Loss, adaptation and new directions: The impact of arm morbidity on leisure activities following breast cancer

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ABSTRACT

The impact of arm morbidity on leisure and quality of life is an understudied area in cancer survivorship. The purpose of this study was to qualitatively describe the impact of breast cancer-related arm morbidity on leisure participation in Canadian women. A grounded theory approach was used to generate thematic categories and a model. Drawing on participants from a larger cohort study (n = 740), 40 women with arm morbidity symptoms were purposively sampled and interviewed. Three themes emerged: a sense of loss, adapting participation, and new directions. Women with arm morbidity may experience an abrupt loss of previously enjoyed leisure activities and engage in a process of adapting to discover new meanings and directions. Comprehensive, person-centred cancer survivorship programs may assist with adaptation to arm morbidity.

Key points
- Psychosocial and emotional adjustment is a significant component of breast cancer recovery and coping with arm morbidity.
- Women living with arm morbidity often experience changes in their capacity to enjoy and benefit from an array of meaningful leisure activities.
- Women who experience breast cancer need to be informed of the possibility of having to negotiate with and adapt to alterations to the body and spirit, and the lifelong requirement for their adherence to advice after surgery on arm care, exercise, and diet.
leisure (defined individually as participants’ responded to questions about activities that they found enjoyable and were not related to paid work) and a coding framework for the data. To this end, NVivo 7 data analysis software was used.

RESULTS

General findings related to disability have been reported elsewhere (Thomas-MacLean et al., 2009). Herein, we focus on the changes connected to the place of leisure in the lives of women with arm morbidity after breast cancer. Three themes emerged from our data analysis: 1) a sense of loss, 2) adapting participation, and 3) new directions.

Theme 1: A sense of loss

First and foremost, the women grieved the loss of leisure activities. One woman, Gina (pseudonyms were assigned to all participants), summarized the deleterious impact of arm morbidity: “There [are] many things that you are not able to do, there are sports that you can’t practise, there are activities that you are oblige[d] to stop.” Gina suffered from arm pain and lymphedema. She tried lymphatic drainage and other treatments, but without much success. She reflected upon the losses accrued since her surgery: “After my surgery for the breast, I was really limited. Before the surgery… I was doing fitness training three times per week, I was doing roller-blading, skiing, cycling, walking, so if you compare this life with the one that I have now, now it is really boring.”

Caroline also spoke of her awareness of loss. She had lost the ability to participate in identity-defining activities, as well as the comfort and pleasure of shared endeavours with her spouse. As with Gina’s experience, the potential benefits of physical engagement had also been lost. The losses were, thus, multilayered for Caroline with evident significant impact, as she spoke of leisure activities in the past tense:

“We’re trappers. I went trapping with my husband. He had a little trap and I have a trap… I would say I was on the snow machine nearly every day. We did things together in the workshop. We’d… build, he built a lot of stuff and I used to be there helping him with lumber, plywood… I’m not as active as I used to be…I’m blaming all this on my breast cancer… my aches and pains, on my arm. I blame it all on breast cancer.

In her discussion of golf, Anne addressed the lower confidence bred by this loss—what might be viewed as an intersection between physicality and emotion:

“It is certain that with my arm, I won’t be able to play golf again. I do not have the same mobility with this arm now… I was feeling good, but since a while, I am more anxious, more pensive, I do not feel in a great shape like I was not a long time ago.”

For these participants, leisure carries multiple levels of meaning and significance, both at present and in the anticipated future. Arm morbidity threatens leisure in a variety of ways, including a dejected sense of boredom (Gina), a double loss of companionship and activity (Caroline) and anxiety (Anne). Participants also had different ideas about what constituted leisure. For example, Marielle described housework in the same terms other participants used to describe more recreational pursuits: “I love to, just tidy up the house. Changing
the bed, or whatever the case may be, I like to do my small household chores, which is not a chore for me.” Snow shovelling, in particular, represented an enjoyable outdoor activity for her, one in danger of being lost:

Shovelling snow, to me, I’ve always loved it. And I find that it’s too difficult. It’s going on two years...in April, for surgery. And what if this is as good as it’s going to get? It’s a tough reality when you’re not even 50 years old. I mean, you might have to accept the fact that this is it. This is as good as it’s going to get.

