Introduction

The number of breast cancer cases in Australian women is increasing. In 2010, the figure increased from 5303 (recorded in 1982) to 14,181. By 2020, it is anticipated that annual recorded diagnoses will total approximately 17,210 (Cancer Australia, 2014). Age remains the strongest risk factor, with approximately three quarters of all cases diagnosed in women over the age of 50 years. However, due to improved treatment and early detection, mortality rates have fallen. Australian women are now believed to have an 89% chance of surviving at least 5 years post-diagnosis (National Breast and Ovarian Cancer Centre, 2012).

There is considerable literature about breast cancer experiences; however, what has received limited attention is the experiential accounts of what happens in the period post-treatment. Paying attention to this particular period is important because public discourse suggests that the patient is well again, when that may not entirely be the case (McCann et al., 2010). In order to understand women’s experience post-treatment, there is a need to first appreciate what happens psychologically and socially as a result of being a patient within an oncology system. Conventional treatment stops when surgery, chemotherapy, radiotherapy and adjunct...
hormone therapies conclude (Breast Cancer Network Australia, 2014). While treatment side-effects such as scars, fatigue, alopecia, sexual difficulties and lymphoedema can be distressing, most side-effects are temporary; however, others may be permanent and impact on a woman’s ability to psychologically and socially move on from treatment (Carver et al., 2006; Crompvoets, 2006; Rosedale, 2009).

Public discourse regarding cancer informs and influences western culture (Little et al., 2002; Rosedale, 2009). Those with cancer might seek out information about their diagnosis (Sulik, 2009); however, the magnitude of available information may appear overwhelming (Thorne and Murray, 2000; Willig, 2011). A Google search using the words ‘life post breast cancer’ results in excess of 63,000,000 social media and other websites. While accessible information informs the interested public on treatments, fundraising and education about the disease, there is limited analysis of the widely available information about cancer on social media to determine how effective it is for women struggling to find meaning, or seeking to understand long-term issues, and life post-treatment (Helgeson and Tomich, 2005; Little et al., 2002).

Being diagnosed with cancer can result in a shift from a position of prior health into a space of illness, and a conceivable shift in how an individual may think and talk about themselves (Mathieson and Stam, 1995). Bodily changes such as hair loss or fatigue can be signifiers of being a cancer patient (McCann et al., 2010). In turn, becoming a patient may lead to self-perceptions of difference to others, or could influence social interactions (Gallia and Pines, 2009; Iacob, 2011). For example, a cancer patient may express relief because a previously undiagnosed complaint has been substantiated; yet, they may withdraw from social activities because of physical limitations.

Societal expectations can be both driven by, and reflected in the media. For instance, a public expectation is the imperative to think positively, and avoid unacceptable discussions of potential death. This censoring of experience could be challenging for patients who want to discuss both the negative and positive aspects of their experience. Their concerns, however, may be suppressed in environments where others do not wish to consider negative outcomes (Willig, 2011). The influence of positive thinking as a defence when fighting cancer is often reflected in media stories. These tend to reflect affirmative, engaging stories, sometimes involving celebrities. Such accounts provide hope and positivity; however, they could also leave some women feeling unable to live up to such standards, diminish the potentially distressing effects of the experience (Bellizzi et al., 2006).

Positive thinking is reinforced through the use of military metaphors. Descriptions of ‘battling’ and ‘fighting’ against the disease position sufferers as ‘combatants’ actively choosing to engage in a ‘war’ (Sontag, 1978). An implication is that if someone chooses not to fight, they are somehow passive. As a patient, they have autonomy and a choice in how they manage their disease (Willig, 2011). However, individual cancer experiences are more complex than that (McCann et al., 2010; Wilkes et al., 2003). Similarly, the term ‘survivor’ positions the woman as a ‘hero’, having come through the experience with wounds, but being stronger for it (Rosedale, 2009). Some women may find it difficult to reconcile the term ‘survivor’, particularly because doctors cannot guarantee remission, with recurrence an ever-present risk (McKenzie and Crouch, 2004).

