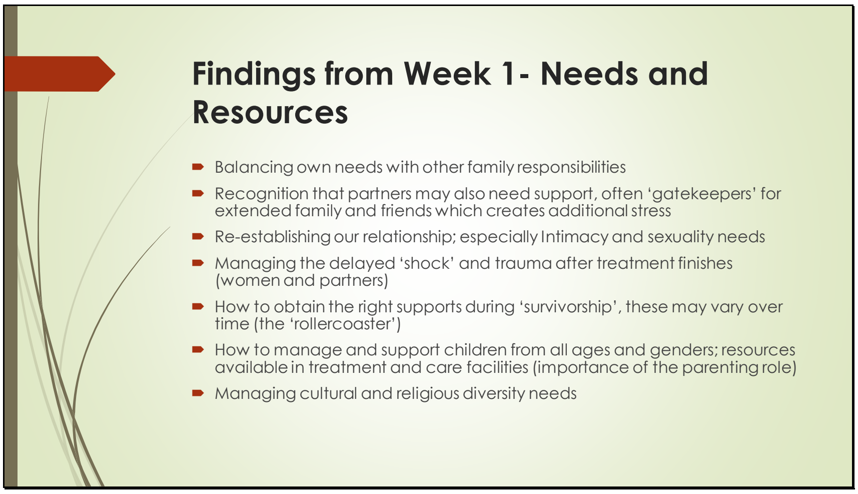
Slide 14



Findings from Week 1- Needs and Resources

- Prevention of cancer using targeted nutrition and exercise programs (for ‘elite’ sportswomen as well as other wellness strategies
- Surveillance for cancer (contact with medical professionals, follow up tests)
- Assessment of needs; physical, psychological and emotional
- Preparation for what to expect following ‘active treatment’ e.g. surgery, chemotherapy and radiotherapy
- Obtaining reliable and reputable information (‘filtered’)
- Managing fatigue, medications and side effects, lymphoedema and cording (need specialised health professionals, education and affordable treatment)
- Body image- coping with the new ‘me’
- Psychological and emotional support for women and partners; assistance for anxiety, depression, poor surgical outcomes, fear of recurrence

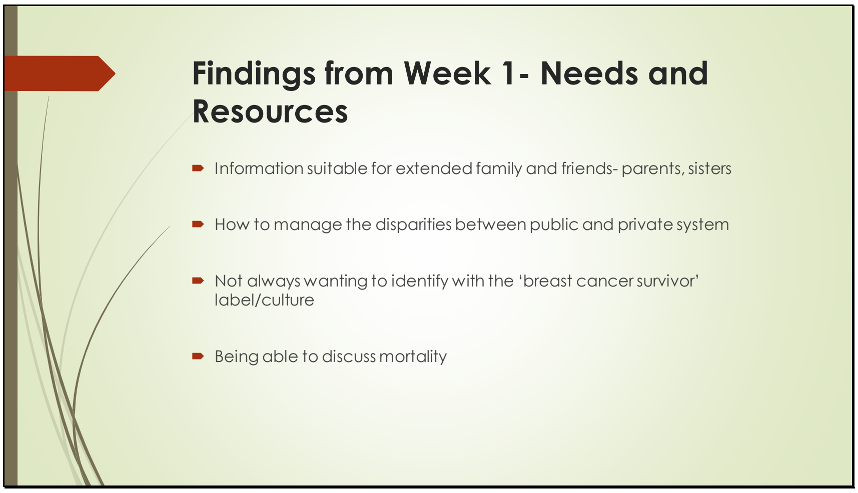
Slide 15



Findings from Week 1- Needs and Resources

- Balancing own needs with other family responsibilities
- Recognition that partners may also need support, often 'gatekeepers' for extended family and friends which creates additional stress
- Re-establishing our relationship; especially Intimacy and sexuality needs
- Managing the delayed 'shock' and trauma after treatment finishes (women and partners)
- How to obtain the right supports during 'survivorship', these may vary over time (the 'rollercoaster')
- How to manage and support children from all ages and genders; resources available in treatment and care facilities (importance of the parenting role)
- Managing cultural and religious diversity needs

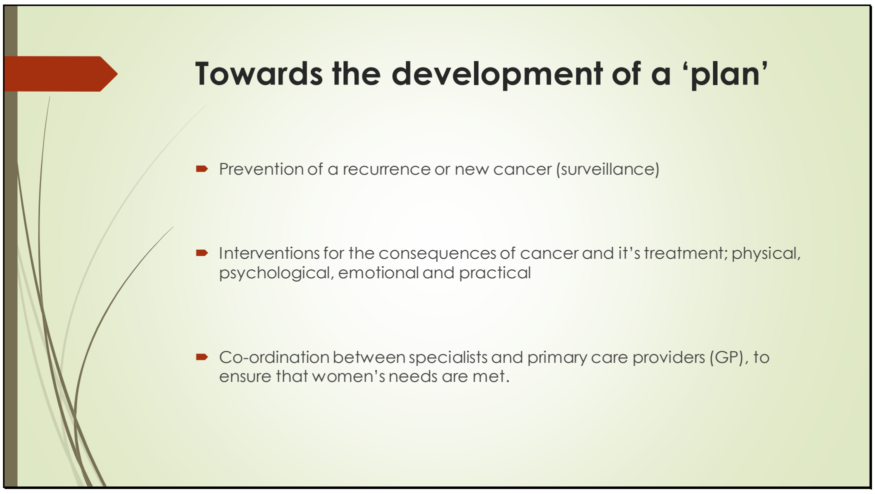
Slide 16



Findings from Week 1- Needs and Resources

- Information suitable for extended family and friends- parents, sisters
- How to manage the disparities between public and private system
- Not always wanting to identify with the 'breast cancer survivor' label/culture
- Being able to discuss mortality

