



Survivor identity and post-traumatic growth after participating in challenge-based peer-support programmes

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Objectives. The social construction of breast cancer (BC) survivor identity has produced a powerful image of woman as survivor. Group membership through peer-support programmes can provide positive role models, shape survivor identity and promote post-traumatic growth (PTG). The main objective of this study was to conduct a qualitative investigation based on a phenomenological framework in order to understand the lived experience of BC survivors participating in a peer-support programme based on a challenge event.

Design. This is a qualitative semi-structured and written narrative study. Interviews were subjected to interpretative phenomenological analysis and the written narratives *via* thematic analysis.

Method. Interviews were conducted with 27 participants who were new to the peer-support event for women diagnosed with BC, and 10 participants who had taken part in multiple events provided written narratives of their experience. Interviews and surveys were completed pre- and post-event.

Results. Important elements of the peer-support environment included a safe network of other survivors, which provided understanding and acceptance. Overcoming challenges during the event and the opportunity to bond with positive role models affirmed a strong survivor identity and promoted PTG. For some participants, a shift in identity was evident with a newfound positive identification with the term *BC survivor*.

Conclusions. Peer-support programmes based on challenge events have the potential to extend the type of supportive care that is available for women diagnosed with BC by providing an alternative to the traditional support group format.

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A breast cancer (BC) diagnosis is not necessarily marked by a discrete event with a certain trajectory or endpoint. The journey that begins from the moment symptoms are detected or from time of diagnosis can initiate new experiences that may be marked with fear, uncertainty, and anxiety (Cordova & Andrykowski, 2003). This life-threatening experience can be a catalyst that induces cognitions, behaviours, or emotions that may not have occurred without being diagnosed with cancer. Alongside the cancer-related distress, a shift in schemas and a positive approach to appraising the world can emerge (Calhoun & Tedeschi, 2006; Cordova, Giese-Davis, Golant, Kronenwetter, Chang, & Spiegel, 2007). Adjustment to BC is not necessarily a mere endpoint indicated by a return to pre-diagnosis physical and mental functioning (Brennan, 2001). Rather, adjustment can be viewed as an active psychosocial process resulting in both positive and negative life changes (Brennan, 2001). From this experience, a new social identity can be formed based on being a *BC survivor* and extend well beyond the period of illness (Harwood & Sparks, 2003; Zebrack, 2000).

Discourse involving BC survivor identity has emerged over the last few decades, thrusting the person diagnosed with cancer into the role of battling this disease and becoming a survivor. With BC predominantly occurring in women, the social construction of BC identity has been shaped by the feminist movement and a long history of activism that has influenced public perception and health policy (Kedrowski & Sarow, 2007). In comparison to other types of cancer, such as colorectal or prostate cancers, BC advocacy has broken taboos surrounding public discussion, shown a willingness to speak out, participate in support groups, have mass media coverage, and engage in political action (Kedrowski & Sarow, 2007; MacKenzie, Chapman, McGeechan, & Holding, 2010). As a result, the social movement that exists behind BC advocacy has produced a powerful image of woman as survivor (Kedrowski & Sarow, 2007).

A study assessing the extent to which women identify with the term *BC survivor* found approximately half the women did not refer to themselves as a survivor (Kaiser, 2008). Some women rejected this terminology as they feared recurrence or believed they were not sick enough to now be a survivor. Other women refused to become part of the social identity of being a BC survivor and did not want to be labelled as such (Kaiser, 2008). For others, the meaning of survivor identity varied; for example, identification with survivorship can imply survival from the disease, surviving treatment, becoming a survivor after discovering an inner strength, or surviving the disease for the rest of their life (Kaiser, 2008). The use of BC survivor was often coupled with a positive reframing of the term into a justified use of this term (Kaiser, 2008).

Identification as survivor and what this term implies can be influenced through social group membership (Harwood & Sparks, 2003). Group membership, such as being female or having BC, and identifying with positive role models within those groups can influence the perception of self as a proactive cancer survivor and potentially promote positive life change (Cameron, 2004; Harwood & Sparks, 2003). The powerful image of a strong survivor is often promoted through peer-support programmes based on challenge events such as Dragons Abreast. Peer-support programmes based on challenge events incorporate action-oriented activities in contrast to the talk-based peer-support groups (Emslie, Whyte, Campbell, Mutrie, Lee, Ritchie, & Kearney, 2007). The benefits gained from challenge-based programmes may include a positive perception of self and a new identity as an athlete (Sabiston, McDonough, & Crocker, 2007). Belonging to this type of peer group allows for an understanding of survivorship and overcoming physical challenges encourages a regained sense of control over physical and psychological health (Sabiston *et al.*, 2007; Thorne & Murray, 2000). Identifying as a proactive cancer

survivor can shape positive health behaviours and adaptive coping (Thorne & Murray, 2000).