A sense of accomplishment may be embedded in Marielle’s pleasure in carrying out these chores. Having a diminished capacity to continue them may well have deprived her of perceived life purpose and achievement.

Participants experienced leisure in a variety of ways and intensities (see also Greenwood Parr & Lashua, 2004; Holland, 2009; Kim, 2008; Siegenthaler & Vaughan, 1998). Leisure was idiosyncratically defined and when participation in such meaningful activities was no longer possible, a multitude of losses were incurred. Moreover, studies have revealed that leisure activity is linked to stress relief, comfort, and personal fulfilment (Pullagar, 2008; Hutchinson et al., 2008; Iwasaki, 2006, 2007, 2008; Ormel, Lindenberg, Steverink, & Vonkorff, 1997). Thus, both the leisure literature and the present data demonstrate the impact of lost leisure activities on identity in the context of cancer survivorship.

**Theme 2: Adapting participation**

Several women who reported enjoying regular leisure physical activity prior to breast cancer treatment expressed their intention to maintain or regain levels of participation similar to their pre-breast cancer leisure experiences—a process of adaptation. Tracy spoke of the straining effort and doubts involved: “I am trying to adapt... I don’t know how much I should use my arm. Should I use it a lot? Less? I don’t know. I have a lot of questions. What could increase lymphedema? It makes me really anxious, and I will try to find answers.”

Often adaptation involved creative strategies of getting around or negotiating the limitations brought on by arm morbidity. Yvonne, for instance, sought a way to continue her favourite past-time of riding horses:

I ride both Western and English and my Western saddles were old wonderful saddles, world-renowned, but they’re heavy...they’re around 50 pounds [and] for me to lift it on the horse, I absolutely couldn’t do it anymore. So I bought a saddle of about 35 pounds [and] I can deal with it.

She added that she had not anticipated the degree of adjustment after breast cancer surgery and, upon reflection, was surprised at her naivety. While Yvonne noted a degree of loss, she also discussed the process of adapting, and this is where she began and ended her account of leisure.

Other women similarly reported finding a means to adapt to life with arm morbidity.

Sometimes this meant taking more time and being more cautious. Caroline said arm morbidity “slowed me down with my...crocheting, knitting, threading a needle, threading a sewing machine, all that.” Caroline also enlisted her husband’s assistance in food preparation, toward which she had mixed feelings:

He’s there to help me now. I’ll put everything in jars, but he’ll lift the pressure cooker, or the pressure canner off the stove for me and help me take the jars out. We do it together now. As a hobby for him, a hobby for me. We do it all together. And I miss that—being by myself. It was my quiet time when I was by myself which I enjoyed.

This example illustrates that, for some women, adaptation did not necessarily mean transcendence of their disabilities, but was more often a matter of negotiation or compromise. Many participants said they had to pace and prioritize their activities in order to manage their daily lives; they used strategies such as, “doing it on several days instead of one shot,” “taking a break when...doing something,” and “knowing when to stop and when to go.” On the other hand, Mary noted that this reduced pace can have psychosocial and emotional benefits:

I mean I never stopped... it was just rush, rush, rush. Today, I don’t rush anymore. I have some leisure time. I just take my time... it is very different, but I can say that in a sense, in lots of ways I see there’s less stress and I’m more peaceful and I have slowed down and, you know, I’m glad that I have slowed down... It’s my choice.

In summary, then, adapting can mean a variety of positive and negative changes in a person’s life. Our participants demonstrated different manners of adapting that permitted them continued participation in meaningful, enjoyable activities.

**Theme 3: New directions**

While some women adapted their approach to existing activities and found peace with their compromises, two found opportunity to pursue novel leisurely engagements, which they saw as transformations of their life orientation. Terry said that joining a dragon boat team with other breast cancer survivors had “given me a new something” and encouraged her to “get a kayak and try kayaking.” Judy spoke of more thoughtful changes, a new approach to life that included the notion of leisure as self-caring (Rojek, 2005) and relaxation (Kleiber, 2000):

I started doing yoga, which I didn’t know if I’d get into. Like, the first few days it was kind of ‘Oh God, this is kind of hokey!’... But, I stuck with it and every morning I would do this... It was very calming and just focusing on that helped me relax and I think it was more a mental relaxation, metaphysical, like, it helped me more that way.