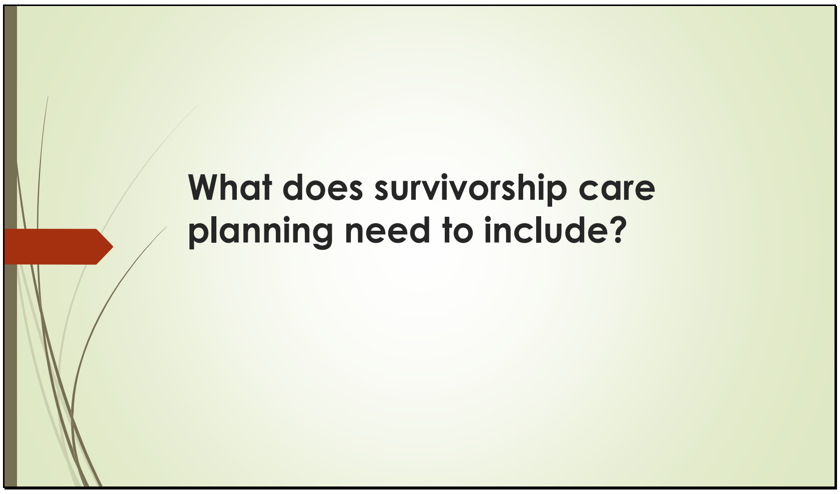
Slide 17



Towards the development of a 'plan'

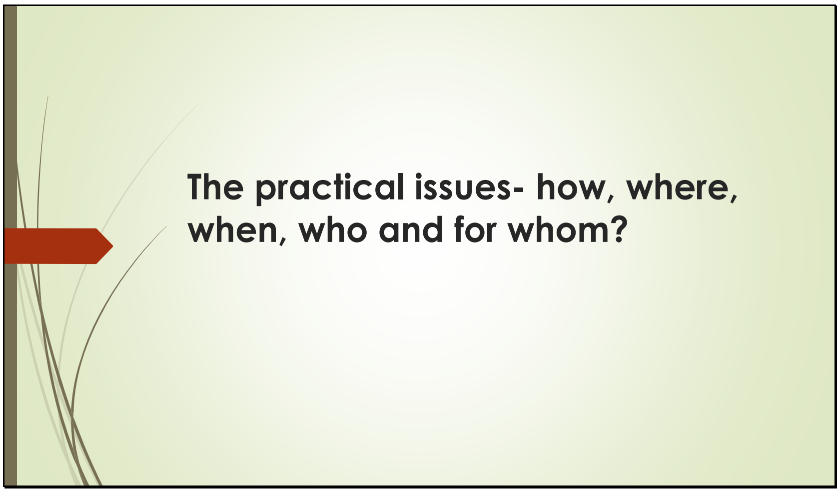
- Prevention of a recurrence or new cancer (surveillance)
- Interventions for the consequences of cancer and it's treatment; physical, psychological, emotional and practical
- Co-ordination between specialists and primary care providers (GP), to ensure that women's needs are met.

Slide 18



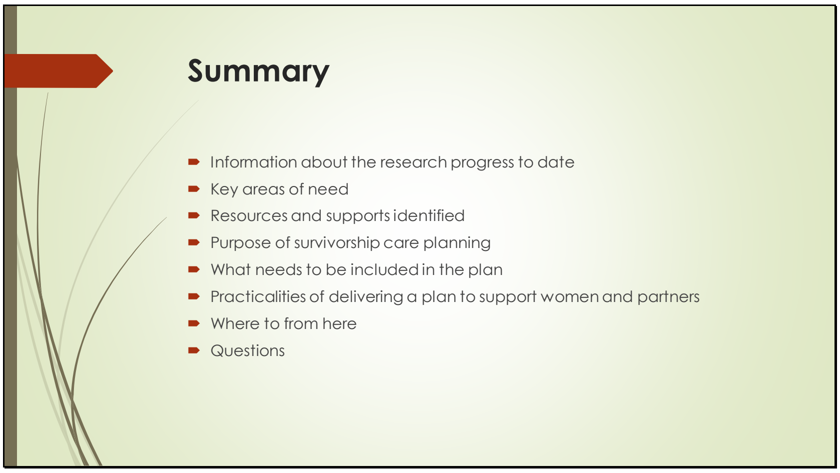
What does survivorship care planning need to include?

Slide 19



The practical issues- how, where, when, who and for whom?

Slide 20



Summary

- Information about the research progress to date
- Key areas of need
- Resources and supports identified
- Purpose of survivorship care planning
- What needs to be included in the plan
- Practicalities of delivering a plan to support women and partners
- Where to from here
- Questions

Slide 21

Thankyou for your participation ☺

Slide 22

Appendix H Stage four Delphi survey tool

Delphi round one

Exploring the views of occupational therapists regarding the services and supports for women survivors of breast cancer and their partners living in Australia The survey is presented in two parts. Part one consists of 9 demographic questions (5 mins). Part two consists of 9 descriptive questions (15 mins). Please provide as much information in part two as you can.

Part one 1. Consent: The following conditions are observed if consent is provided: i. Participation is voluntary. ii. I may withdraw at any time without prejudice. iii. There are no known risks. iv. All information will be treated in a confidential manner. v. Reports and research publications will not identify any participants. Participants will not be identifiable to each other. vi. Return of completed questions is considered as consent to participate.

○ I consent to participate (1)

2. Name (this will be de-identified using a numeric code)

3. Gender

○ Female (1)
○ Male (2)
○ Other (3)

4. What is your age range?

○ 20-29 (1)
○ 30-39 (2)
○ 40-49 (3)
○ 50-59 (4)
○ 60 + (5)

5. What is your highest level of qualification?

○ Bachelor's degree (1)
○ Honours degree (9)
○ Post graduate certificate/Diploma (5)
○ Master's degree (2)
○ PhD (3)
○ Other (please specify) (4) ____________________

6. Number of years (in total) of experience working with people who have cancer

○ Less than one year (4)
○ 1-5 years (1)
○ 5-10 years (2)
○ 10 + years (3)

7. How would you describe the service type that you currently work in? (Please answer as your most recent experience working in this practice area)

○ Community clinic (1)
○ Hospital- private (3)
○ Hospital- public (4)
○ Non-government organisation (2)
○ Private practice (5)
○ Other (please specify type) (6) ____________________

8. What is your service location?

○ Northern Territory (1)
○ NSW/ACT (2)
○ Queensland (3)
○ South Australia (4)
○ Tasmania (5)
○ Victoria (6)
○ Western Australia (7)