It has been suggested that challenge events combine physical activity, social support, emotional expression, active coping, and acceptance, and that these elements contribute to an improved self-perception (Mitchell, Yakiwchuk, Griffin, Gray, & Fitch, 2007). Bonding with a new social network and taking part in challenge events conducted in a public forum can also provide an environment conducive to self-learning and personal growth (Dunn, Campbell, Penn, Dwyer, & Chambers, 2009; Harwood & Sparks, 2003). Perceiving personal growth from adversity is commonly reported after struggling with the challenges associated with cancer (Stanton, Bower, & Low, 2006). Personal growth such as improved relationships, personal strength, appreciation of life, and health-related changes are prevalent after diagnoses of life-threatening illnesses (Hefferon, Grealy, & Mutrie, 2009; Morris, Shakespeare-Finch, & Scott, 2010; Sawyer, Ayers, & Field, 2010). Positive life change, or post-traumatic growth (PTG), after adversity suggests that a person is capable of developing 'beyond their previous level of adaptation, psychological functioning, or life awareness' (Tedeschi, Park, & Calhoun, 1998, p. 3).

Calhoun and Tedeschi (2006) propose a model of PTG that can be applied to a person's cancer experience, describing an interaction between rumination, self-disclosure, and socio-cultural influences. In particular, Calhoun and Tedeschi (2006) discuss three aspects of a person's immediate social environment that may influence the perception of PTG, including the response from significant others to self-disclosure about cancer; congruent ruminations about the cancer experience with significant others; and PTG modelled behaviour in others. In this view, group membership in peer-support programmes can play an integral role in a person's socio-cultural environment. These support groups may influence PTG by normalizing their cancer experience and providing positive role models through interacting with other survivors (Calhoun & Tedeschi, 2006; Harwood & Sparks, 2003).

Rationale and aims of the study

Studies have highlighted the benefits of taking part in challenge-based peer-support activities for women diagnosed with BC. These studies have shown that these types of programmes can improve perceptions of self (Mitchell *et al.*, 2007; Sabiston *et al.*, 2007) and PTG (Dunn *et al.*, 2009). What is lacking, however, is an exploration of how these peer-support groups may contribute to a positive *survivor identity* and how this new identity may impact on PTG. Theoretically it has been proposed that broader group membership, such as being female, can influence the perception of self as a proactive cancer survivor and potentially promote positive life change (Cameron, 2004; Harwood & Sparks, 2003). The image of BC survivor as a strong woman and role model is portrayed in the media and promoted by a powerful social movement (Kedrowski & Sarow, 2007). Therefore, the current study will explore how challenge-based peer-support programmes contribute to both BC survivor identity and PTG.

In order to understand the lived experience of the BC survivor, this study aims to investigate women participating in Amazon Heart Thunder (AHT) from a phenomenological framework. AHT is a peer-support challenge event for women diagnosed with BC who get the opportunity to ride Harley-Davidson motorcycles over 1,000 miles. An initial study of the AHT experience identified that elements of this peer-support programme contributed to PTG, including forming a new social network and close connections with the other women (Dunn *et al.*, 2009). This study aims to extend previous research by exploring

whether AHT also influences women's perception of their BC survivor identity alongside the perception of positive life change. The current study will use a phenomenological framework to capture the lived experience of this peer-support programme, including group cohesion, social and illness identity, and positive and negative life changes that may have occurred since their diagnosis and AHT. In addition to this, the experiences of the riders who have taken part in multiple AHT rides will be explored to ascertain why women re-engage in this event.

Method

Participants

Twenty-seven participants new to AHT events completed pre- and post-ride interviews and were from two rides taking place in Australia ($n = 16$) and in the United States ($n = 11$). Three riders from the Australian event and one rider from the US event did not take part in the study. Ten participants who had been on multiple AHT events completed pre- and post-surveys of a written narrative describing their experience. The current study is part of a larger project that also incorporated quantitative assessment. As reported elsewhere (Morris, Chambers, Campbell, Dwyer, & Dunn, 2010), analyses showed that participants from the Australian and US events did not significantly differ on socio-demographic factors, disease-related variables, or on any standardized measures in pre- and post-ride surveys. Therefore, data were pooled for analyses including the qualitative analysis outlined in the current article.

Participants had a mean age of 49.82 years ($SD = 7.04$), mean age at diagnosis of BC was 42.63 years ($SD = 7.17$), and the average time since diagnosis was 6.39 years ($SD = 3.89$). Frequencies of socio-demographic and cancer-related factors are presented in Table 1.

Amazon Heart Thunder

The original purpose of AHT was to address a gap in supportive care needs for women diagnosed with BC and provide an alternative to the purely discussion-based support groups. Applications were sought internationally for motorcycle riding and support van positions for a 10-day ride on Harley-Davidson motorcycles. Some women who applied for riding positions obtained their licence specifically for this event and were required to complete a minimum of 1,000 practice miles prior to the ride. Once participants were accepted, an online discussion group was established 6 months prior to the ride allowing women to meet each other and share their experiences. The two AHT facilitators, who were BC survivors themselves, also took part in the online discussion group.