While public attention is focused on the disease and the patient, it has been argued that there is little attention paid to the holistic experiences post-treatment, leaving survivors without researched recognition of their issues (Little et al., 2002). When the concentrated periods of treatment end, there are often adjuvant approaches that continue; yet, public discourse suggests that the patient is well again. However, there are potential psychological and social changes, which can be exacerbated by societal expectations of newfound wellness (McCann et al., 2010). For those who do not die, ongoing survivorship can be a challenge that can only really be told by those who have lived that experience.
This research aimed to develop a better understanding of women’s subjective experiences of breast cancer post-treatment, and the social contexts of these experiences in order to add to public discourse about this topic, and to provide valuable information to both those who treat the disease and those who experience it firsthand.

Context of the study

The interest in exploring women’s experiences of breast cancer is borne from the first authors’ (N.P.) experience of breast cancer. While this experience provided the impetus, listening to other narratives provided a richer, more textured understanding of issues faced by women post breast cancer. The benefit of sharing a similar experience is acceptance, which builds trust with participants that may be harder to develop otherwise (Breen, 2007). Interviews were conducted as part of a larger study that found a number of themes concerning diagnosis, treatment and social support. This article will report on findings concerning the experiential accounts of the period post-treatment.

Method

Research design

A phenomenological methodology as described by Hayes (2000) was employed in order to best explore the idiosyncratic experiences of women. This enabled consideration of the participants’ context, how they made sense of the phenomenon and how this may have influenced their behaviour. Semi-structured interviews were used to gather data with an inductive thematic analysis employed to analyse the data. This approach was adopted because oral narratives present participants with the opportunity to portray in detail their thoughts and feelings about their experience, also affording the researcher an opportunity to better understand the subtleties of personal concepts and ideas as they unfold (Hyden, 2008; Smith and Osborn, 2008).

Participants and recruitment

Recruitment was undertaken via convenience sampling, using snowballing (Dwyer and Buckle, 2009), an approach utilising the existing social networks of the crew of ‘Dragons Abreast’ a local dragon boating team.1 Eligibility for participation was limited to any female who had previously had a primary or secondary breast cancer and who had finished all treatment, including hormone and targeted therapies (such as tamoxifen or arimidex). Participation was welcomed regardless of ethnic or cultural background, occupation, socioeconomic status, marital status or sexual orientation.

After five in-depth interviews, similarities in the narratives emerged, which resonated with the literature. A further three interviews were conducted, with differing issues arising in the eighth interview, and a last ninth interview saw similarities reappear. A lack of further take up of interested participants, combined with resource and time constraints meant that no further interviews were conducted. In total, 15 women volunteered; however, six were still receiving hormone treatment and were not interviewed. All participants were Caucasian and six were retired or semi-retired. The average time since diagnosis was 8 years. Demographic and treatment statistics are outlined below (Table 1).

Research procedure

Ethics approval from Charles Sturt University’s Human Research Ethics Committee was granted before interviews were conducted. An email with an information sheet was distributed to the members of the dragon boating crew. Through a method of snowballing, a number of members passed on the information to others whom they knew had experienced breast cancer, and volunteers were invited to contact the researcher to arrange a time and place to meet.

The interview schedule was piloted with a breast cancer survivor known to N.P. This pilot resulted in a modified process whereby the researcher briefly detailed her breast cancer...
### Table 1. Participant demographic and treatment details.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age at diagnosis</th>
<th>Age at interview</th>
<th>Mastectomy</th>
<th>Lumpectomy</th>
<th>Lymphatic node removal</th>
<th>Chemotherapy</th>
<th>Radiotherapy</th>
<th>Hormone/targeted therapy</th>
<th>Reconstruction</th>
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<tr>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
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</tbody>
</table>

Pseudonyms were used for all participants.
experience at the start of each interview. Sharing her experience validated and acknowledged the researcher’s position within the research. Digitally, audio-recorded, semi-structured interviews were conducted with each participant in a location of their choosing. The majority of interviews were conducted in participants’ homes and were guided by three key questions asking about life pre-breast cancer, their experience of breast cancer and how participants might describe themselves post breast cancer.