9. What is the postcode of the service location?

Part two Please read this case study and answer the questions to follow: Tracey (46) and Tom (48) Tracey was diagnosed with breast 2 years ago and had a bilateral mastectomy, chemotherapy, radiotherapy, breast reconstruction and preventative hysterectomy. Her breast reconstruction was complicated by repeated infections as well as lymphoedema, chronic pain and significant scarring over the surgery sites. She is currently taking Tamoxifen, is reviewed by her oncologist every 6 months and anticipates further surgery to modify her breast reconstruction. Tracey previously worked full-time as an Office Manager and has been married to Tom for 12 years, the couple have two children aged 8 and 11. Her interests include; home renovations, attending the gym (has competed in triathlons), boxing classes, travel, enjoying meals with friends, gardening and attending her children's sporting activities. Tracey returned to her previous position as an Office Manager approximately 6 months ago, but is experiencing difficulties due to fatigue, poor sleep and her concentration is impaired. She is feeling anxious and concerned that she is not managing her work responsibilities as well as she had hoped, following her illness. Tracey is concerned about the financial ramifications of reducing her work hours.

Tracey is also having difficulties with gardening and resuming exercise due to pain and decreased range of motion in her (R) shoulder and is frustrated with her reduced fitness. She also experiences hot flushes and mood swings. She feels guilty because she isn't the active, confident mum and wife she was prior to her breast cancer treatment. Tracey is currently upset with her perception of her body, stating that she still feels 'broken', with a 'concave chest and a big tummy'. She has loss of sensation in her breasts and feels like 'her body isn't hers', she has gained approximately 15 kgs since diagnosis, and has no interest in intimacy or sexual activity with her husband. She has trouble finding clothes to fit and avoids her previous friends and social occasions, stating that other people 'don't seem to understand why I'm not the same person any more'. Tom is also feeling concerned about his wife's current difficulties, and reports that he thought everything would 'go back to the way it was before the surgery'. He is anxious about their lack of intimacy and sexual relationship. He finds it hard to discuss his concerns with her (or anyone else) and is worried about what the future holds for their relationship and the family. Tracey and Tom are both concerned about the cancer recurring and poor results from the breast reconstruction. Tom continues to take on a lot of the commitments relating to the children; school and sporting pick-ups and drop-offs and is feeling overwhelmed with his day to day responsibilities including full-time work and assisting with home management tasks. Both are concerned about the future of their relationship and caring for the children.

Q1. From your experience, which of the problems reported in the case study could be experienced by women and their partners following completion of treatment? Please provide as many as you can.

Q2. Referring to the problems identified in Q1, what kind of supports and services are needed to address these problems? Please provide as many as you can.

Q3. In your opinion, who should provide these supports and services? Please provide as many as applicable.

Q4. Does your current service offer any supports that would help Tracey and Tom with the problems reported in the case study? If so, please describe them.

Q5. If not offered at your service, where could they obtain these supports? Who would provide them?

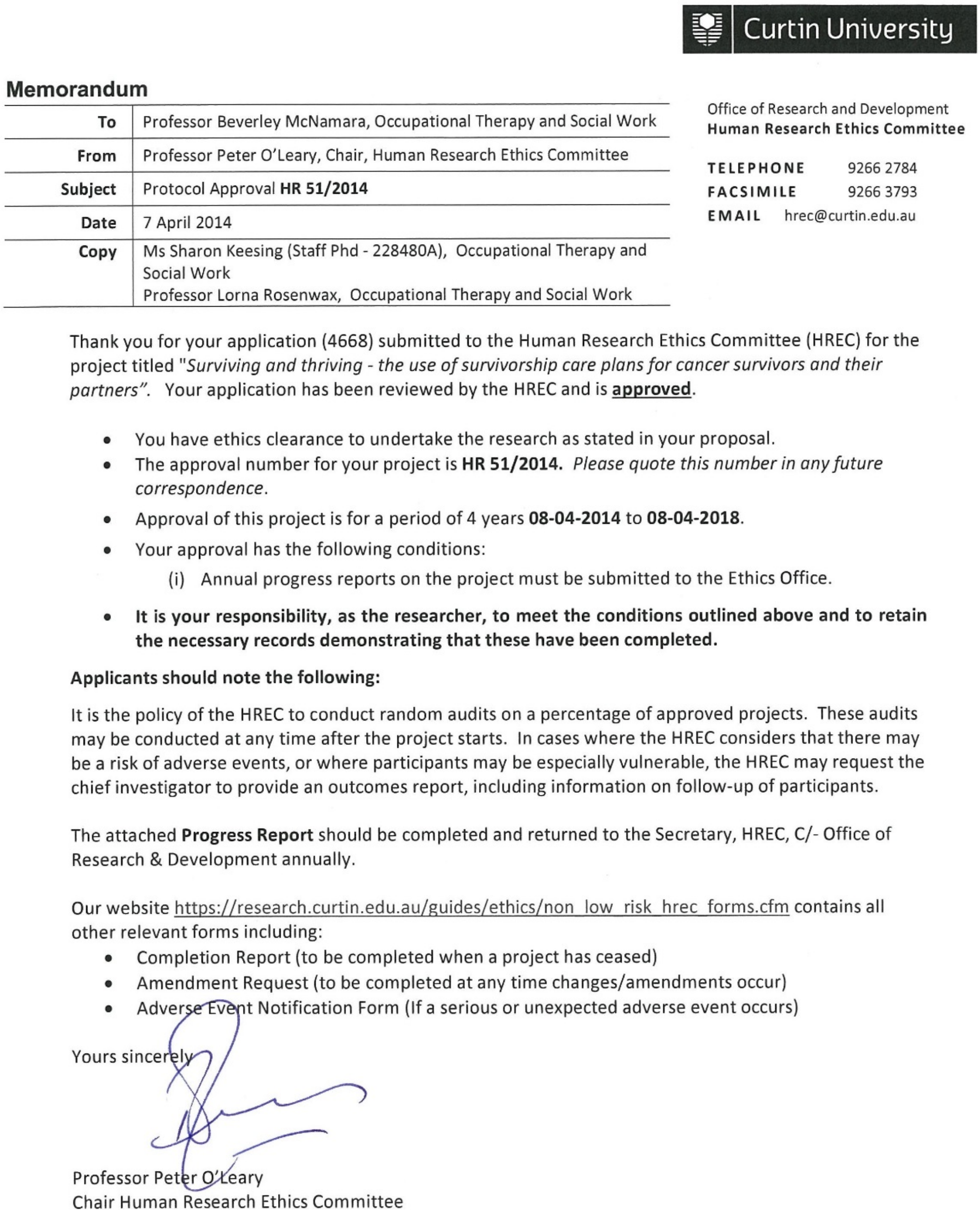
Q6. What are the barriers or concerns regarding the provision of ongoing care for people like Tracey and Tom?