As part of the requirements for AHT, women committed to raising \$1,500 (AUD) in donations for BC causes. Two days prior to the ride, participants met to discuss the nature of the event, their expectations of the ride, and to share their experiences. This preparation also gave women time to practice riding their loan Harley-Davidson motorcycles, learn the strategies needed to ride in group formation, and discuss pertinent road rules (particularly for the benefit of the women from other countries). For safety, small ride groups of five or six women were formed within the larger ride group to effectively manage traffic. The rides each took place over 10 days and AHT events have taken place in countries such as Australia, United States, and the United Kingdom.

Table 1. Frequencies of participant demographic and cancer-related variables

	%
Relationship status	
Married/partner	51
Married/partner—same sex relationship	16
Single	12
Widowed	4
Divorced/separated	17
Country of birth	
Australia	41
North America	39
New Zealand	8
South Africa	4
United Kingdom	4
Asia	2
Europe	2
Education	
Postgraduate/undergraduate university	63
Trade or technical college or diploma	20
Senior high school	12
Primary school	2
Work status	
Employed full-time	55
Employed part-time/casual	13
Full-time home duties	4
Unemployed/looking for work	6
Retired	8
Permanently ill/unable to work	8
Self-employed	6
Recurrence of breast cancer	
Yes	14
No	86
Family history	
Yes	31
No	59
Not sure	10
Finished treatment	
Yes	76
No	24
Types of treatment (non-exclusive)	
Bilateral mastectomy	16
Partial mastectomy	10
Radical mastectomy	24
Modified mastectomy	10
Prophylactic mastectomy	2
Lumpectomy	61
Radiotherapy	67
Chemotherapy	75
Hormonal therapy	39

Procedure

Ethical clearance was obtained from Griffith University, Australia and all women registered for the Australian and US ride were invited to participate in the study. Participants were sent an information sheet, consent form, and survey *via* e-mail from the AHT facilitators in the month preceding the event. Participants returned their completed surveys to the researcher before the ride began. New riders were contacted by the researcher and invited to take part in a telephone interview before and after the ride. Post-ride surveys were e-mailed to participants 3 weeks after the event. The first author took part in both events to gain familiarity with the group dynamic and the AHT experience through participant observation.

Materials

All participants completed pre-ride survey questions regarding socio-demographic and disease-related factors. The semi-structured pre-ride interviews included topics such as reasons for doing AHT, expectations for the ride, and positive/negative life changes since being diagnosed. Post-ride interview topics included group cohesion, social and illness identity, and positive/negative life changes since being diagnosed and taking part in AHT. For the US ride, surveys were sent to riders who had participated in multiple AHT events asking open-ended questions requiring a narrative response. Pre-ride surveys explored why these participants were taking part in AHT again, and what their expectations were for the ride. Post-ride surveys asked participants whether the current ride was different from previous events and whether AHT had influenced their self-identity.

Qualitative research approach

In-depth telephone interviews conducted with new riders were audio-recorded and transcribed verbatim. Transcripts were inputted into the qualitative data programme NVivo (version 8.0) and subjected to interpretative phenomenological analysis. Written narratives completed by repeat riders were investigated using thematic analysis, based in an interpretative phenomenological framework that is extensively used in health psychology research (Riessman, 2008). An interpretative phenomenological framework is concerned with capturing the lived experience of the participant and adopts a shared understanding from the perspective of the researcher and the interviewer (Smith & Osborn, 2003). The coding approach involved becoming thoroughly familiar with the transcripts through several readings and continual reviewing process while coding (Smith & Osborn, 2003). Concepts were noted and emergent themes identified by grouping similar concepts. A systematic coding and indexing process prioritized data and final themes are reflective of shared understandings among participants. Overarching super-ordinate themes emerged from the identified component themes through an iterative process. Prior theory serves as a resource for interpretation of themes; however, an interpretative phenomenological framework also allows for uncovering novel and discordant themes (Riessman, 2008). The first author's reflective journal kept during the rides provided context to data and analysis, and was used during coding to evaluate and assist in interpretation of component themes and creation of super-ordinate themes.

Reliability and validity of qualitative data

A rigorous approach to qualitative analysis was achieved through reaching data saturation and analysis through NVivo (version 8). Component and super-ordinate themes were discussed amongst authors and confirmed against the transcript data. While

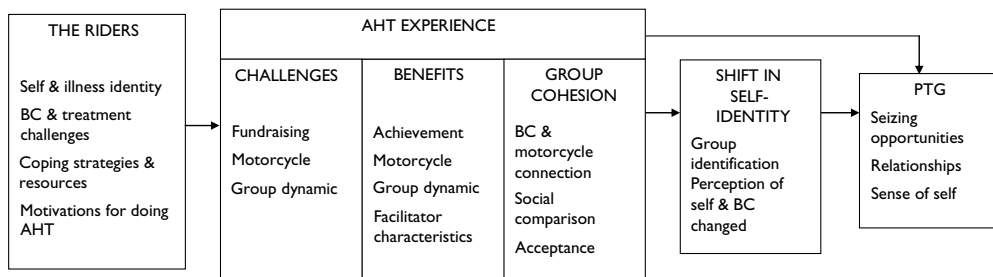


Figure 1. Overview of themes reported by Amazon Heart Thunder riders before and after the event. Note. BC, breast cancer; AHT, Amazon Heart Thunder; PTG, post-traumatic growth.

a computer analysis programme does not replace reading and manual coding of themes, this type of analysis maintains rigour in the analysis process (Bazeley, 2007). This system provides a framework to keep concepts and themes organized and a thorough approach to the ongoing process of qualitative analysis (Bazeley, 2007). Matrix queries allowing for text searches in NVivo provided an auditing process of the emergent themes to ensure reliability of the data.

