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Personal accounts of exercise and quality of life from the perspective of breast cancer survivors

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Abstract

Objectives The purpose of the study was to examine breast cancer survivors' perceptions of exercise and their quality of life (QoL).

Methods About 289 breast cancer survivors completed a survey addressing exercise attitudes, behaviour and perceived QoL. In addition, the breast cancer survivors completed two open-ended questions designed to explore perceptions of exercise and QoL throughout their cancer experience. Inductive and deductive content analyses were used to analyse responses.

Results About 19 first-order themes were identified, which were clustered into five second-order themes that included; Exercise behaviour, Lifestyle, Limitations and barriers, Growth and priorities, and Personal beliefs and values. The findings identified a framework of multifaceted views held by breast cancer survivors in relation to their QoL and outlook on their disease.

Conclusions Given that cancer survivors are faced with a number of treatment related morbidities 2 years post-diagnosis, there is a need for health professionals to carefully address a cancer survivor's exercise needs in an attempt to help improve their future QoL.

Keywords Breast cancer · Cancer survivors · Exercise · Quality of life · Psychological factors

Surviving cancer requires finely balancing the feelings associated with fighting a life-threatening disease, but also from facing the consequent long-term health implications of that disease. Thus, throughout a cancer journey, a person can experience attendant debilitating and often distressing physical and psychological side effects of treatments, which can then impact upon an individual's quality of life (QoL). Many of these negative effects can persist over the ensuing months [1–2], but can also endure over the longer term [3–5]. This is particularly evident as we move into an era where more than 75% of cancer patients in most developed countries, are surviving beyond the 5 year post-diagnosis period [6].

Many cancer survivors can face emotional and physical sequelae long after treatment has ceased [5, 7]; it is therefore important to evaluate the full meaning of cancer for a person's QoL by gaining an insight into the survivor's experiences [8]. For many long-term cancer survivors, some of the most prominent concerns reported include fear of recurrence [9], distress caused within the family and uncertainty about the future [10]. While the identification of these negative consequences of cancer is important for long-term psychological health, by also identifying the positive aspects of a cancer diagnosis, health practitioners could help provide cancer patients with the skills needed to adapt and cope with the illness and its side effects over the longer term [11].

Indeed, survivors are often described as engaging in a process of interpreting meaning from their diagnosis and the impact that cancer has had on their lives [3, 8, 12]. This process typically leads to individuals considering and assessing their QoL. For example, in this search for

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meaning from a cancer experience, spirituality has been identified as a positive coping mechanism for some women low on hope [13–15] and can help establish a sense of control within their lives [16].

Increased focus on the advantageous consequences of cancer has been demonstrated by a growing number of women reporting advantageous changes after a diagnosis [17–18]. In particular, women are describing a new sense of priority and appreciation for life, which includes personal growth and taking time to enjoy the simpler things in life [10, 19–20]. For many, this has lead to a change in lifestyle and health behaviours [17].

Certainly, within exercise research, these emerging themes are important, particularly because of the finding that exercise has been shown to improve functional and physical well-being (and to a lesser extent emotional and social well-being) for those cancer survivors who engaged in activity both before and after their cancer diagnosis [21]. However, what have not been examined are cancer survivors' personal accounts of how exercise affects their QoL and long-term well-being after their treatment has ceased. Also previously unexamined is the importance that cancer survivors place on exercise relative to alternative QoL enhancing behaviours such as diet or relaxation. Thus, the primary aim of this study was to conduct an exploratory analysis of participants' perceptions of their exercise behaviour and other salient health behaviours post-diagnosis with cancer. The second aim was to examine how these health behaviours related to perceptions of QoL. The findings may provide a framework of key dimensions on the role of exercise in QoL from which future research can be established.