Q7. Would you refer Tracey and Tom to any other health professionals? For what reason/purpose?

Q8. What resources or tools would you use to support people like Tracey and Tom?

Q9. (Last question) Do you have any other comments or suggestions regarding Tracey and Tom’s care?

Appendix I Research ethics approval



Curtin University

Office of Research and Development
Human Research Ethics Committee

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Memorandum

To	Professor Beverley McNamara, Occupational Therapy and Social Work
From	Professor Peter O'Leary, Chair, Human Research Ethics Committee
Subject	Protocol Approval **HR 51/2014**
Date	7 April 2014
Copy	Ms Sharon Keesing (Staff Phd - 228480A), Occupational Therapy and Social Work Professor Lorna Rosenwax, Occupational Therapy and Social Work

Thank you for your application (4668) submitted to the Human Research Ethics Committee (HREC) for the project titled "*Surviving and thriving - the use of survivorship care plans for cancer survivors and their partners".* Your application has been reviewed by the HREC and is **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 51/2014.** *Please quote this number in any future correspondence.*
- Approval of this project is for a period of 4 years **08-04-2014** to **08-04-2018**.
- Your approval has the following conditions:
    (i) Annual progress reports on the project must be submitted to the Ethics Office.
- **It is your responsibility, as the researcher, to meet the conditions outlined above and to retain the necessary records demonstrating that these have been completed.**

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **Progress Report** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development annually.

Our website https://research.curtin.edu.au/guides/ethics/non_low_risk_hrec_forms.cfm contains all other relevant forms including:

- Completion Report (to be completed when a project has ceased)
- Amendment Request (to be completed at any time changes/amendments occur)
- Adverse Event Notification Form (If a serious or unexpected adverse event occurs)

Yours sincerely

Professor Peter O'Leary
Chair Human Research Ethics Committee

Standard conditions of ethics approval

These standard conditions apply to all research approved by the Curtin University Human Research Ethics Committee. It is the responsibility of each researcher named on the application to ensure these conditions are met.

1. **Compliance.** Conduct your research in accordance with the application as it has been approved and keep appropriate records.
    a. **Monitoring** - Assist the Committee to monitor the conduct of the approved research by completing promptly and returning all project review forms that are sent to you.
    b. **Annual report** - Submit an annual report on or before the anniversary of the approval.
    c. **Extensions** - If you are likely to need more time to conduct your research than is already approved, complete a new application six weeks before the current approval expires.
    d. **Changes to protocol** - Any changes to the protocol are to be approved by the Committee before being implemented.
    e. **Changes to researcher details** - Advise the Committee of any changes in the contact details of the researchers involved in the approved study.
    f. **Discontinuation** - You must inform the Committee, giving reasons, if the research is not conducted or is discontinued before the expected completion date.
    g. **Closure** - Submit a final report when the research is completed. Include details of when data will be destroyed, and how, or if any future use is planned for the data.
    h. **Candidacy** - If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
2. **Adverse events.** Consider what might constitute an adverse event and what actions may be needed if an adverse event occurs. Follow the procedures for reporting and addressing adverse events (http://research.curtin.edu.au/guides/adverse.cfm).Where appropriate, provide an adverse events protocol. The following are examples of adverse events:
    a. Complaints
    b. Harm to participants. This includes physical, emotional, psychological, economic, legal, social and cultural harm (NS Section 2)
    c. Loss of data or breaches of data security
    d. Legal challenges to the research
3. **Data management plan.** Have a Data Management Plan consistent with the University's recordkeeping policy. This will include such things as how the data are to be stored, for how long, and who has authorised access.
4. **Publication.** Where practicable, ensure the results of the research are made available to participants in a way that is timely and clear (NS 1.5). Unless prohibited from doing so by contractual obligations, ensure the results of the research are published in a manner that will allow public scrutiny (NS 1.3, d). Inform the Committee of any constraints on publication.
5. **Police checks and other clearances.** All necessary clearances, such as Working with Children Checks, first aid certificates and vaccination certificates, must be obtained before entering a site to conduct research.
6. **Participant information.** All information for participants must be approved by the HREC before being given to the participants or made available to the public.
    a. **University logo.** All participant information and consent forms must contain the Curtin University logo and University contact details for the researchers. Private contact details should not be used.
    b. **Standard statement.** All participant information forms must contain the HREC standard statement.

        This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 51/2014). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

    c. **Plain language.** All participant information must be in plain language that will be easily understood by the participants.

Please direct all communication through the Research Ethics Office

Curtin University

HREC Progress Report

The Form is to be completed and returned to *the Secretary, Human Research Ethics Committee, c/- Office of Research & Development.* hrec@curtin.edu.au

If a Form C Co-ordinator, approved your application please submit your completed form to your school Form C Co-ordinator.

Annual completion of this form fulfils researchers' obligations under section 5.5.5 of the National Statement on Ethical Conduct in Human Research.

All questions must be answered or the Form will not be processed.