Results

Four super-ordinate themes emerged from the data, including; BC experience and pre-ride survivor identity, AHT experience (challenges, highlights, group cohesion), shift in survivor identity, and PTG. Figure 1 provides an overview of the super-ordinate and component themes. The following presentation of these themes will highlight the PTG domains reported by all participants and how AHT contributed to a positive survivor identity for some participants.

BC experience and pre-ride survivor identity

Participants discussed a survivor identity that had emerged since being diagnosed with BC. For example, many women discussed being thrust into the position of role model in their community since their diagnosis and an active role in raising awareness and funds for BC:

'I have been doing fundraising for breast cancer since I've had it'. (205)

'I think what's happened is you walk away from it and think 'I think I could be an inspiration to people'. I sound like Joan of Arc. It's not that all . . . it's nice to talk to [other breast cancer survivors] and say 'you can treat it like a chronic disease and you can carry on and do fun things and have a life''. (208)

When asked if they identified with the term *BC survivor*, the response varied:

'No because I'm not trying to survive it. I just had it and it's gone'. (212)

'Yes I can proudly say I'm a survivor. I'm not a victim. It means I've fought through the battle and I've overcome, I'm surviving'. (214)

Those participants who did identify with being a BC survivor attributed positive meanings to this term and discussed feelings of strength and group membership by labelling

themselves as a survivor. This strength was reported as a strategy to actively cope with continued challenges from their diagnosis and treatment. For example

'I have the constant reminder, I mean you take your clothes off and there's the reminder staring at you every day. So it's hard to forget'. (225)

Some participants refused to identify as a BC survivor due to the potential for being seen as a victim of their illness:

'It means being a victim of something in a negative way. And I think I learnt so much from having had cancer so I don't feel being a victim in a negative way. They don't say a heart attack survivor'. (206)

Many participants discussed other peer-support groups that they had accessed before joining AHT. In particular, dragon boating was reported as a beneficial experience for many women and these participants perceived that there would be similarities with AHT. Some participants perceived that AHT and dragon boating were unique compared to traditional cancer support groups that were conversation or discussion based.

'I went to two meetings of a traditional cancer support group and really didn't enjoy them and didn't get what I had hoped from them. But the paddling group, it's sort of like this group in that you can or you don't have to talk about cancer. You can if you want to and that makes it kind of really good for most people. It's a good social outlet as well as having some physical fitness involved'. (216)

This quote highlights that discussing cancer was optional rather than a requirement, which was a substantial benefit to some participants. Regardless of whether cancer was discussed, a shared understanding of the cancer experience and acceptance from peers was evident.

Participants predominantly described their motivations for joining AHT as 'for the first time I am doing something for me' (203) and the desire for camaraderie and support from other survivors. Other motivating factors for joining AHT included wanting fun, love of motorcycles, fundraising/advocacy, seizing opportunities, and pushing boundaries. In particular, this last theme described a strong attraction to this event:

'I think that's the challenge of doing it . . . you know, taking yourself out of your comfort zone and doing something different and also grabbing the public's eye'. (202)

Amazon Heart Thunder experience

Three main component themes described the AHT event; challenges, benefits, and group cohesion. Often, themes such as fundraising, motorcycle riding, and group dynamics were both challenges and benefits. For example, in the 6 months leading up to the ride, the fundraising that was required to take part in AHT was a challenge for many women. For some, this was the first time they had reached out in their community and told their cancer experience to people outside their immediate social network. The challenge of making their story public was also reported as a positive experience as some women were pleasantly surprised by the support that they received. Adverse weather and riding conditions were also described as a difficulty that was surpassed, leading to a sense of achievement that was a catalyst for increased personal strength.

Other challenges were evident as some participants reported that their reactions and emotions were not consistent with how they perceived themselves to be at home

and this was a challenge and a learning experience as they struggled with their identity within the group:

'I haven't been in a situation where I didn't know anyone for a long time. I learned, I think, a lot about myself. I was actually very surprised about myself, how I acted and didn't act. I always thought of myself as very open and silly and outgoing and social, and I really feel like I wasn't myself for most of the trip'. (226)

For some participants, being in a new social network was an avenue for re-establishing behaviours or cognitions, creating a shift in self-perception. Some participants reported group dynamics as challenging at times due to personality clashes or not always feeling included in the group. Generally, group dynamics and cohesion were major contributing factors to the overall positive experience of AHT. The online discussion group before the ride was important to form early bonds with other women and establish a connection with the AHT group. The discussions generated *via* e-mail extended the immediate connection of BC and motorcycles into deeper relationships based on sharing, understanding and acceptance:

'I'd never been able to talk about it to anyone let alone family but that was one of the things that I felt was the acceptance of the group. They didn't . . . none of them judged me'. (203)

The formation motorcycle riding required in this event stipulated that within the larger group, small ride groups of five or six women were formed. Many participants described the strong friendships established in these ride groups as a result of challenges faced together each day and the trust that emerged between each rider in that group. Group cohesion was also influenced by different room allocations each night. While this was discussed as a challenge, participants also perceived this as a benefit as the forced socialization allowed for connections with the larger group.