Method

Ethics and participants

The data is part of a broader study, which was granted ethical approval by The University of Western Australia's Human Research Ethics Committee and from the Confidentiality of Health Information Committee (CHIC). A self-reported survey was sent to 1045 breast cancer survivors listed on the Western Australian Cancer Registry (WACR). The survey comprised medical and demographic questions and standardised scales concerning the individual's exercise behaviour, exercise motivations and perceived QoL prior to their cancer diagnosis, during treatment, as well as at the time of the survey. About 289 responses were received (from a total of 558 survey respondents, full details reported in Milne et al. [22]) in response to two open-ended questions at the conclusion of the survey that addressed issues concerning the impact of exercise on QoL. The questions were:

1. Since your diagnosis, has exercise been part of your life? If so, what impact has exercise had on your quality of life?
2. What other factors (positive or negative) do you believe have contributed to your quality of life?

Data analysis

All responses were transcribed verbatim and entered into a software programme designed for the analysis of qualitative data, NUD*IST (N6) QSR for Microsoft Windows [23]. Transcribed text from responses to each question were imported and subsequently coded into emerging sub-themes. The programme allowed for both a top-down (themes identified in context of the relevant literature) and a bottom-up (themes grounded within the data from all participants) approach to be taken via a process of 'constant comparison' [24]. Before commencing the analysis, some themes were pre-identified from the literature on QoL for long-term survivors and new themes were identified throughout the process of data driven discovery. This approach ensured that both specific themes and subtler minor themes were identified. Each response was reviewed line by line and considered within the context of the surrounding text (typically a paragraph). To ensure trustworthiness of the data categorisation process, congruency, concordance and validity were established via 3 senior researchers who firstly checked the validity of the full set of categories against current literature; and who then coded a random sample of 15 sub-theme extracts. Four extracts showed incongruence and the meaning of the associated seven categories was reviewed and discussed. Once agreement was reached regarding the appropriate sub-theme content for the categories, reclassification was established and relationships between the sub-themes were determined for grouping into broader central themes.

Results

Participant characteristics

Of the 289 participants, the mean age was 59.5 ± 10.9 years (range 33–94 years), while the average time of diagnosis prior to the mail-out was 25.4 ± 3.5 months (range 20–31 months). The participants who were Australian (59%) had resided in Australia for an average of 49 years. About 93 percent of the participants were non-smokers, and the majority of participants had high school education qualifications (52.6%) and were married (70.2%). Nearly half (47.6%) of the participants reported receiving an annual income of less than $40,000. In terms of medical details, 53.6% had been early breast cancer patients (stages I and II), and nearly all participants had undergone surgical intervention (99.3%), of whom 55% opted for a lumpectomy. About 39 percent of participants received radiotherapy, or chemotherapy (17.6%), or a combination of both (40%). The full demographic and medical details are presented in Tables 1 and 2 respectively.

Table 1 Participant demographic details

	Mean ± SD or *n*	Range or %
Age	59.5 ± 10.9	33–94
Height	163.2 ± 7.2	150–181
Missing data	41	11.6%
Weight	69.8 ± 12.6	45–101
Missing data	14	4.0%
Smoker		
Yes	20	6.9%
No	269	93.1%
Education		
1. Primary	16	5.5%
2. Trade certificate	7	2.4%
3. High school	152	52.6%
4. Diploma/degree	102	35.3%
5. Masters/PhD	12	4.2%
Marriage		
1. Single	11	3.8%
2. Living with partner	8	2.8%
3. Married	202	69.9%
4. Separated	8	2.8%
5. Divorced	27	9.3%
6. Widowed	31	10.7%
Missing data	2	0.7%
Income		
1. <$25,000	89	30.8%
2. $25,000–$39,000	50	17.3%
3. $40,000–$59,000	43	14.9%
4. $60,000–$79,000	33	11.4%
5. $80,000–$99,000	27	9.3%
6. >100,000	21	7.3%
Missing data	26	9.0%
Employment		
1. Disability	10	3.5%
2. Part-time	45	15.6%
3. Full-time	50	17.3%
4. Retired	88	30.4%
5. Home-maker	59	20.4%
6. Temporarily unemployed	2	0.7%
7. Student	2	0.7%
8. Volunteer	5	1.7%
Missing data	28	9.7%