Approval Number:	
PROJECT TITLE:	

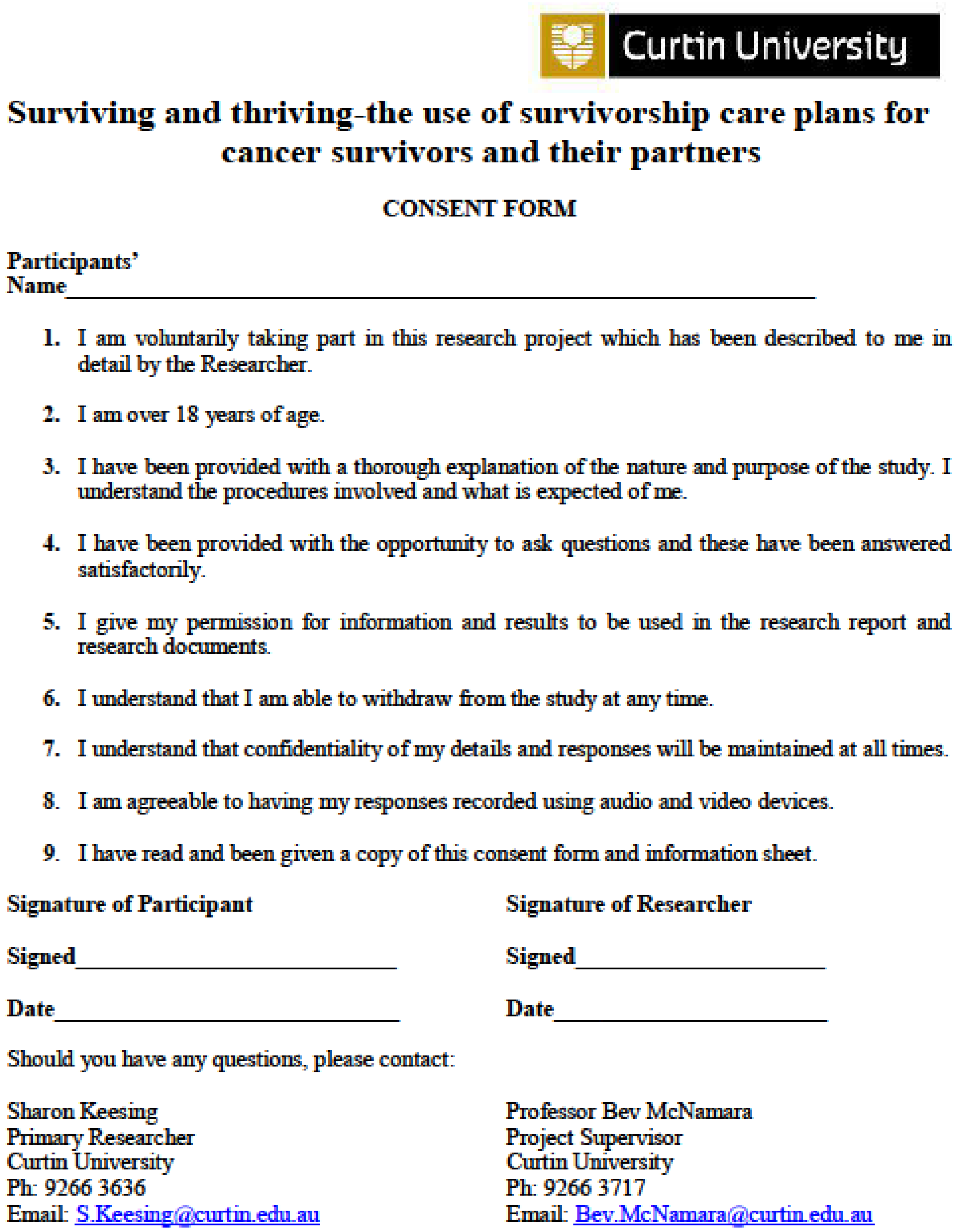
1	**Please confirm the project is proceeding exactly as specified in the protocol.**	**YES☐**	**NO☐**
If NO, please provide details______ *(Attach additional comments on a separate sheet of paper if necessary)*			
2	**Have any ethics related issues emerged in regard to this project since you received Ethics' Committee approval? (e.g. breach of confidentiality, harm caused, inadequate consent or disputes on these).**	**YES☐**	**NO☐**
If yes, please provide details______ *(Attach additional comments on a separate sheet of paper if necessary)*			
3	**Have any ethics related issues in regard to this project been brought to your attention by others? (e.g. study respondents, organisations that have given consent, colleagues, the general community etc).**	**YES☐**	**NO☐**
If yes, please provide details ______ *(Attach additional comments on a separate sheet of paper if necessary)*			
4	**Please outline the progress made to date. (e.g. Number of participants recruited; Data collected / analysed; Papers published)**	**YES☐**	**NO☐**
(Attach additional comments on a separate sheet of paper if necessary)			
5	**Please detail what arrangements have been made for the ongoing storage and security of the research records in accordance with the Western Australian University Sector Disposal Authority (WAUSDA).** http://uim.curtin.edu.au		
(Attach additional comments on a separate sheet of paper if necessary)			

Investigator:		Signature:	
		Date:	
Co-Investigator:		Signature:	

School/Department:			
Head of Area: *Or equivalent*		Signature:	
Date:			

Office Use Only
APPROVED:______________________________ DATE: ______/______/______

Appendix J Participant consent form



Curtin University

Surviving and thriving-the use of survivorship care plans for cancer survivors and their partners

CONSENT FORM

Participants' Name____

1. I am voluntarily taking part in this research project which has been described to me in detail by the Researcher.
2. I am over 18 years of age.
3. I have been provided with a thorough explanation of the nature and purpose of the study. I understand the procedures involved and what is expected of me.
4. I have been provided with the opportunity to ask questions and these have been answered satisfactorily.
5. I give my permission for information and results to be used in the research report and research documents.
6. I understand that I am able to withdraw from the study at any time.
7. I understand that confidentiality of my details and responses will be maintained at all times.
8. I am agreeable to having my responses recorded using audio and video devices.
9. I have read and been given a copy of this consent form and information sheet.

Signature of Participant	**Signature of Researcher**
Signed_______________________	**Signed**____________________
Date_________________________	**Date**______________________

Should you have any questions, please contact:

Sharon Keesing
Primary Researcher
Curtin University
Ph: 9266 3636
Email: S.Keesing@curtin.edu.au

Professor Bev McNamara
Project Supervisor
Curtin University
Ph: 9266 3717
Email: Bev.McNamara@curtin.edu.au

Appendix K Stage one information form

PARTICIPANT INFORMATION FORM- STAGE ONE

Survivorship care planning for women survivors of breast cancer and their partners

Introduction

You are invited to participate in a new research project that examines some of the current issues for cancer survivors and their partners living in Western Australia. The study is being conducted by a Researcher who is an Occupational Therapist and is working towards a Doctor of Philosophy (PhD) degree at Curtin University. The study has been approved by the Human Research and Ethics committee (HREC) at Curtin University.