The interviews took 40–65 minutes to complete. To facilitate trustworthiness, transparency and accuracy, participants were invited to review their own transcripts and were encouraged to provide feedback. N.P. undertook the interviews, and used the process of bracketing to acknowledge their experience and knowledge of breast cancer (Hayes, 2000). Reflexive notes were also maintained in order to capture intersubjectivity within the interviews that included age differences, experiences and preconceptions (Finlay, 2008). Elements of these notes have been incorporated into the findings (Mauthner and Doucet, 2003). As such, the findings are an amalgamation of perceptions of intersubjectivity, the participants’ narration of their experiences and the researchers’ analysis of the data.

Data analysis

Data were analysed using an inductive thematic analysis (Hayes, 2000). First, interviews were transcribed and then each read numerous times. Items of importance to the research aims and of particular interest to the participants were separately annotated onto a spreadsheet. This process resulted in 26- to 43-coded items per participant. These items were then sorted and reduced into 15 categories which Hayes (2000) describes as ‘proto-themes’ (i.e. early grouping of similar issues). Possible linkages between proto-themes were examined to see how these connections might have shaped the participants’ experiences. In order to assess the accuracy of the interpretation, further questions were posed to five of the participants via email. The questions also sought elaboration of the participants’ thoughts on their bodies and feelings at key points during their experiences (Nutt Williams and Morrow, 2009).

Where repetition or similarity of data content was present, the proto-themes were further reduced leading to three manifest themes (Joffe, 2011). Transcripts were re-read several times with convergent and divergent data annotated onto the spreadsheet for integration into thematic categories. This process facilitated the initial labelling of each theme. Themes were then named and defined, taking into account the meanings outlined by participants.

A second more concentrated review of the literature was then undertaken to assist with the contextualisation of the themes, as reflected in the findings. While there were a number of meaningful constructs that emerged from the data of the larger project, only selected ones will be discussed in detail in this article. These focus on narratives concerning the period post-acute treatment. The themes presented were believed to be those that would add to the public discourse concerning the holistic experiences of people post-treatment.

While N.P. conducted the interviews, there was detailed collaboration among the research team. The second (J.G.) and third authors (R.S.) read all the transcripts, in particular reviewing for congruence between what participants said and the emergent themes. The initial bracketing, as well as the collection of reflexive considerations, was an important part of the data analysis, intuiting and describing the insights gathered from the study (Hayes, 2000).

Study findings

A number of the women in this study reflected on what life was like for them during the post-treatment period. They revealed their thoughts about the social position of being a ‘patient’, a label commonly used within the medical profession. They spoke about the nature of their relationships with their doctors, and the vulnerability experienced upon cessation of treatment, the loss of contact with medical carers,
expectations they held about themselves, as well as the psychological and social changes they experienced. Lastly, the notion of moving from a sick role back to ‘normalcy’ was discussed.

**Being a patient.** A diagnosis of cancer, whether expected or not, can be hard to accept (Elmir et al., 2010). Some of the women in this study talked about their reactions to their diagnoses, which came as a considerable shock. Heather, a 68-year-old retired tertiary teacher, described her thoughts about diagnosis in the following way:

> You almost feel as if you’ve stepped into a parallel universe, it’s like … um, you still function all right, but you feel as though everything’s … either stopped or changed or something. (Heather)

Throughout her interview, Heather talked about herself as someone who likes to know what is going on and be informed. This seemed to afford her some comfort and control. However, Heather’s diagnosis of cancer presented an unexpected existential challenge; even though she could still function, she described not being mentally and emotionally present. Her struggle to describe her feelings about everything having ‘stopped or changed or something’ demonstrates her struggle to make sense of her current situation. Receiving such unexpected news appears to place an individual in an immediately unfamiliar space, where the relative certainty of health and personal longevity has suddenly been disrupted, an experience most people are not generally prepared for (Cancer Australia, 2014).