Table 2 Participant medical details

Stage	*n*	Percent
Diagnosis and treatment		
I	88	30.4
II	67	23.2
III	36	12.5
IV	10	3.5
Don't know	88	30.4
Surgery		
Yes	287	99.3
No	2	0.7
Type of surgery		
Lumpectomy	159	55.0
Mastectomy	114	39.5
Bilateral mastectomy	14	4.8
Missing data	2	0.7
Chemotherapy		
Yes	125	43.3
No	164	56.7
Radiotherapy		
Yes	183	63.3
No	106	36.7
Type of adjuvant therapy		
Radiation alone	114	39.4
Chemotherapy alone	58	20.1
Chemotherapy + radiation	116	40.1
Missing	1	0.4

Higher order themes

All the narrative comments made by participants were written in the first person. The respondents reflected on their cancer experience, with some comparing their life after their cancer diagnosis to the life they remembered pre-diagnosis. Others reported that their cancer diagnosis was still impacting their lives at the time of completing the survey, which for some was up to 2 years post-diagnosis. This is consistent with the findings of Ferrans [25], who reported that earlier experiences continued to influence breast cancer survivors in both positive and negative ways.

The recurrent feature underpinning responses was the belief that QoL stemmed from more than just simply exercising, rather QoL resulted from overall lifestyle as well as one's outlook on life. Consequently 19 independent (lower order) themes were identified (presented in Table 3) and were categorised into a number of higher order themes including; Exercise behaviour, Limitations and barriers, Lifestyle, Growth and priorities, and Personal beliefs and values. These themes are reported below and supported with representative quotations provided by the participants.

Table 3 Summary of the emergent themes from the data reduction

Questions	Higher order themes	Lower order themes
1. Since your diagnosis, has exercise been part of your life? If so, what impact has exercise had on your quality of life?	Exercise behaviour	
	–	Well-being
	–	Normality
	–	Sense of control
	–	Domestic/work/transport
	–	Social
	–	Lack of information
	Limitations and barriers	
	–	Treatment side effects
	–	Fatigue
	–	Body image
	–	Other medical conditions
	–	Motivation
	–	Time/age/lack of rural access
2. What other factors (positive or negative) do you believe have contributed to your quality of life?	Lifestyle	
	–	Change of health habits
	–	Alertness to health
	Growth and priorities	
	–	Positive attitudes
	–	Self-growth/survival
	–	Support
	Personal beliefs and values	
	–	Survivor spirit
	–	Faith and spirituality

Exercise behaviour

The two prominent themes were (1) related to general exercise behaviour and (2) factors regarded as limitations or barriers to exercise (discussed below). As such, the participants provided a range of personal definitions for perceived 'exercise'. Some participants defined exercise in a very broad manner, considering it as an avenue for release and enjoyment, as well as a social vehicle which involved dancing and walking with friends:

> "We do dance and exercise to beautiful music and it is very gentle, but gives you a good workout, and it makes you feel so good, it has been very therapeutic for me and I think it would be good for other cancer patients" p159

For many, exercise provided an avenue for seeking support and enjoying time with others, as well as retaining social networks. Often the women's focus was not about the exercise per se, but about sharing and appreciating a meaningful experience, albeit alone or with friends:

> "Being outdoors in my garden or taking a walk at the beach is quality time that I can enjoy being by myself or with friends" p188

Often participants, perceived these social exercise times as 'therapeutic' and necessary for their own recovery:

> "For me, it is about enjoying taking time out—the support from friends has really helped me emotionally and physically" p43

Many participants indicated that they were adjusting to their new bodies and trying to overcome the limitations they were facing as part of that recovery process. Exercise was seen as one mechanism for achieving a sense of normality and regaining some control over their bodies in the recovery process:

> "I think that exercising has been the only way that I have been able to feel normal again—like I am in charge of what is happening" p206

While many participants described the value of exercise for maintaining their health and overall QoL, irrespective of their cancer, often exercise was recognised for its specific role in relation to rehabilitation. These beliefs are demonstrated by the following quote:

> "Exercise is essential in recovery. Slowly, slowly but my quality of life would be poor without it—both physically and mentally" p17

For others, exercise afforded a sense of control, particularly whilst living with an illness that had such an overpowering impact on their lives. For these women exercise was cited as a vehicle for regaining control over their body and moving forwards:

> "Once of the worst things about cancer treatment is that you are no longer in control of your body. When treatment finishes, exercise is vital to regain that control and helps to restore well-being. I am now feeling and looking well and my weight has dropped and stabilised" p61

Overall, exercise was perceived as an important and useful aspect within the lives of the participants, both in terms of a vehicle for enjoyment, but also as a way to assist in recovery.