Please read through the following information which will explain what the study is about and how you will participate.

Purpose of the study

The purpose of the study is to understand more about the experiences of cancer 'survivors' and their partners, following the completion of treatment for cancer. The study will involve collecting information from cancer survivors, their partners, health professionals, service providers and others. Participants will contribute their ideas about the survivorship journey, the resources that may/may not have been used, supports accessed/not accessed and their day to day routines following the treatment period.

What the study will involve

The study involves your agreement to be interviewed by the Researcher. The interview will be conducted at a mutually agreed location (your home or venue at Curtin University) and will last approximately one hour. The interview will be tape recorded and then typed, word for word to form a transcript. The questions will focus on your thoughts and experiences as a cancer survivor (or partner), following the completion of treatment. You may refuse to answer any of the questions, take a break or terminate the interview if you do not feel comfortable. A copy of the interview transcript will be forwarded to you for checking and corrections made if necessary.

Confidentiality

All information provided to the Researcher will be considered confidential. The interview transcript will be saved on to a computer using only a number code and your name will not be recorded. This information will be protected by password, known only to the Researcher. The original recording will be destroyed. All other information including research reports and documents will be stored in a locked filing cabinet in the Researcher's office at Curtin University.

Benefits

There are no direct benefits to participation. However, it is anticipated that the information collected from the research will assist in the delivery of services for cancer survivors and their partners in the future.

Discomfort and risk

The interview questions will focus on your opinions and experiences as cancer survivor. It is not anticipated that these questions will create any difficulties, however if this occurs you may terminate the interview, resume at another time or withdraw from the study completely. Follow-up support with a health professional will be arranged by the Researcher if required.

Voluntary participation and withdrawal

Your participation in this study is voluntary and you may withdraw for any reason at any time.

Questions or concerns

If you have any questions or concerns about the study, please do not hesitate to contact the Researcher.

Sharon Keesing	Professor Bev McNamara
Researcher	Research Supervisor
Phone: (08) 9266 3630	Phone: (08) 9266 3717
Email: S.Keesing@curtin.edu.au	Email: Bev.McNamara@curtin.edu.au

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 51/2014)The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral care workers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Ethics Committee, c/o Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845, by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Thank you for your participation

Appendix K Stage three information form

PARTICIPANT INFORMATION FORM- STAGE THREE

Survivorship care planning for women survivors of breast cancer and their partners

Introduction

You are invited to participate in an ongoing research project that examines some of the current issues for women affected by breast cancer and their partners living in Western Australia. The study is being conducted by a Researcher who is an Occupational Therapist and is working towards a Doctor of Philosophy (PhD) degree at Curtin University. The study has been approved by the Human Research and Ethics committee (HREC) at Curtin University. Please read through the following information which will explain what the study is about and how you will participate.

Purpose of the study

The purpose of the study is to understand more about women and partners priorities and preferences for 'survivorship care planning'. Survivorship care planning refers to the explicit care and co-ordination of services and resources provided to women and their partners following cessation of treatment for breast cancer. This is the third stage of the study, with previous stages including interviews with women and their partners about their experiences during survivorship as well as an online survey completed with local health care providers. Your contribution to the third stage of the study will inform further discussions with these local service providers, with the aim of enhancing the care and resources provided to women affected by breast cancer and their partners living in WA (i.e. stage four).

Eligibility

The study will involve collecting information from women affected by breast cancer and their partners. If you do not have a partner, you are still eligible to participate. Participants will contribute their ideas and preferences for care required during survivorship; what they consider to be important areas of concern and how this care should be provided.

What the study will involve

The study involves your agreement to participate in two focus groups, scheduled to take place about one month apart. These groups will be conducted at Curtin University and each will last approximately one hour. Questions for discussion during the first group will include your thoughts and ideas regarding priorities and preferences for survivorship care planning as a woman affected by breast cancer (or partner), following the completion of treatment. One of the aims of the discussion will be to explore and determine the essential components of care required during survivorship.

The second group will involve the presentation of summarised information from the previous group and discussion aimed at achieving consensus between participants in order to prioritise areas of need; to determine the essential elements of survivorship care planning and the format and delivery of services to address these needs. You may refuse to answer any of the questions, take a break or leave the session at any time if you do not feel comfortable. The groups will be audio recorded and then typed, word for word, to form a transcript. A copy of the focus group transcripts will be forwarded to you for checking and corrections made if necessary.

Confidentiality

All information provided to the Researcher will be considered confidential. The focus group transcripts will be saved on to a computer using only a numeric code and your name will not be recorded. This information will be protected by a password, known only to the Researcher.

Benefits

There are no direct benefits to participation. However, it is anticipated that the information collected from the research will assist in the delivery of services for women affected by breast cancer and their partners, in the future.

Discomfort and risk

The focus group questions will focus on your opinions and experiences as a woman affected by breast cancer (or their partner). It is not anticipated that these questions will create any difficulties, however if this occurs you may leave the session at any time, resume at another time or withdraw from the study completely. Follow-up support with a health professional will be arranged by the Researcher if required.

Voluntary participation and withdrawal

Your participation in this study is voluntary and you may withdraw for any reason at any time.

Questions or concerns

If you have any questions or concerns about the study, please do not hesitate to contact the Researcher.

Sharon Keesing	Professor Bev McNamara
Researcher	Research Supervisor
Phone: 0412219181	Email: Bev.McNamara@curtin.edu.au
Email: S.Keesing@curtin.edu.au	

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 51/2014)The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral care workers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Ethics Committee, c/o Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845, by telephoning 9266 2784 or by emailing hrec@curtin.edu.au

Thank you for your participation

Appendix K Stage four information form

PARTICIPANT INFORMATION FORM

Exploring the experiences of women survivors of breast cancer and their partners.