The reassurance and safety of medical professionals. While oncology staff provide tangible treatment, they also embody expertise and assurance during what has been described as a time of need and concern (Costanzo et al., 2007). The majority of women in this study spoke very positively about their experiences and the relationships they developed with their oncologists and general practitioners. Ashley, who at 49 had been diagnosed with breast cancer only 10 months after a difficult marriage break up and was 4 years past that diagnosis at the time of the interview reflected:

> … I had a fantastic experience with my surgeon who was Doctor [name] … he was, he was just the best, he was lovely … so that was a really
good experience. Um … as well as you can have under those sort of circumstances. (Ashley)

In reflecting on ‘a good experience’ that she had with her surgeon, Ashley seems to put this in the perspective of her more recent, and comparatively unpleasant experience of her marriage breakdown. Ashley’s narrative situates her illness experience against the breakdown and subsequent struggles of raising teenage children as a single parent. While she does not paint breast cancer as a comparatively positive experience, she does talk fondly of some of the people she encountered, most notably her surgeon.

Certainly for many of the women in this study, the confidence and assurance that medical oncologists represent allowed them to feel comfortable, deferring to the expert, and adopting the compliant sick role, confident in the expertise of their oncologists. Constant appointments, medication, direction from staff and other triggers meant that patients disputably come to understand their position within the medical system. These triggers provide a routine, and patients may not be prepared to move away from the protection, status or expectations seemingly afforded to the patient role. They may be keen to be cured, and not be labelled ‘sick’; however, the reality of leaving that space and certainty can be confronting as the ties to associated comforts are also severed.

Reducing the frequency of interactions between patient and doctor, when a trusting and conceivably dependent relationship has developed, can therefore be challenging. Susan described this feeling using the analogy of coming to the end of a holiday:

It’s a bit like coming home from a fabulous holiday trip, you know and you fall flat on your face. (Susan)

For Susan, the end of the contact appeared to jolt her back to a changed reality, much like the realisation of returning to routine life after being away on a holiday. Susan spoke about feeling lost when all her treatment was done. She had experienced intensive personalised care after her surgery, which involved both a mastectomy and reconstruction. This was to ensure the reconstruction was successful and there were no complications. However, what that created was a period of heightened care and attention, and then a return to life at home away from that bespoke support and attentiveness. The need to take back responsibility for day-to-day routine may be challenging for the patient who had others determining the ‘routine’ and daily activities for them for the duration of their treatment.

Heather, who had retired after 20 years working in tertiary education, discussed believing that she would be emotionally and cognitively fine, even though her doctor warned her that she might feel somewhat neglected:

… I thought I was super woman, but I think I just expected I’d go back to feeling quite normal … and I was quite surprised that I didn’t. In fact I thought there was something really wrong with me, um, and when I’d finished my radiation and I’d been to see [oncologist], and he said to me ‘so basically this is … the end of your treatment … look you might feel a little bit, um sort of neglected’.

Heather’s doctor outlined, her life had, for a period, become that of a compliant patient, being told what to do. Effectively, Heather’s life had been regulated by the medical system with its omnipresent appointments, check-ups and interactions with medical professionals. This finding is consistent with other research that when regular
contact with treating medical staff stops, it can feel like a significant safety net had been removed, heightening uncertainty and anxiety (Costanzo et al., 2007; Ganz et al., 2004).

The feeling of losing the safety net seemed to influence the behaviour of one of the participants in a fairly remarkable way. In order to facilitate the delivery of chemotherapy and Herceptin, Jane’s oncologists fitted her with a port-o-cath in her chest. At the time when Jane could have had it removed, she chose not have it done. Instead, she left it in for a further 2 years, using the justification that she very much disliked general anaesthetics, which were required to remove it. However, Jane, a 66-year-old retired preschool teacher acknowledged the symbolic importance to her of keeping it in:

So, in a way it became like a, I don’t know, I felt it became like a, I couldn’t get rid of it because it was, I don’t know, it was silly because the nurses down there used to say ‘why don’t you get rid of it, it must just remind you, that you’ve had cancer’ all the time, but I think because it kept me in the system, and it made me, you know, there were still people that were sort of looking after me, I don’t know what it was, it was something weird and quite psychological. (Jane)

Jane appears to have symbolised the existence of the port-o-cath as an ongoing safety link to medical professionals. The existence of the port-o-cath facilitated Jane’s ongoing connection with the medical system, hence leaving herself in the position of being a patient. The role of patient arguably allows an individual to express and legitimise societal expectations and emotions, such as being lethargic, being anxious, having a depressed mood and develop dependence on medical professionals for assistance and support (Little et al., 2002). These expectations can reduce stress, and the dependence enables patients to share the burden of dealing with cancer (Willig, 2011).

