

In the eye of the dragon: Women's experience of breast cancer and the occupation of dragon boat racing

Anita M. Unruh ■ Natalie Elvin

Key words

- Occupation (human)
- Breast diseases
- Dragon boat racing

Abstract

Background. Women with breast cancer are at risk of developing lymphedema following surgical and/or medical treatment of the disease. Recently, women have challenged traditional advice about limiting upper extremity activity to prevent lymphedema by participation in dragon boat racing. **Purpose.** In this qualitative pilot study, three women were interviewed about the meaningfulness of dragon boat racing in their lives. **Methods.** The women were interviewed twice and their interviews analyzed using thematic analysis. **Results.** Seven themes are discussed: attraction of dragon boat racing; physical and emotional well-being; competition; social support; transcendence/connectedness/oneness; re-occurrence of cancer; and, public awareness. Competition enabled the participants to rebuild self-confidence and to regain control over their physical health and emotional well-being. Balancing support and competition was key to finding satisfaction in this occupation. The women did not believe that dragon boat racing affected their risk for developing lymphedema. **Practice Implications.** People who engage in the occupation of dragon boat racing find it meaningful and develop new coping strategies. Participating in dragon boat racing can decrease stress and shift the meaning of having breast cancer to a more positive view of the experience.

Résumé

Description. Les femmes atteintes de cancer du sein risquent de provoquer un lymphoedème à la suite d'un traitement chirurgical ou médical de la maladie. Récemment, des femmes ont défié le conseil traditionnel visant à limiter les activités des membres supérieurs pour prévenir un lymphoedème, en participant à des courses en bateaux-dragons. **But.** Dans le cadre de cette étude pilote qualitative, trois femmes ont été interrogées sur le sens de la course en bateaux-dragons dans leur vie. **Méthodologie.** Les femmes ont été interviewées à deux reprises; ces entrevues ont été examinées à partir d'une analyse thématique. **Résultats.** Les sept thèmes suivants ont fait l'objet d'une discussion : l'intérêt de ces femmes pour la course en bateaux-dragons; le bien-être physique et émotionnel; la compétition; le soutien social; le sentiment de transcendance et d'unicité; la réapparition du cancer; et, la sensibilisation de la population. La compétition a permis aux participantes de retrouver leur confiance en elles et de reprendre les commandes de leur santé physique et de leur bien-être émotionnel. L'un des facteurs clés leur ayant permis d'éprouver de la satisfaction face à cette occupation a été de trouver un équilibre entre le soutien et la compétition. Ces femmes étaient persuadées que la course en bateaux-dragons ne risquait pas de provoquer un lymphoedème. **Conséquences pour la pratique.** Les personnes qui participent à des courses en bateaux-dragons considèrent cette occupation comme étant porteuse de sens et acquièrent de nouvelles stratégies d'adaptation. La participation à la course en bateaux-dragons peut réduire le stress et donner aux femmes atteintes de cancer du sein une perspective plus positive de cette expérience.

Anita M. Unruh, PhD, RSW, OT(C)
RegNS is a Professor, School of
Health and Human Performance,
Dalhousie University, 6230 South
Street, Halifax, NS B3H 3J5
E-mail: anita.unruh@dal.ca

Natalie Elvin, BSc (OT) is an
occupational therapist,
Brunswick Centre, Saint John, NB

Occupational therapists who work with women experiencing breast cancer are concerned with the physical and psychosocial effects of cancer on the capacity to be involved in occupations that are meaningful for the client. Occupational therapists aim to maintain occupational routine, adapt occupations where needed, and consider, with the client and the family, occupations that support coping and living meaningfully with a serious health crisis (Lloyd & Coggles, 1989, 1990; Penfold, 1996; Seales, 1997). These goals may include strategies to provide symptomatic relief of lymphedema and to enhance occupational performance (Dennis, 1993). The impact of cancer as well as the effects of procedures to treat cancer can have a devastating effect on occupational life. An additional concern for women with breast cancer is the possible occurrence of lymphedema (Dennis, 1993).