Stage four- the views of occupational therapists

Introduction

You are invited to participate in a research project that explores the views of occupational therapists regarding the services and supports for women survivors of breast cancer and their partners.
The study has been approved by the Human Research and Ethics committee (HREC) at Curtin University and is being conducted by a PhD student. The following information explains what the study is about and what it involves, should you choose to share your expertise through participation.

Purpose of the study

The study involves collecting information from occupational therapists who have had some experience and awareness regarding the diagnosis, treatment and survivorship period for people with cancer; the resources and services that are offered; and your ideas about the care available for these people.

What the study will involve

If you choose to participate, you will complete three rounds of responses as part of a 'Delphi' study, via email. This method of research involves asking questions to 'expert' participants to develop information and knowledge about a particular topic.

In round one, participants (not identified to each other) will be provided with a short series of questions concerning a case study. We are interested in your opinion so there are no right or wrong answers (this will take approximately 20 minutes to complete).

In round two, the opinions of all respondents will be summarised and sent to all participants with a series of statements asking you to agree or disagree with these statements. Again, there are no right or wrong answers (this will take approximately 10 minutes).

In round three, a summary of the round two responses will be sent to all participants for further opinion (this will take approximately 10 minutes).

The overall findings and a conclusion will be summarised and returned to you.

Confidentiality and privacy

All information provided to the Researcher will be confidential. Participants will not be identifiable to each other, and responses will de-identified and consolidated. The responses will be saved on to a computer using a numbered code so your name will not be recorded. This information will be protected by password, known only to the Researcher. All information will be stored in a locked filing cabinet in the Researcher's office at Curtin University.

Benefits

There are no direct benefits to the occupational therapists who participate. However, it is anticipated that the research will assist in the provision and delivery of services for women survivors of breast cancer and their partners in the future.

Discomfort and risk

The questions will focus on your opinions and experiences and it is not anticipated that these questions will create any difficulties. However if this occurs you may terminate your participation, resume at another time or withdraw from the study completely.

Voluntary participation and withdrawal

Your participation in this study is voluntary and you may withdraw for any reason at any time.

Questions or concerns

If you have any questions or concerns about the study, please do not hesitate to contact the Researcher.

Sharon Keesing	Professor Bev McNamara
Researcher	Research Supervisor
(08) Phone: 9266 3630 or 0412219181	Email: Bev.McNamara@curtin.edu.au
Email: s.keesing@curtin.edu.au	

Thank you for your participation

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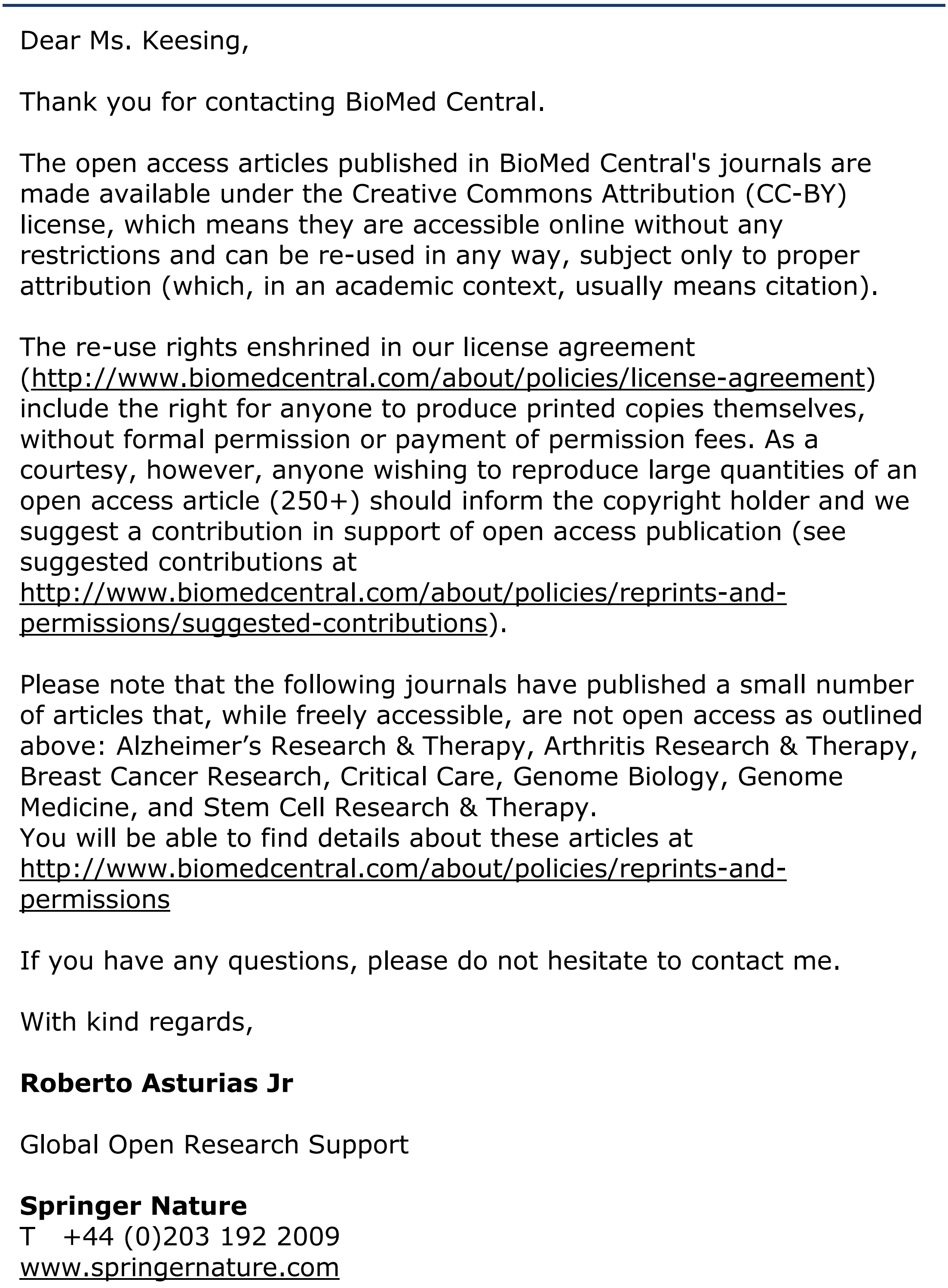

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With kind regards,

Roberto Asturias Jr

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--------------Your Question/Comment -----------------

Dear Editor,

I am writing to ask permission regarding my paper that was published in BMC Women's Health 'A dyadic approach to understanding the impact of breast cancer on relationships between partners during early survivorship', DOI 10.1186/s12905-016-0337-z.

