

The Untold Story of Late Effects: A Qualitative Analysis of Breast Cancer Survivors' Emotional Responses to Late Effects

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Abstract

Purpose Breast cancer survivors are at increased risk of adverse outcomes, called late effects, years after the completion of active treatment. Late effects can significantly impair physical functioning. The current study aimed to explore breast cancer survivors' experiences, perceptions and concerns about late effects.

Methods 36 women treated for breast cancer in the last 10 years participated in semi-structured telephone interviews. Participant views were sought with respect to knowledge, experience and perceived longer-term risk. A thematic analysis was conducted.

Results Four themes emerged from the data: (1) late effects awareness, (2) framing and coping, (3) uncertainty and (4) management. There was a range of emotional responses to late effects however many participants reported being unaware of their risk of late effects. Participants conceptualised late effects as any long-term effect of treatment regardless of the time of onset. Women reported living with constant uncertainty and feared cancer recurrence. Many were focused on managing long-term treatment side effects, rather than late effects.

Conclusion Many women undergo treatment and remain unaware of associated late effect risks. National guidelines recommend patients be informed about late effects however the results of this study suggest a gap between policy and practice. Evidence-based interventions are needed to equip women with strategies to physically and emotionally manage late effects.

Introduction

Early detection of breast cancer through screening and increasing treatment efficacy means survival rates have increased to over 90% [1]. Breast cancer treatments can be aggressive and patients experience a number of *short-term side effects* during treatment, *long-term side effects* that persist indefinitely after completing treatment and *late effects* that are further changes in functioning, which emerge months to years later [2, 3, 4]. The literature does not clearly differentiate between long-term side effects and late effects yet differentiation is vital as they have different onsets, durations and assigned meanings that may produce diverse emotional responses in women [5, 6].

Late effects after breast cancer treatment can be classified into four categories [7]. They can be (a) 'system specific' such as congestive heart failure or lung fibrosis [8, 9], (b) 'second malignant neoplasms' associated with cumulative doses of alkylating agents [10, 11, 12] or (c) 'functional changes' such as lymphoedema [13]. Long-term side effects such as pain, peripheral neuropathy, cognitive impairment and fatigue, all long-term side effects of treatment, can also be considered late effects [14, 15, 16, 17]. Finally, late effects can also be (d) 'associated comorbidities' such as cardiovascular disease, arthritis and osteoporosis [18].

All breast cancer treatment modalities have the potential to cause significant late effects, yet there is only a small body of research exploring their psychosocial impact [19, 20]. In primarily heterogeneous cancer

survivor populations, late effects have been shown to negatively affect mental and physical quality of life, ability to work, personal relationships, self-esteem and body image satisfaction [21, 22, 23, 24]. Survivors with late effects report significantly lower mental and physical health, greater utilisation of health services and more unmet needs than those without late effects [25]. Many survivors also report they perceive their late effects to be chronic and incurable; however they can reduce their impact through improved coping skills [26].

Some of the most commonly reported unmet needs among breast cancer survivors are information about late effects and self-management strategies to manage the illness at home [27]. Insufficient information results in women feeling unprepared for the development of late effects [28]. From the perspective of health professionals, education about late effects is considered an important focus for follow-up post-treatment [29]. However, the emotional impact of breast cancer survivors' experiences of late effects is yet to be systematically explored.

Thus, the current study aimed to explore women's experiences of late effects, their emotional responses to existing or potential late effects and their perceived impact.

Method

Participants

Eligibility criteria for the study included being diagnosed with breast cancer in the last ten years, completion of active treatment and being older than 18 years with sufficient English to participate in a telephone interview.

Participants were recruited through Breast Cancer Network Australia (BCNA), a national support and advocacy organisation for Australians affected by breast cancer. An e-mail invitation was sent to BCNA members who had previously agreed to be contacted about research. Participants were able to access further information about the study and an online consent form via a URL link embedded in the email invitation. Participants who consented to the study completed an online survey and provided contact details for the researchers to arrange a telephone interview at a mutually convenient time.

Data Collection

Participant characteristics were collected via the online Qualtrics survey (Qualtrics, Provo, UT) and included demographic (age, gender, education, employment and language) and clinical information (date and stage of diagnosis and treatment(s) received) to characterize the sample. Emotional wellbeing was assessed using the Depression, Anxiety and Stress Scale (DASS-21) [30], and Fear of Cancer Recurrence Inventory Short-Form (FCRI-SF) [31]. High scores on the DASS-21 and FCRI-SF indicate greater morbidity.