Limitations and barriers

Interestingly, those participants that did not engage in exercise still recognised the value of exercise as both a health promoting strategy and as a means of support and control. These participants offered explanations surrounding the barriers, which they perceived as preventing them from exercising. The most commonly reported barriers were age, lack of time, lack of facilities and lack of motivation:

> "My ability and effort for exercise is unrelated to my cancer. I just don't have the time. I work 50 h per week and still have one child in high school, which leaves little time for exercise. Plus I have a low level of motivation to exercise" p270

However, one specific barrier should be noted. Many participants defined 'exercise' in a limited way by associating it with formally organised and structured activity. From these comments it was clear, particularly where clinicians had encouraged the participant to partake in a formalised exercise session, that exercise was perceived as hard work, rather than being fun with enjoyment attached:

> "My clinician said that 'I have to exercise'… I started a gym-based exercise programme but it does not feel natural, no matter how hard I try, I just can't seem to do it" p211

Critically these participants concomitantly reported a lack of commitment and motivation, as well as difficulties in sustaining any formalised exercise regime. The participant below expressed this as a 'time' issue:

> "I don't understand why I can't just enjoy my garden and walking my dog, I could always find time for that!" p61

In addition to lack of motivation, one of the dominant lower order themes identified was how treatment side effects interfered with, and limited exercise. Side effects impacted on participant's desires of attaining normality, and this was deemed a constant reminder of their disease. Treatment side effects were reported by over a quarter of participants and ranged from mild physical symptoms to symptoms disruptive enough to interfere with activities of daily living, including exercise:

> "Getting breast cancer twice has changed my life style. I miss terribly not being able to do the things I did before my diagnosis for example, lawn mowing and raking etc. because of discomfort in both arms and lack of energy" p93

Certainly, from all the side effects experienced, pain has been reported as one of the most debilitating and crippling with the capacity to interfere with the smallest daily tasks. It is reported that up to 25% of chronic pain problems were a direct consequence of the adverse effects of adjuvant cancer therapy [26]. Since most of the participants were 2-years post-diagnosis, pain was described mainly as a product of hormone therapies but was still experienced by over 10 percent of participants, and for many interfered with their ability to continue exercising. For example, one lady stated:

> "The Tamoxifen has side effects—profuse perspiration and pain in the bones. I can't exercise anymore because of it—it is too painful" p88

Fatigue, is another enduring side effect that is experienced by almost all cancer patients at some point during their treatment or in the years afterwards [27]. For some participants, fatigue was the recurring issue that had a significant impact on their activity levels, as well as interfered with daily living and exercise. Consequently, it was hard for some participants to achieve a sense of normality, especially if their normality included exercise:

> "I have to say that your energy levels change so dramatically day to day on chemo, it can be hard to motivate yourself to do anything at all—least of all go for a run" p28

Although chronic health problems were reported to stem from the cancer treatments, some participants reported poor health or illness as a consequence of other independent medical conditions. In particular, degenerative conditions associated with old age such as arthritis, cardiac problems and diabetes were identified. With respect to limitations, the degeneration and pain experienced interfered with normal daily living, particularly for those in older age groups:

> "I feel that because my cancer was discovered in its early stages it hasn't really impacted on my current lifestyle. The pains experienced are not due to cancer but to other conditions (such as arthritis)" p62

Consequently, it is important that comorbid conditions and any other physical ailments be given full consideration by professionals when assessing an individual's ability and motivation to participate in exercise regimes.