I am about to submit my PhD thesis and would like to include this as one of my peer-reviewed articles. Can you tell me if there is likely to be a problem with copyright for this? I will, of course, include this letter and your reply in the final submission.

Kind Regards

Sharon

Sharon Keesing
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Appendix L Copyright declaration three

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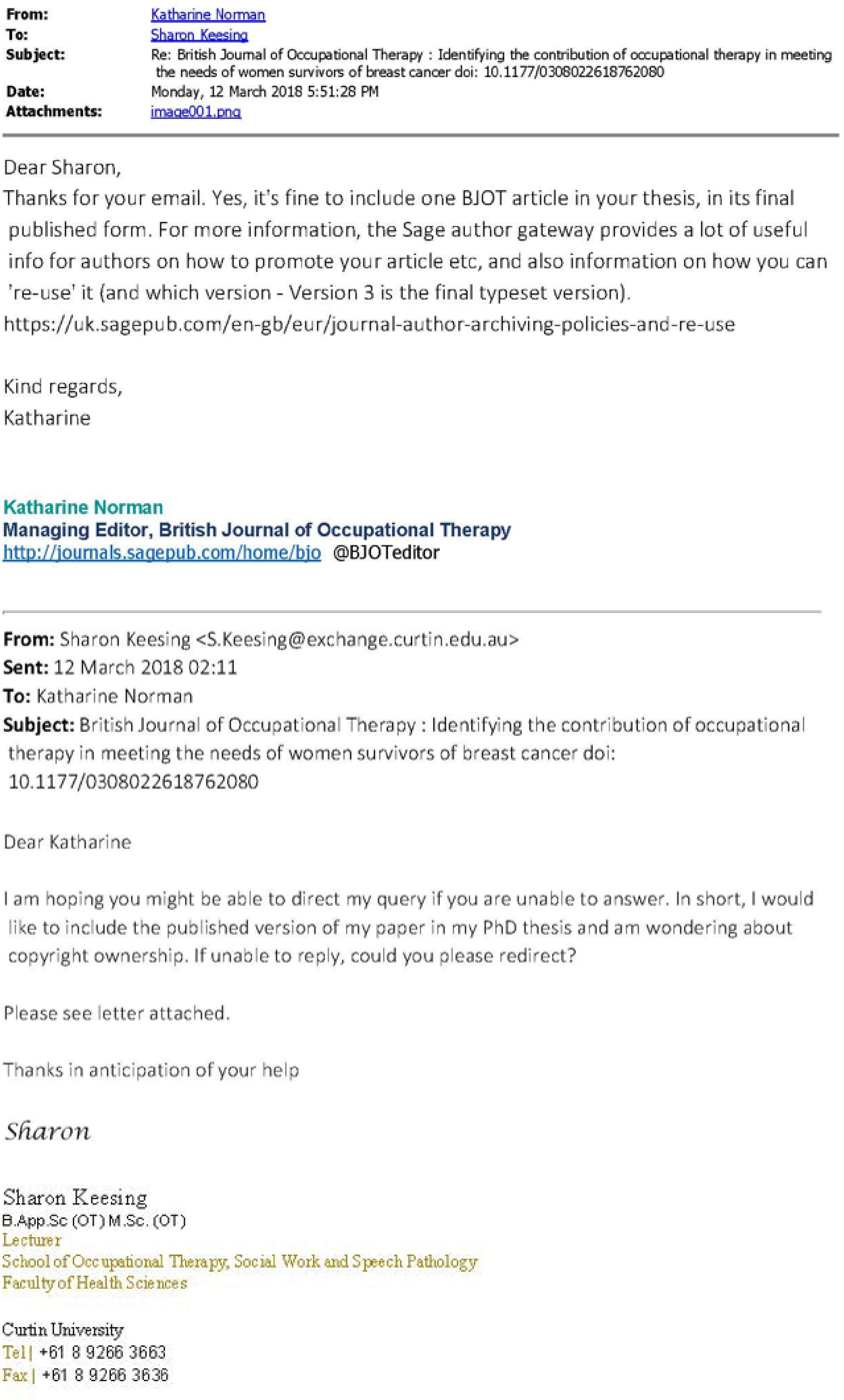

From: Katharine Norman
To: Sharon Keesing
Subject: Re: British Journal of Occupational Therapy : Identifying the contribution of occupational therapy in meeting the needs of women survivors of breast cancer doi: 10.1177/0308022618762080
Date: Monday, 12 March 2018 5:51:28 PM
Attachments: image001.png

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Kind regards,
Katharine

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From: Sharon Keesing <S.Keesing@exchange.curtin.edu.au>
Sent: 12 March 2018 02:11
To: Katharine Norman
Subject: British Journal of Occupational Therapy : Identifying the contribution of occupational therapy in meeting the needs of women survivors of breast cancer doi: 10.1177/0308022618762080

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Please see letter attached.

Thanks in anticipation of your help

Sharon

Sharon Keesing
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Lecturer
School of Occupational Therapy, Social Work and Speech Pathology
Faculty of Health Sciences

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Appendix M Publication three acceptance

From: Women & Health
To: Sharon Keesing
Cc: sburns@ucdavis.edu
Subject: Women & Health - Decision on Manuscript ID WWAH-2017-0107.R2
Date: Tuesday, 1 May 2018 2:28:56 AM
Attachments: Ms2017-0107R2.docx

30-Apr-2018

Dear Ms. Keesing:

Ref: A call to action: the need for improved service co-ordination during early survivorship for women with breast cancer and partners.

Our referees have now considered your paper and have recommended publication in Women & Health. We are pleased to accept your paper with the minor edits tracked in the attached version, which will now be forwarded to the publisher for further copy editing and typesetting.

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