Semi-structured telephone interviews explored women's late effects experience, the emotional impact of this experience and potential risk of future late effects as well as coping strategies for existing late effects. The interview schedule is provided in Online Resource 1. Interviews were conducted between

June and August 2019 by a trained qualitative researcher and were audio-recorded and transcribed verbatim.

Data Analysis

Participants' survey data were analysed descriptively and summarised with means and overall percentages. Qualitative data were thematically analysed using a framework approach [32]. The authors familiarised themselves with the data by actively re-reading transcripts multiple times. Two authors (JR and JS) double coded ten interviews to identify preliminary codes and develop a draft thematic framework. Differences were resolved through discussion and consensus. The draft thematic framework was then applied to subsequent transcripts. Codes were iteratively charted by grouping them into more meaningful subthemes based on theoretical links. Finally, each theme was named and a thematic map was created.

The University of Sydney Human Research Ethics Committee approved the current study (2019/376) on 29th May 2019.

Results

54 women consented to participate and completed the online survey whilst 36 eligible women participated in interviews. Reasons for non-participation in the interview included no longer wanting to participate ($n = 1$), not being contactable ($n = 13$) or not meeting eligibility criteria ($n = 3$). Table 1 summarises all participants' socio-demographic and clinical information. Mean age was 57 and many were university educated ($n = 34$, 64.15%). 54% ($n = 29$) were diagnosed with early stage breast cancer (stage 0–2). Overall participants were psychologically well; although anxiety was higher than in the general population [33] and fear of cancer recurrence was high ($M = 17.61$, $SD = 6.14$) with 32% of participants meeting the consensus FCR clinical cut off (> 22) [34].

Table 1
Participant Characteristics

Age: mean (SD) range		57 (9.96) 35–77 years old
		Number of participants (%)
Education	None or Primary	2 (3.77)
	Intermediate Certificate/Year 10	1 (1.89)
	Higher School Certificate/Year 12	3 (5.66)
	Technical Certificate	13 (24.53)
	Tertiary	34 (64.15)
Employment Status	Full Time	17 (32.10)
	Part Time	16 (30.12)
	Retired	14 (26.42)
	Unemployed	3 (5.66)
	Home Duties	3 (5.66)
	Student	0 (0)
Language Spoken at Home	English	53 (100)
	Other	0 (0)
Stage Diagnosed	0	1 (1.89)
	1	15 (28.30)
	2	14 (26.42)
	3	19 (35.85)
	4	0 (0)
	Unsure	4 (7.55)
Treatments Received	Surgery alone	2 (3.77)
	Surgery + Chemo	9 (16.98)
	Surgery + Radio	8 (15.10)
	Surgery + Chemo + Radio	32 (60.38)
	Radio alone	2 (3.77)
	Hormone Therapy	41 (77.36)

Age: mean (SD) range		57 (9.96) 35–77 years old
DASS-21 Depression Subscale		
	0–4	35 (66.04)
	5–6	11 (20.74)
	7–10	3 (5.66)
	11–13	3 (5.66)
	14+	1 (1.89)
DASS-21 Anxiety Subscale		
	0–3	31 (58.49)
	4–5	10 (18.87)
	6–7	4 (7.55)
	8–9	3 (5.66)
	10+	5 (9.43)
DASS-21 Stress Subscale		
	0–7	37 (69.81)
	8–9	6 (11.32)
	10–12	4 (7.55)
	13–16	4 (7.55)
	17+	2 (3.78)
FCRI-SF	0–12	10 (18.87)
	13–21	27 50.94)
	22+	16 (30.19)

Participants reported on average 3.06 effects from treatment, the most prevalent being joint pain (n = 22), neuropathy (n = 14), fatigue (n = 13) and cognitive impairment (n = 12). Most participants did not distinguish between long-term side effects and late effects.

Based on the framework analysis, four distinct themes emerged from the interviews: (1) late effects awareness, (2) framing and coping, (3) uncertainty and (4) management. Supplementary quotes are provided in Online Resource 2. Figure 1 depicts the thematic map of relationships between themes that influence emotional responses to late effects in breast cancer survivors.

1. Late Effects Awareness

Participants' awareness of late effects influenced the meaning they assigned to them. Some women who were well informed about late effects experienced worry and concern about the perceived severity of the effects. Yet others reported that being informed provided them agency and reduced the uncertainty associated with their potential onset and management. Of those who reported being unaware of late effects, some reported high anxiety upon developing late effects as they assumed symptoms signified a cancer recurrence. Interestingly, despite learning about late effects years after completing treatment, most women stated they would have made the same treatment decisions.