Jane seemingly understood her need for ongoing contact with people who were looking after her, acknowledging that she struggled to move away from that assurance and support. While she did acknowledge this, it was in direct contradiction to a point she raised earlier in our discussion where she had complained:

… you seem to spend every minute at some medical facility don’t you? (Jane)

Throughout Jane’s narrative, she spoke with strength and resilience, both about her experience and about her life post breast cancer. However, when she spoke about her need for an ongoing connection with medical staff, it was clear that she felt vulnerable. Ostensibly her need for support outweighed her frustration of not being in control of her own time. Paradoxically, she wanted the safety of medical support around her, but at the same time, she wanted autonomy and independence from the constraints of illness.

Neither sick nor healthy. Regular medical contact appeared to enable these women to understand that they continued to be medically stable. However, when appointments stretch to 6 or 12 months apart, that peace of mind can wane as women are left in a suspended state of ambiguous health, awaiting the next appointment when they hope to be provided with clear test results. A number of the women in this study commented on this, as exemplified in comments by Jane and Meg, 64, who is a retired teacher for the deaf:

I would say the first, oh ten years every time that yearly mammogram came around, you know beforehand you were just that little bit, on edge. (Meg)

I still worry that you know it might recur, you kind of get over the five years and you think right, I’m right, but then you do hear of people who I think it does probably get them in the end, somehow or other, hmm, I don’t know, you can’t worry about it all your life can you? (Jane)

In many of the women’s narratives, strength and positivity played a role in their endeavours to move on; however, the concern of recurrence endured, with some suffering persistent unease. A number of researchers have described
this ongoing concern of recurrence as leaving women in an ambiguous state. Neither being a sick patient, nor having fully returned to health, has been referred to as liminality (Blows et al., 2012; Crouch and McKenzie, 2000; Johnston, 2011). As outlined by Johnston (2011: 368), Turner (1969) described people in a liminal state as those who ‘… elude or slip through the network of classifications that normally locate states and positions in cultural space’. They are ‘… stuck betwixt and between …’. As highlighted by Meg and Jane, there can be a recurrent concern that previous ongoing expectations of normal health have now been brought into question. For many years post-treatment, these women have faced the fear of recurrence, and are presumably left with that thought for a significant period of time. Crouch and McKenzie (2000) found in interviews with Australian women that this can be ‘… a permanent state of unease concerning the possible recurrence of disease’ (p. 208). A state of being which was evident throughout the women’s narratives.

Arguably societal expectations are both driven by and reflected in the media. The public discourse concerning cancer tends to reflect someone who has finished treatment as ‘cured’, having beaten cancer. This apparent ‘return to life as before’ leaves others with an expectation of a return to physical and mental normalcy (Crouch and McKenzie, 2000). It has been found that women are sometimes ill-prepared for the ongoing physical symptoms such as fatigue, not realising the time required for recuperation. This state can be frustrating and can lead to psychological distress as women attempt to understand what they have been through (Ganz et al., 2004; Johnston, 2011). Carolyn, 57, volunteers at a local gallery and presented in our interview as assured and self-sufficient. Her husband had retired from the military, and she described herself as a typical ‘Service’ wife, independent and very much the one who keeps the home running. Carolyn experienced conflict between what her body was physically able to do and her belief that she would simply be able to return to normality:

All of a sudden your brain says ‘all right treatments over, you should be fine’, but your body’s saying ‘no you can’t do that, you have to, try it again later’, or that sort of thing. (Carolyn)