Themes regarding challenges, benefits, and group cohesion provided a rich description of the experience and it was the process of overcoming difficulties and group identification that led to a sense of achievement and personal strength:

'The uncertainty of whether or not I should do [Amazon Heart Thunder] in the first place. Then the perseverance with getting my licence, being scared to death and wondering if I had made the right decision in the first place because I got a bike to start learning, and then realising how much fun it is. Yeah, I think fun and the freedom is just great'. (225)

'To be able to say, 'Oh my God I'm a breast cancer survivor and I'm gonna go on this Harley ride,' really shows a lot of strength and courage and fortitude and independence'. (227)

This sense of achievement was felt as they managed physical and psychological challenges every day while manoeuvring a Harley-Davidson motorcycle through traffic and adverse weather conditions.

Positive role models within AHT were central to women reappraising their own situation positively through the social comparison process of upward identification. In particular, women who were currently experiencing recurrences of BC were praised for their positive attitude:

'Sarah* just blew my mind as did Barbara* and I would like to think that that's how I will be when, I'm using the word when, mine [cancer] does come back because that can be very inspirational'. (204) *names changed

Upwardly identifying with positive role models and group identification as an AHT rider created or reinforced their perception of personal strength. Participants also reported

the AHT facilitators acted as positive role models and influenced group dynamics and individual experiences. As BC survivors themselves, participants reported a shared understanding and feeling of total acceptance from the facilitators. Characteristics of the facilitators such as strength, flexibility, organization, leadership, and kindness were consistently reported by participants as contributing to the positive experience of AHT. In particular, many participants reported that they felt that the facilitators provided a safe environment, thus allowing them the freedom to explore their cancer experience amongst peers and also have fun.

Shift in survivor identity

For some participants, the ride created a shift in how they perceived themselves as a cancer survivor:

‘That ride made me admit that I’ve had cancer, openly, you know, whereas before I was embarrassed. I was really embarrassed that it had happened to me. Then I realized it’s not something that I did, that I inherited, it’s you know unexplainable, it’s not my fault’. (214)

These participants attached new meaning to their cancer experience and for some women who had not previously viewed themselves as a BC survivor, this changed after the ride. Identifying as an Amazon Heart warrior created a post-ride identity based on strength and a positive discourse regarding *BC survivor*:

‘I put myself down [regard myself] as a survivor now’. (229)

Participants also discussed a transition period felt after the ride was over:

‘You come home and you start telling people about your trip and then, you know a couple of minutes into it everyone has kind of lost interest in listening to your trip. But they can’t even comprehend what an amazing trip it was. So that’s why maybe we will stay in contact because no one else quite gets it, you know’. (224)

This quote exemplifies the strong sense of belonging to the group and a desire to do the ride again in order to relive the AHT experience. Contact was maintained by many women and, for some, a new social and survivor identity was formed based on AHT group membership.

Post-traumatic growth

For some women, attributing positive meaning to their cancer survivor identity was facilitated through AHT group membership and overcoming the challenges of the ride.

‘I feel pretty proud of being part of that group and pretty privileged that I was able to do it. I’m proud of myself for being able to achieve this and I doubted myself a lot of whether I could do it so I’m really glad that I pushed myself to be able to do it as well. I had a lot of self doubt before I went’. (229)

Identifying as a proactive cancer survivor after being part of the AHT group gave women strength in their day-to-day lives and for some it was a catalyst for personal growth in other aspects of their life. Participants reported that their newfound sense of personal strength gained during AHT continued after the ride was over, stating that positive life changes were evident once they returned home, for example

'I can ride a Harley on the Sydney Harbour Bridge, I can do that. There's not much else I can't do now'. (201)

These women discussed the need to continue pursuing activities that exemplified their desire to get the most out of life.

Regardless of whether a shift in survivor identity occurred, all participants reported positive life changes, or PTG, since being diagnosed with cancer and taking part in AHT. PTG domains included enjoying life and seizing opportunities, fun and freedom, and relationships with others. Also, an improved perception of self was a rich theme consisting of reports describing personal strength, pride in self, and self-nurturing. In particular, two PTG domains describing a newfound or re-discovered sense of personal strength and enjoying life were prevalent:

'I guess to me, it was like we all embraced it. Here we were. We were all breast cancer survivors and we're going out and we're telling the world we can do it. We're not sitting at home, crying or whatever. We still have a lot of life left in us'. (227)

Fun and freedom were often discussed as essential elements of re-prioritizing, engaging in life, and seizing opportunities:

'Having had cancer kind of puts everything into perspective and because my mother died from cancer, so it's like what's important? Is it important if someone has that last bag of chips or if I don't mop the floor? When important is living'. (206)