Lifestyle

Many participants who discussed limitations and barriers preventing them from exercising connected these same limitations and barriers to their general QoL. Not being able to continue with daily activities because of fatigue, pain, weight-gain, and/or lymphoedema were considered highly detrimental to general satisfaction with QoL:

> "Since my chemotherapy my whole self has changed. I have a very poor memory, eyesight, aching bones, tiredness etc.—it has really impacted on my ability to do everyday things and my confidence to exercise" p36

Most respondents commented however on the positive factors in their life, in particular those they deemed as facilitative in their recovery. Commonly cited lifestyle factors included changing general health habits and daily activities. Furthermore, the participants described the need to change a number of concurrent factors rather than just one. Therefore, in addition to exercise, the participants described their increased awareness of health, and consequently began practicing better health habits generally. In this context, as demonstrated below, a key finding was that exercise was considered central in achieving general good health and well-being:

> "My diagnosis did cause me to review my lifestyle and fitness. I am more aware of the need for a healthy body and I am actively attempting to lose weight and get fit" p86

Therefore, general health maintenance was an issue, with the participants reporting an increased sensitivity and alertness to healthier lifestyles, including healthier nutritional choices, stress management and health check-ups and exercise was situated as an integral process for this:

> "I take nutritional supplements, eat a healthy diet, some organic foods, lead a fairly stress free life and am working on making exercise a regular part of my life—I find it hard even though I do understand the benefits" p159

Growth and priorities

Growth and priorities represented an important theme, which many participants perceived as instrumental for improving QoL. Experiencing cancer gave an opportunity to take heed of their life and to reprioritise their commitments and responsibilities and focus more positively on their health. In the process, their QoL was enhanced. In line with previous research [10, 19–20] a number of participants commented that they had a greater appreciation of their life and believed that maintaining a positive attitude was a high priority. In addition, there were a number of participants who indicated that in spite of all the morbidities experienced, they believed they had been granted a second chance at life. For this, they were grateful:

> "The side effects of Tamoxifen are difficult to live with; however, I am grateful to be ALIVE and want to make the most of this 2nd chance" p99

Because of this second chance, some participants reported less concern for the trivial everyday matters that used to cause them anguish and worry, but rather had a heightened appreciation for their lives. These positive outcomes have been reported previously [3, 25, 28], where respondents began to make life changes that they were unable to do before they were diagnosed with cancer:

> "I feel my life has been enhanced by my cancer—it has given me permission to change my lifestyle and try to be more active and healthy" p64
> "Cancer totally makes you reorganise your priorities.........Cancer made me realize—life can be to short, so get on with it and live your dreams and so I am" p114

In addition to their own personal perceptions and feelings, the participants also commented that social support from important others was an important element in maintaining a good QoL. Perceptions of support from people in their immediate surroundings varied across individuals. The majority of comments related to support were very positive, emphasising the importance of having a social network of family and friends, particularly for emotional support:

> "Support of family and exercise are the two most important elements to provide hope and faith in the future. Cancer is a devastating disease that affects the victim and the family" p149

Personal beliefs and values

Participants' own personal beliefs and values were strongly conveyed in their responses. Considering themselves to be survivors rather than victims represented a positive step in taking responsibility for their health. Having faith in God, spirituality, and a strong belief system represented three factors described by some participants as providing a means of support that assisted their coping. Some respondents noted how their faith had strengthened during their cancer experience:

> “Above all, it is the grace of an unfailing God which has sustained me through this ordeal. Jesus has been and is the anchor of my soul. Knowing him and his love has given me hope, peace and strength” p195

Indeed, in previous work, spiritual support was noted to be a primary source of support for cancer patients, who reported that it offered them the strength they needed to get them through their most vulnerable times [29].

Discussion

The key finding of this analysis was that QoL in the context of exercise was a very broad holistic concept that could be defined by a number of factors. Certainly, QoL appears to encapsulate what is deemed good and satisfactory about a person’s life at a point in time. Nonetheless, as Dow [30] explained, QoL is a dynamic construct for which cancer survivors have a multifaceted perspective. Exercise needs to be viewed in this context. The diversity of views regarding QoL was demonstrated by the participants’ responses explaining that exercise represented only one component of survivors’ perceived QoL.