I think for a lot of people information is power and if you have that knowledge you can act on it and do something about it (P23)

The breast being you know enlarged... and sometimes a little bit of pain there with it and so you worry that you've got another cancer in that breast (P21)

Participants made recommendations about how to better manage patients' expectations of late effects in order to mitigate negative emotional responses. Many women desired early knowledge about chronic or permanent side effects to set more realistic expectations for what life post-treatment would look like. Many expressed a desire for more information about when to expect late effects and how to manage them, so as to avoid mistaking late effects for cancer recurrence, and prevent onset or ameliorate their severity. Many participants recommended patients should receive this information in a dedicated late effects consultation after completing active treatment, separate from their final treatment consultation.

If you are like okay you don't have a choice because you need this treatment but know on the other side you will have to deal with neuropathy you have already taken most of the anxiety away (P13)

Had I known more prior I possibly wouldn't have ended up with as much lymphoedema as I do (P52)

2. Framing and Coping with Late Effects

Surviving cancer changed each woman's attitude toward life. This influenced how they later framed and coped with late effects. Some participants reported they perceived their late effects as daily physical reminders of their cancer experience and this prevented them from moving on.

It does make me anxious ...any time my heart beats a little faster you think oh my god it was the radiation (P21)

For many, late effects acted as triggers for fear of cancer recurrence with women reporting they were fearful of planning for the future, had trouble sleeping, and in severe cases, had 'panic attacks'. Many reported dismay or disappointment about the restrictions late effects placed on their life, precluding a return to normal. In contrast, one participant could positively frame her late effects as confirmation that her treatment was effective.

The reason that my body aches is because I have no oestrogen and having no oestrogen is a good thing so I've managed to convince myself that having my body ache is a good thing (P09)

Some women framed their late effects through the lens of social comparison. Upon hearing of other survivors' lack of late effects (through online forums or personal relationships), many women reported concern and frustration with their own poor post-treatment recovery. In contrast, some participants reported experiencing gratitude upon observing others who were worse off but also worry that their own situation may worsen.

You will meet up with someone who is really struggling with their lymphoedema and it's pretty horrifying to think that that could happen at anytime (P51)

Women who perceived their trust in their medical teams had been breached reported negative responses, as they perceived late effects to have been avoidable. However, women who trusted their medical teams perceived late effects as a necessary evil and a 'small price to pay'.

If you want to be around [in ten years] you are going to do what they say and you are going to swallow those pills (P30)

Receiving validation for their experiences with late effects, either from medical teams or online forums, also influenced women's emotional responses. Participants reported relief after learning that others experienced similar symptoms. However, others who perceived their experiences were dismissed reported frustration, worry and even anger.

The surgeon and the oncologist are like 'nah it's all in your head' [breathing difficulties due to damaged lungs], 'it's not a problem'. And it's like no I do notice a difference, you know. I am the one that is breathing here (P50)

3. Uncertainty about Late Effects

Emotional responses were also influenced by the uncertainty surrounding the duration, eventual severity and impact of late effects. Women were ultimately worried about losing control over their quality of life. Participants reported they were unable to plan ahead and were fearful of being unable to fulfill their work and social roles. This in turn resulted in women experiencing anxiety, bitterness and resentment towards their late effects, making coping more difficult.

I think to myself well yep that wasn't something I signed up for (P30)

Despite the uncertainty, some participants reported acceptance. These participants perceived it was futile to worry about something out of their control, yet some remained sad about the limits late effects placed on their lives. Additionally, participants also used hope and avoidance to assert some control over the uncertainty. Some were optimistic that a "wonder pill" will be available by the time they develop late

effects whilst others reported they will “cross that bridge” when it comes, thereby delaying any emotional response.

4. Management of Late Effects

Many participants reported being proactive in adapting to a “new normal”, modifying behaviour or engaging in preventative self-management to reduce the physical and emotional impact of late effects. This increased coping and reduced uncertainty, and in turn, negative responses to late effects. Some strategies were contingent on women’s knowledge about late effects such as risk minimisation behaviours (e.g. healthy diet, regular exercise) as well as various treatments (e.g. supplements for joint pain, lymphoedema therapists). Other reported strategies were based on behaviour change (e.g. changing shoes they wear, having smaller expectations for what can be achieved in one day).

The more I was able to start to make a change and see the differences and not be at the impact quite as much, the more I was kind of like now I’m okay (P34)

However, when management strategies were ineffective, many participants experienced greater worry, concern or frustration.