The richness and prevalence of quotes regarding fun and freedom highlighted the importance of this new life priority since being diagnosed and taking part in AHT. Re-prioritizing fun as an important part of life may be consistent with recognizing that they need to look after their own needs in addition to others. For many women, taking part in AHT was an outcome of this realization and the ride affirmed the need for self-nurturing:

'Most of us are very caring people and we've spent a lot of time caring for other people and not taking care of our own health and I believe that's part of why we got cancer. So having had it you start to think 'I've got to look after myself'. But it changes your perspective of what's important in your life'. (216)

Repeat riders experience of AHT

For women participating in multiple AHT events, the motivations behind repeating the experience included for the support, love, understanding, and acceptance from AHT riders; the opportunity to contribute to fundraising, awareness, and advocacy for BC; fun and freedom; empowerment from being a 'warrior' (111); and grasping every opportunity in life. Unlike the first ride, which was about self-exploration, subsequent events were also to help the new riders and watch their transformation. In the post-ride survey, repeat riders discussed AHT as an opportunity to normalize the BC experience and reported a renewal of self-confidence as a result of taking part in events. They predominantly described the recent ride as different from previous events as they knew what to expect, were more relaxed, and had less 'breast cancer baggage' (112). The closeness felt with other riders was a strong motivation to repeat this experience as the group provides total understanding and acceptance.

'The knowledge that in some way we are wired in a similar way, when life got brutal, we got on a bike. That is enough for a lifelong connection'. (111)

For some, AHT shaped their self-identity and participating again reinforced positive life changes made previously. The following quote exemplifies the shift in emphasis that women place on their BC after taking part in AHT:

‘Amazon Heart Thunder has made me feel like a biker [motorcycle rider] who happens to have breast cancer as opposed to a woman with breast cancer who rides a bike [motorcycle]’.
(112)

Discussion

This study provided a phenomenological investigation into the challenge-based peer-support experience and how this can contribute to survivor identity and PTG after BC. Three important elements of the AHT experience were identified as group cohesion, and challenges and benefits of the ride. Connections the women created with each other and with AHT were integral components of the experience, synonymous with previous research showing that group cohesion enhanced well-being, promoted a sense of solidarity and equality, and provided emotional support (Midtgaard, Rorth, Stelter, & Adamsen, 2006). In the current study, initial bonds were established through BC. However, this was not the primary focus of the group or group discussions. Regardless of whether cancer was discussed, a shared understanding of the cancer experience and acceptance is evident in support programmes based on physical activity (e.g., Emslie *et al.*, 2007; Midtgaard *et al.*, 2006). Supportive care provided by participating in a challenge event creates an alternative to the traditional discussion-based support groups.

A previous study of the AHT experience indicated the importance of close connections that women formed with other riders during the event (Dunn *et al.*, 2009). Dunn *et al.* proposed that the peer-support environment provided by AHT contributed to positive life change. The current study extends this previous research by highlighting the role of AHT in, not only promoting PTG, but also shaping cancer survivor identity. For some women, this newfound positive cancer identity enabled them to continue to perceive a newfound personal strength in their day-to-day lives after the ride. Reframing or affirming the attached meanings of *BC survivor* into a positive self-identity was achieved through group membership in AHT, enabling women to identify as a strong survivor rather than a cancer patient (Harwood & Sparks, 2003). This positive identity was evident as some women described themselves as warriors after overcoming challenges associated with both their BC experience and AHT experience. Upward identification with positive role models and group membership promoted a shift in identity. For those participants where a shift in survivor identity was evident, AHT membership presented the opportunity to remove the stigma associated with being a cancer survivor and be a woman capable of anything (Cameron, 2004; Harwood & Sparks, 2003). This was done as the riders publicly pushed the boundaries of what was expected of them both as a woman and as someone diagnosed with cancer. Also, overcoming physical and psychological challenges, and identifying as an AHT rider affirmed or created a sense of personal strength and contributed to the image of proactive survivor.

PTG was reported by all participants that had occurred as a result of struggling with the challenges of being diagnosed with BC and after taking part in AHT. Salient PTG domains of enjoying life and seizing opportunities, personal strength, and strengthened relationships are frequently discussed in PTG research with cancer survivors (Stanton *et al.*, 2006). The predominant themes reported in the current study showed a newfound sense of personal strength and re-prioritization of life priorities to include time for self-nurturing

and fun. For some women, AHT acted as an affirming experience of changes that had already happened prior to the ride. For others AHT was a catalyst for further PTG.

AHT was able to promote PTG by providing a new social environment that allowed the women to shift their cancer identity into that of a proactive survivor. This social context normalized the women's cancer experience and provided positive role models, which have been discussed as components that promote PTG (Calhoun & Tedeschi, 2006; Harwood & Sparks, 2003). The sense of achievement gained from riding a motorcycle for 10 days in challenging conditions also promoted positive life changes that women integrated into their life after the ride. As a result of participating in AHT, women felt encouraged to continue pursuing activities focussed on engaging in life and self-nurturing after they returned home. This is synonymous with previous research showing that being diagnosed with a life-threatening illness can act as a catalyst to re-prioritize life and place importance on leisure activities that give personal meaning (Shannon & Shaw, 2005).