With this transformation in mind, Judy said breast cancer “kind of put things in perspective.”

Both Terry and Judy discussed new directions in leisure that helped them transcend the physical and emotional challenges of arm morbidity into a self-image of positive change and growth. This may be seen as a different strategy to most of the participants, who talked less about new leisure endeavours and more about loss or preserving former activities through compromise.

**CONCLUSION**

As evidenced from the participants, psychosocial and emotional adjustment is a significant component of breast cancer recovery and coping with arm morbidity. Our analyses of interviews with women show that these issues intersect within the
context of leisure activities. Women living with arm morbidity often experience changes in their capacity to enjoy and benefit from an array of meaningful leisure activities. The changes can be lifelong and range from disabling to renewing. We attempted to bring some of these changes to light in order to better guide care and rehabilitation.

Figure 1. Model of leisure participation following arm morbidity

A model of leisure participation following arm morbidity

Congruent with grounded theory, we positioned the three major themes of this study into a model of processes (see Figure 1). The cylinders represent leisure participation, idiosyncratically defined by each individual, before and after arm morbidity. Leisure activities described by our participants varied widely from sports to home making and maintenance, crafts, animal care, as well as entertainment, and tended to coalesce with each individual’s sense of identity. Participants reflected on various forms of loss resulting from arm morbidity and how this impacted their leisure. Losses associated with leisure were reciprocally related to disruptions in physical and emotional wellness, relationships, fulfillment and identity. The model, therefore, supports the literature that describes connections between physical health (fitness) and quality of life (Burnham & Wilcox, 2002; Kendall et al., 2005; McNeely et al., 2006).

We found two major strategies for adapting to loss: many participants negotiated some form of continued involvement, while two women sought to create new life directions by pursuing novel leisurely engagements. However, many others struggled to achieve either possibility, which corresponds with quantitative data on leisure and arm morbidity (Miedema et al., 2011). This underscores a need for comprehensive rehabilitation and psychosocial support to assist survivors’ processes of adapting to the full scope of arm morbidity, as indicated by the foundational box of the model (see also Davies & Batehup, 2010). In addition to treatment of presenting symptoms, women may benefit from more extensive preventative education about the nature, risks and consequences of arm morbidity, especially lymphedema, and the importance of regular exercise both for the affected arm itself, as well as overall health maintenance (Hack et al., 2010; Silver & Gilchrist, 2011). These approaches to care may be facilitated in interprofessional rehabilitation and cancer survivorship centres that can deliver appropriately tailored treatment.

Implications for nursing

Through evidence-based educational support, women who experience breast cancer need to be informed of the possibility of having to negotiate with and adapt to alterations to the body and spirit, and the lifelong requirement for their adherence to advice after surgery on arm care, exercise, diet, and other topics (Hack et al., 1999; Hack et al., 2010; Kwan et al., 2002; Radina & Fu, 2011). Health professionals, including nurses, occupational and physical therapists, should be forthcoming with advice about potential adjustments women may need to make to accommodate these changes with the goal of enabling meaningful leisure participation, as well as the beneficial changes in perspectives and values (Silver & Gilchrist, 2011). Further, nursing administrators may be positioned to promote access to comprehensive, person-centred, psychosocial and behavioural management and rehabilitation programs, which are needed to address the multiple and varied needs of women with arm morbidity after breast cancer (Davies & Batehup, 2010; Hack et al., 2010; Quinlan et al., 2011) within the broader context of new understandings of the impact of chronic illness and disability (Livneh & Antonak, 2005). Components of such programs could include: physiotherapy, occupational therapy, spiritual care, intimacy counselling, and nutritional counselling, as part of cancer survivorship care. Participation in such programs may reduce the degree of loss and support adaptation in all activities, including leisure.

Future directions

Participants in this study unequivocally attributed the impact on leisure to arm morbidity, but possible intersections with other phenomena such as aging and obesity would be worth exploring within the context of our theory of loss, adaptation, and new directions. While this article focuses on changes in women’s leisure activities following breast cancer and the associated social processes, it should also be noted that the effects of breast cancer and associated treatment extend into multiple overlapping spheres of women’s lives including the ability to participate in paid work and meaningful relationships (Quinlan et al., 2011; Radina & Fu, 2011) and these connections would merit further research, including new studies of the model.

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