I think I’m good you know I am really on top of it and then out of the blue there could be problems and I feel like I am back at square one again in my resentment and pity and grief and frustration (P51)

Discussion

This qualitative study aimed to explore breast cancer survivors’ emotional responses to late effects, their impact and the factors associated. The analysis gave rise to four distinct themes: (1) late effect awareness, (2) framing and coping, (3) uncertainty and (4) management. Women did not distinguish between long-term side effects and late effects. Rather, they considered late effects as *any long-term effect of treatment* regardless of time of onset. Overall women reported a range of physical effects from treatment and a range of emotional responses to them. Most women reported limited awareness of late effects, which influenced emotional responses. Results highlighted a need for evidence-based interventions tailored towards educating women about late effects and equipping them with emotional and physical strategies to improve coping. Quantitative measures of the impact of late effects are required, which could be incorporated into future studies on the prevalence of clinically significant emotional morbidity in response to late effects. Improving the ability to identify those at risk of significant worry or concern would be beneficial in order to allow for early intervention.

Not surprisingly, women were concerned about current late effects rather than the potential of developing late effects in the future, even when future late effects were life threatening. After having experienced the existential threat to life posed by cancer, many choose to ‘live in the moment’, which may reduce worry about potential late effects in the future [35]. Thus individuals tend to overestimate the likelihood of proximal threats (e.g. joint pain) rather than distal (e.g. cardiovascular disease) [36].

We found that uncertainty contributed to the challenge of late effects, but some women appeared more able to accept and live with uncertainty. Greater tolerance for uncertainty has been linked to greater emotional wellbeing and less distress [37]. Given the risk of late effects, over and above risk of recurrence, adds another layer of uncertainty to the survivorship experience, future research should investigate tolerance of uncertainty and its potential utility in reducing negative responses to late effects.

Knowledge of late effects had a varied impact on women's emotional responses however the current results indicate that more knowledge is better than less. Consistent with previous studies, women with more knowledge about late effects were more aware of their risk and thus better equipped to prevent and manage late effects [26]. Importantly, they could also distinguish late effects from cancer recurrence. The fact that many women were uninformed about potential late effects is surprising considering national survivorship care guidelines recommend patients be informed and supported in regard to developing and managing late effects [38]. This reveals a gap between policy and practice.

Patients do not generally request information about late effects, highlighting the need for health professionals to raise the topic [6]. Survivorship care plans could provide a viable solution as they note potential late effects based on treatment and personal risk factors and address steps patients should take in the event of developing late effects [39, 40]. Survivorship care plans, if implemented adequately, could satisfy participants' information needs, reduce uncertainty and enhance coping with late effects [41]. However, although recommendations for cancer survivors to receive a survivorship care plan are widely supported, barriers such as limited time and no reimbursement for doctors result in them not being uniformly implemented [42, 19, 43]. These barriers need to be addressed if care plans are to realise their potential.

Our findings suggest that interventions to help women to cognitively reframe late effects to reduce their emotional toll [44] may be helpful, but these are currently lacking [45]. Dedicated late effects clinics incorporated into survivorship care may be helpful. As survivorship clinics have been shown to enhance knowledge, increase quality of life and satisfaction in diverse cancer survivor populations [46, 47 48], it is likely that a similar multidisciplinary approach to late effects will have similar outcomes for patients. Further research is needed to investigate the utility of these clinics in addressing specific concerns about late effects.

The present findings need to be considered in light of a number of limitations. Firstly, all participants were self-selected and recruited through a support and advocacy organisation. Hence results may have been influenced by selection bias. Additionally, perceptions of male breast cancer survivors on late effects remain unknown. The study also only investigated the experience of women with breast cancer and may not reflect the wider experience of late effects across cancers.

The current study contributes to the limited research on late effects by highlighting the importance of awareness, framing and coping, uncertainty and management in affecting the emotional responses of breast cancer survivors. Evidence-based interventions are needed to provide women with strategies to

emotionally and physically cope with late effects. This would increase the quality of life and wellbeing of breast cancer survivors, as well as reduce the survivorship burden on the healthcare system.

Declarations

Funding

No funding was received for conducting this study.

Conflicts of interest/Competing interests

No conflicts of interest are relevant to the content of this article.

Ethics Approval

The University of Sydney Human Research Ethics Committee approved the current study, project number 2019/376, on 29th May 2019.

Consent to Participate

After reading the PIS, participants consented to the survey by ticking a box on the first page of the Qualtrics survey. Participants consented to participating in a telephone interview by voluntarily providing their contact details on the last page of the online survey. Participants verbally consented before the interview commenced.

Consent for Publication

Participants consented to publication by ticking the consent box after reading the following in the PIS, "Study findings may be published but you will not be identifiable in these publications".