Not all participants reported AHT to be a catalyst for changes in survivor identity; however, all participants discussed positive life changes that had occurred since being diagnosed and participating in AHT. Previous research has highlighted the possibility that separate processes may promote different PTG domains. For example, factors such as age, gender, and varying coping styles have been shown to be related to separate PTG domains (Carboon, Anderson, Pollard, Szer, & Seymour, 2005; Luszczynska, Mohamed, & Schwarzer, 2005). Therefore, it may be that changes in survivor identity were associated with PTG themes such as personal strength, pride in self, and self-nurturing. Whereas, positive life change such as a greater appreciation for life, seizing opportunities, fun and freedom, and relationships with others may occur independently of shifts in identity.

Strengths, limitations, and future research

This study has provided a thorough investigation of a challenge-based peer-support programme, highlighting the importance of group cohesion and the challenges that contribute to shifts in identity and positive life changes. Creating an environment that enables women to attach positive meaning to their cancer identity can promote positive life change, such as personal strength. All participants discussed PTG, however not all women discussed a shift in cancer identity. It may be that diverse processes in the peer-support context promote different types of positive life change and future quantitative research could identify the relevant factors associated with PTG domains in challenge-based peer-support programmes. While discussing salient factors evident in the current study, it is important to consider generalizability of such findings to other peer-support contexts, diagnostic groups, and socio-economic groups. Participants were predominantly married or had a partner, highly educated, and employed. The applicability of peer-support programmes, such as AHT, to persons from other populations needs investigation. Also, factors such as gender and strong public advocacy for BC survivors may impact on the peer-support environment and experience of this group (Kedrowski & Sarow, 2007). Further studies can address issues of transferability of results to males, other cancer diagnostic groups, and peer-support programmes.

An interpretative phenomenological framework is not impervious to participant recall bias of their experience and may also be influenced by participants' inability to articulate their experience. When discussing the results of this study, it is also important to acknowledge the impact of the researcher in the interpretation of results. Despite a rigorous data collection and analysis process the researcher's prior knowledge of theory relating to peer support and BC may impact on interpretation of findings.

Participant observation can serve as a check against participants' responses in surveys and interviews and allows the researchers to gain a nuanced understanding of the

physical, social, cultural aspects of the participant's experience. While participant observation can be a powerful tool, this technique may also influence behaviour as participants may be suspicious of the researcher or be eager to please (Smith & Osborn, 2003). Thus, it is important to consider the results of the current study in the context that they were investigated in. The researchers attempted to mitigate the adverse impact of participant observation through gaining permission from all AHT riders for a researcher to be present during the event, keeping a thorough documentation of field notes, and maintaining participant confidentiality.

Conclusion

This qualitative study aimed to capture the lived experience of AHT from a phenomenological framework. The predominant themes reported by BC survivors included a description of their BC experience, the challenges and benefits of the ride, group cohesion, shifts in self-identity, and how this event and their diagnosis contributed to transformative life change. AHT provided BC survivors with the opportunity to step outside their day-to-day roles and take part in an activity focussed on self-fulfilment and advocacy. The safe network of other survivors provided understanding and acceptance, which encouraged self-exploration. The challenges and benefits of the ride, the opportunity to bond with positive role models, and also the potential shift in self-identity can promote positive life change. For some women, the AHT experience created a new positive image of BC survivor and for others the ride affirmed that sense of strength. AHT, and other such events, has the potential to extend the type of supportive care that is available for women diagnosed with BC by providing an alternative to the traditional support group format. Overcoming challenges, group cohesion, and new social identity gained from being part of AHT can be an affirming experience providing a positive perspective of being a cancer survivor and promoting positive life change.

References

- Bazeley, P. (2007). *Qualitative data analysis with NVivo*. Los Angeles, CA: Sage.
- Brennan, J. (2001). Adjustment to cancer—coping or personal transition? *Psycho-Oncology*, *10*(1), 1–18. doi: 10.1002/1099-1611(200101/02)10:1<1::AID-PON484>3.0.CO;2-T
- Calhoun, L. G., & Tedeschi, R. G. (2006). The foundations of posttraumatic growth: An expanded framework. In L. G. Calhoun & R. G. Tedeschi (Eds.), *Handbook of posttraumatic growth: Research and practice* (pp. 3–23). New Jersey: Lawrence Erlbaum.
- Cameron, J. E. (2004). A three-factor model of social identity. *Self and Identity*, *3*, 239–262. doi: 10.1080/13576500444000047
- Carboon, I., Anderson, V. A., Pollard, A., Szer, J., & Seymour, J. F. (2005). Posttraumatic growth following a cancer diagnosis: Do world assumptions contribute? *Traumatology*, *11*(4), 269–283. doi: 10.1177/153476560501100406
- Cordova, M. J., & Andrykowski, M. A. (2003). Responses to cancer diagnosis and treatment: Posttraumatic stress and posttraumatic growth. *Seminars in Clinical Neuropsychiatry*, *8*(4), 286–296. doi: S1084361203000546 [pii]
- Cordova, M. J., Giese-Davis, J., Golant, M., Kronenwetter, C., Chang, V., & Spiegel, D. (2007). Breast cancer as trauma: Posttraumatic stress and posttraumatic growth. *Journal of Clinical Psychology in Medical Settings*, *14*, 308–319. doi: 10.1007/s10880-007-9083-6
- Dunn, J., Campbell, M., Penn, D., Dwyer, M., & Chambers, S. K. (2009). Amazon Heart: An exploration of the role of challenge events in personal growth after breast cancer. *Journal of Psychosocial Oncology*, *27*, 119–135. doi: 10.1080/07347330802616084
- Emslie, C., Whyte, F., Campbell, A., Mutrie, N., Lee, L., Ritchie, D., *et al.* (2007). 'I wouldn't have been interested in just sitting round a table talking about cancer'; exploring the experiences