It was apparent in the narratives provided by many survivors that a ‘wellness’ orientation was present, including what Loescher, et al. [28] described as ‘getting on with living’, or moving forwards, dealing with the limitations and barriers they faced, and continuing on as best they could. This positive outlook played a central role in the descriptions of a cancer patient’s/recovery. As one lady wrote:

> “As you can see I am healthy of body, mind and soul and whatever is in store for me in the future I shall handle it as and when it happens” p113

What was also apparent was that self-help strategies appeared to augment QoL over and above a sense of wellness or disease-freedom that the participants achieved from receiving cancer therapies. Participation in exercise did play a major role in achieving this level of wellness. For many, exercise was considered to be a mechanism for gaining back a sense of control. In addition, exercise provided a sense of normality combined with changes in diet, relaxation and increasing health related behaviours per se. Any factors that were within the participant’s direct control were nominated as central to QoL.

However, responses made by participants were not focused simply on lifestyle changes, such as improved diet and reducing stress. Participants also wrote about how they initiated health care measures and were aware of what they needed to do to stay well, with each participant having their own individual approach to achieving these goals. These findings support previous research [10, 19–20] and were reflected in the participants’ narratives. These extended beyond simply making lifestyle changes, and more broadly described a new appreciation for personal growth, of changing priorities, as well as having a high regard for living and reliance on other sources for hope and support including their immediate social support network. For some spirituality was considered an important facet within overall QoL. This finding is consistent with Ferrell et al. [11] who stated that spirituality offered survivors both a coping mechanism, as well as a means of realising a positive outcome when faced with adversity.

Most participants recognised the value of exercise and the benefits that exercise had on improving QoL. Of importance, is that previous research has shown that cancer patients are open to advice and guidance about health promotion initiatives and exercise in particular [31]. However, advice regarding safe exercise procedures and appropriate exercise programme design represent major considerations that should be made by health providers when designing rehabilitation programmes for cancer patients. Programme design should also consider medication-based barriers, comorbid conditions, age and time since diagnosis. Yet, as the participants discussed, exercise advice that is too formalised can be detrimental to participation. Encouragement of naturally occurring exercise behaviours such as gardening, walking and dancing may be more effective and deemed less prescribed. This approach may lead not only to more general activity, but increased sense of well-being gained through engaging in enjoyable and social activities.

The findings above have important implications for cancer rehabilitation in that it implies that cancer patients should be encouraged to focus on their own long-term health goals and methods of self-care. For many cancer survivors, the months following post-treatment represented a time for self-reflection and for personal change. Therefore, this period may represent an ideal time for cancer patients to commence an individually tailored exercise programme. Ongoing individualised assessments would need to take account of the definition of exercise and its role as one part of a general self-care strategy, or how it can be integrated into the participant’s general definitions of QoL and lifestyle. In designing exercise programmes, health practitioners should not neglect the barriers to exercise, which in turn affect motivation to exercise. These barriers include time and issues related to age and health. Additionally, access to suitable exercise facilities, age-specific programmes, and lack of information regarding the benefits of exercise, should also be considered.

Greater consideration of these factors may also allow us to understand more about the impact of short-term prescribed exercise programmes on patients' health perceptions. In particular lack of information regarding the side effects of adjuvant therapies in cancer and the role that these side effects had on exercise prescription. The availability of this type of information has been shown to be helpful to cancer patients, particularly during the recovery phase [25], and can be instrumental in reducing anxiety, especially when a cancer patient is about to embark on an exercise programme.

It is important to note that conducting large population-based qualitative research does result in a number of limitations. A possible criticism of the study method was that often the comments supplied did not have the rich in-depth detail that can be extracted during an interview or focus group situation. However, in order to counterbalance this issue, a large sample size was used in this study, while line by line coding combined with a 'top-down' deductive coding system and a 'bottom-up' inductive coding system were used to better facilitate data analysis.

Future qualitative research should consider that although most of the research has been conducted on breast cancer, and to some extent ovarian cancer [15], exercise has been shown quantitatively to have a positive effect on other cancers such as prostate cancer [32], colorectal cancer [33] and lymphomas [34]. Greater insight into the meaning of exercise and QoL would also assist in the design of exercise programmes in other areas of cancer that have not been well studied. The themes that emerged in this study, should contribute towards developing a holistic, conceptual framework from which future research can be based. Furthermore, recognising the coping processes associated with long-term survival provides important information that can inform the development of health-based exercise programmes.

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