Availability of data and material

Interview schedule and participant quotations are provided in Online Resource 1 and Online Resource 2 respectively.

Code availability

Not applicable.

Author's Contributions

Dr. Shaw and Dr. Butow conceived the presented idea in collaboration with Danish colleagues. Jodie Rosenberg developed the theory, collected the data and performed the analysis under the supervision of Dr. Shaw. All authors discussed the results and contributed to the final manuscript.

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Figures

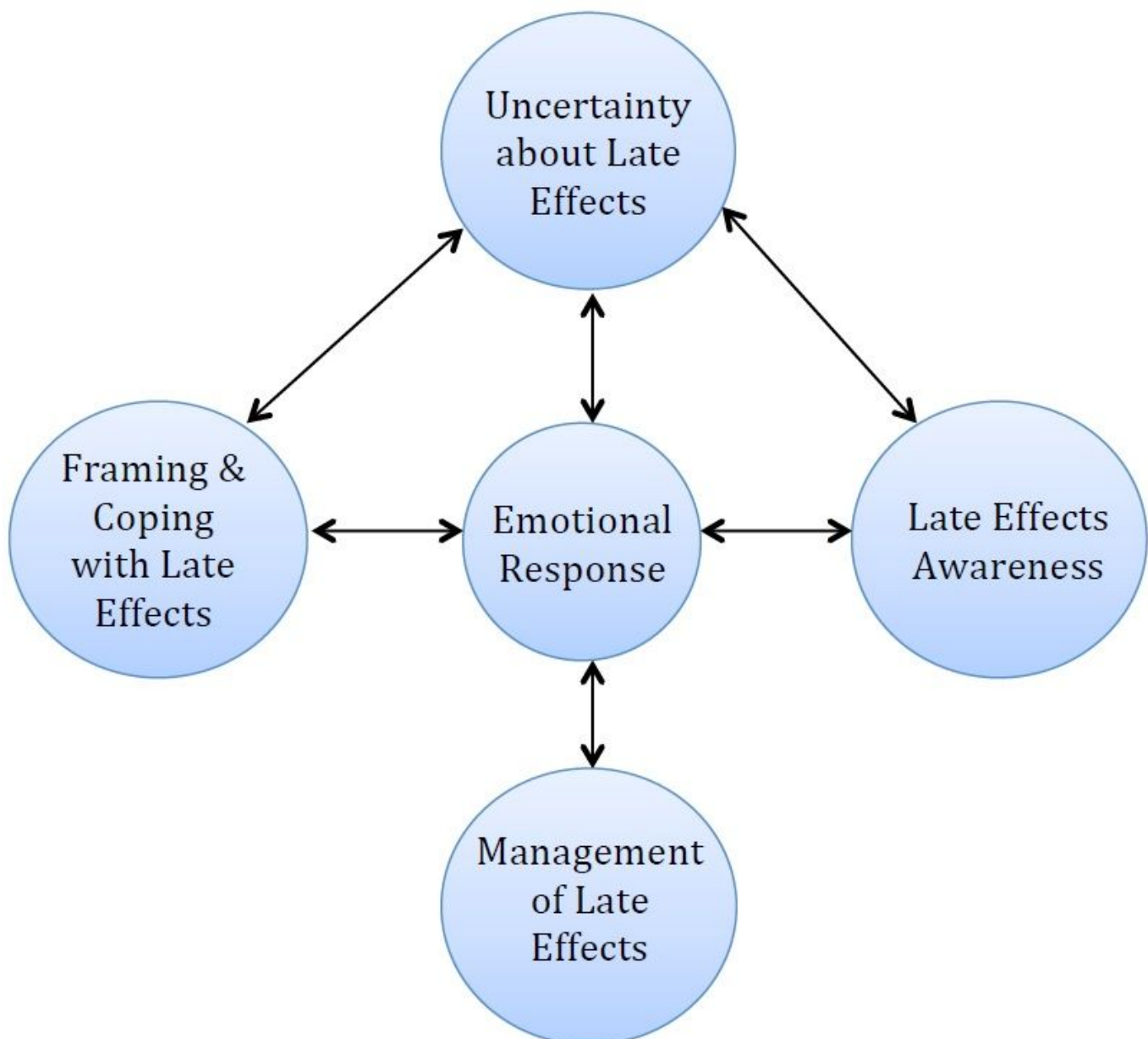


Figure 1

Thematic map of the relationships between themes that influence emotional responses to late effects in breast cancer survivors

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [OnlineResource1.pdf](#)
- [OnlineResource2.pdf](#)