- of women with breast cancer in a group exercise trial. *Health Education Research*, 22(6), 827–838. doi: 10.1093/her/cyl159
- Harwood, J., & Sparks, L. (2003). Social identity and health: An intergroup communication approach to cancer. *Health Communication*, 15(2), 145–159. doi: 10.1207/S15327027HC1502_3
- Hefferon, K., Greal, M., & Mutrie, N. (2009). Post-traumatic growth and life threatening physical illness: A systematic review of the qualitative literature. *British Journal of Health Psychology*, 14(2), 343–378. doi: 10.1348/135910708X332936
- Kaiser, K. (2008). The meaning of survivor identity for women with breast cancer. *Social Science & Medicine*, 67, 79–87. doi: 10.1016/j.socscimed.2008.03.036
- Kedrowski, K. M., & Sarow, M. S. (2007). *Cancer activism: Gender, media, and public policy*. Chicago: University of Illinois Press.
- Luszczynska, A., Mohamed, N. E., & Schwarzer, R. (2005). Self-efficacy and social support predict benefit finding 12 months after cancer surgery: The mediating role of coping strategies. *Psychology, Health & Medicine*, 10(4), 365–375. doi: 10.1080/13548500500093738
- MacKenzie, R., Chapman, S., McGeechan, K., & Holding, S. (2010). 'A disease many people still feel uncomfortable talking about': Australian television coverage of colorectal cancer. *Psycho-Oncology*, 19, 283–288. doi: 10.1002/pon.1567
- Midtgaard, J., Rorth, O., Stelter, O., & Adamsen, L. (2006). The group matters: An explorative study of group cohesion and quality of life in cancer patients participating in physical exercise intervention during treatment. *European Journal of Cancer Care*, 15, 25–33. doi: 10.1111/j.1365-2354.2005.00616.x
- Mitchell, T., Yakiwchuk, C., Griffin, K., Gray, R., & Fitch, M. (2007). Survivor dragon boating: A vehicle to reclaim and enhance life after treatment for breast cancer. *Health Care for Women International*, 28, 122–140. doi: 10.1080/07399330601128445
- Morris, B. A., Chambers, S. K., Campbell, M., Dwyer, M., & Dunn, J. (2010). *Facilitating post-traumatic growth for breast cancer survivors through motorcycle adventures*. Manuscript submitted for publication.
- Morris, B. A., Shakespeare-Finch, J., & Scott, J. L. (2010). *Posttraumatic growth after cancer: Enhancing the applicability of current quantitative measures*. Manuscript submitted for publication.
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Los Angeles: Sage.
- Sabiston, C. M., McDonough, M. H., & Crocker, P. R. E. (2007). Psychosocial experiences of breast cancer survivors involved in a dragon boat program: Exploring links to positive psychological growth. *Journal of Sport & Exercise Psychology*, 29, 419–438.
- Sawyer, A., Ayers, S., & Field, A. P. (2010). Posttraumatic growth and adjustment among individuals with cancer or HIV/AIDS: A meta-analysis. *Clinical Psychology Review*, 30, 436–447. doi: 10.1016/j.cpr.2010.02.004
- Shannon, C., & Shaw, S. (2005). "If the dishes don't get done today, they'll get done tomorrow": A breast cancer experience as a catalyst for changes to women's leisure. *Journal of Leisure Research*, 37(2), 195–215.
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). Thousand Oaks, USA: Sage Publications.
- Stanton, A. L., Bower, J. E., & Low, C. A. (2006). Posttraumatic growth after cancer. In L. G. Calhoun & R. G. Tedeschi (Eds.), *Handbook of posttraumatic growth: Research and practice* (pp. 138–175). New Jersey: Lawrence Erlbaum Associates.
- Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (1998). Posttraumatic growth: Conceptual issues. In R. Tedeschi, C. Park & L. Calhoun (Eds.), *Posttraumatic growth: Positive changes in the aftermath of crisis* (pp. 1–22). New Jersey: Lawrence Erlbaum Associates.
- Thorne, S. E., & Murray, C. (2000). Social constructions of breast cancer. *Health Care for Women International*, 21, 141–159. doi: 10.1080/073993300245221
- Zebrack, B. J. (2000). Cancer survivor identity and quality of life. *Cancer Practice*, 8, 238–242.