

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

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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

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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 co-facilitator/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 Clarke³⁰ 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 I: 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.

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