It is during this period of recovery, when the focus on active treatment has ceased, that some find there is space to deal with emotional issues arising from their cancer experience (Lethborg and Kissane, 2003). To illustrate, Carolyn, who described herself as someone who likes to be in control, explained that she had become noticeably angry. She believed this was a coping mechanism that came from not allowing herself to deal with her thoughts and feelings while undertaking treatment:

And it was a case of well, I’ve got enough on my plate, dealing with getting my body to deal with it, my brains not ready to deal with the emotions, so they were put away, until I was at a stage where I could say all right, pull it out. You know it’s going through, a bit like for me, going through a memory box. I’d put it in there, because I wasn’t ready to deal with it, and when I was I’d drag it out and deal with it then. Um, I think it’s always been a coping mechanism for me. (Carolyn)

Carolyn had learnt more about herself, about how she felt a need to be in control and that not dealing with her feelings was her way of coping until she was ready to do so. Feelings such as disruption, anxiety and anger that many breast cancer patients experience have been acknowledged in previous studies (Little et al., 2002; Weber and Solomon, 2008). Carolyn talked at length about the anger she felt, and that she now believes she has learnt from this experience.

As argued by Little et al. (2002), there is a vast amount of public attention and research concerning the disease and the patient during treatment, but not concerning issues post-treatment. Heather, who volunteers with a breast cancer support group, was highly concerned that relevant information was lacking, in particular for younger women who would often find incorrect or irrelevant information on the Internet:
often all the information and advice stops with the medical treatment ... (Heather)

The experiences of the women in this study suggest that there may be a lack of knowledge about what to expect during the post-treatment period. While not all the women talked about the issues occurring post-treatment, the emotions and behaviour of those who did struggle were considerable. Some women were uncertain about what to expect after breast cancer and took time to get their life back to what they might consider to be normal. Living with this uncertainty can be challenging, and for some, the profound experience that breast cancer can be lead to changes in themselves and their lives.

Conclusion

This research aimed to develop a better understanding of women’s subjective experiences of breast cancer post-treatment, and the social contexts of these experiences. The findings of this study, which complement previous works, suggest that there is need for further investigation of issues that can arise during the period immediately post-treatment. A diagnosis of cancer for anybody who may perceive themselves as relatively healthy and active could come as a shock. This was certainly the case for the participants in this study whose narratives reflected the paradoxical shift from positive to negative emotions, feeling healthy and then being diagnosed with a life-threatening disease. The experiences of the women in this study suggest that there is a lack of knowledge about what to expect during the period post-treatment.

There are some limitations associated with this study worth noting. By its nature, snowball sampling can lead to a relatively homogenous participant group, as was the case in this study. While the results of this study cannot be readily generalised to the broader population, the results have enabled a better understanding of what it is to be a breast cancer survivor, and what issues can arise after treatment has ceased, hence providing an avenue for future research, particularly into life post-cancer treatment. Participants will only recall so much information in any one sitting, so more than one interview with each participant may have afforded an opportunity to revisit issues of particular significance to gain a richer understanding of these issues.

Further study looking into people’s expectations post-treatment would be valuable. Also research seeking to analyse the widely available social media to determine how effective it is for women struggling to find meaning, or seeking to understand long-term issues, and life post-treatment, and how people have psychologically and socially adapted back into their lives. Analysis of public discourse assumptions concerning a patient’s return to well-being might also provide insights into the social factors associated with the period post-treatment. Together with this study, further research would provide beneficial information to both those who treat it and provide longitudinal care, and to those who experience it firsthand.

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Notes

1. Dragon boating is a water sport involving a crew of 22 people in a canoe-like boat. Dragons Abreast is a national organisation of mainly breast cancer survivors who participate for fitness and support.

2. Manifest content describes the visible and obvious content of text. In contrast, latent content refers to what is inferred in the text and is ascertained through the interpretation of the underlying meaning within the text.

3. A port-o-cath is a catheter, which connects to a vein under the skin. It allows drugs to be injected and blood samples to be withdrawn.
References