Literature review

Breast cancer and lymphedema

Lymphedema is an insufficiency of the lymphatic system that results in the swelling of a body part, usually a limb (Dennis, 1993). Lymphedema may occur following radiation or surgery involving the axillary nodes (Erickson, Pearson, Ganz, Adams, & Kahn, 2001; Meek, 1998). These procedures are thought to interfere with the axillary lymphatic system resulting in fluid accumulation in the subcutaneous tissue of the extremity (Erickson et al., 2001).

The incidence of lymphedema ranges from 20% to 56% of women with breast cancer who receive surgery and/or radiation (Erickson et al., 2001). Combined axillary radiation therapy and axillary surgery, high dose axillary radiotherapy, hypertension, obesity, and a history of infection to the affected upper extremity are important risk factors (Rockson, 1998). Once lymphedema is established, it tends to be persistent (Rockson, 1998).

Lymphedema often results in restricted movement, swelling, pain, skin changes, changes in sensation in the limb, and perceptions of physical disfigurement (Erickson et al., 2001; Passik & McDonald, 1998) that can have substantial detrimental impact on function, and psychological, social and sexual adjustment (Hull, 2000). In a systematic review of interventions for lymphedema, Harris, Hugi, Olivotto, and Levine (2001) found some evidence that consistent, long-term use of compression garments was helpful but the garments were reported as uncomfortable, unsightly, and difficult to put on.

Due to the difficulties in treating lymphedema, women are generally advised against excessive forceful and repetitive movements of the upper extremity, or excessive limb use, and encouraged to avoid trauma as a precaution (Ganz, 1999; Granda, 1994; Meek, 1998; Price & Purcell, 1997). It is unknown whether strenuous upper extremity

activity increases the risk of developing lymphedema. Recommendations to limit vigorous use of the upper extremity are based on professional opinion and clinical experience, but there is little research to support these recommendations and they can precipitate substantial life-style changes and depression if adopted (Ganz, 1999).

Psychological well-being and leisure occupations

Prevention of lymphedema is extremely important due to its impact on function, physical health, and psychological well-being. However, restriction of activities, particularly leisure occupations that can be powerful coping strategies (Unruh, Smith & Scammell, 2000), may also have a detrimental impact. Often, occupations such as gardening, sports, and playing musical instruments involve repetitive and/or strenuous upper extremity activity. A woman with breast cancer may need to decide between limiting leisure occupations and reducing psychological well-being, and ignoring cautionary medical and rehabilitative advice while worrying about the risk of possible negative impact on health.

Women do not always comply with advice from health professionals. Recently, some women have publicly challenged precautionary advice by participating in dragon boat racing, a particularly strenuous and repetitive upper extremity activity (Harris & Niesen-Vertommen, 2000; McKenzie, 1998; Mitchell & Nielsen, 2002).

Dragon boat racing

In ancient Chinese folklore, the dragon was considered a divine spirit that lived in the water and controlled distribution of water for agriculture and human subsistence (Latsch, 1984; Wong, 1967). The Chinese Dragon Boat Festival may have originated from rites to appeal to the river god but over time it was linked with the commemoration of the death of a well-loved Chinese poet and political figure in 278 B.C. (Latsch, 1984). Although there are many Chinese folktales featuring malevolent dragons (e.g. Giskin, 1997), the ancient Chinese dragon was usually regarded as a benevolent deity that could bestow good fortune (Latsch, 1984).

Dragon boat racing is now an international sport with competitive and recreational teams (Harris & Niesen-Vertommen, 2000). Dragon boats are narrow, multi-coloured and usually built to represent the dragon in some way. They vary from 12 to 14 meters in length, and can weigh 2,250 kilograms when filled with their 20 paddlers, a drummer and a steersman (Beaton, 1999; Dragon Cup USA, 2000). To achieve high racing speeds, the blade of the paddle must hit the water in a horizontal position with a quick, backward pull, an action that requires considerable trunk and upper extremity muscle strength (Harris & Niesen-Vertommen, 2000). A seasoned team will have a

stroke rate of approximately 70 to 80 strokes per minute (Dragon Cup USA 2000).

"Abreast In A Boat" was the first known dragon boat team to consist of women with breast cancer. The team was formed in 1996 in Vancouver, British Columbia through the efforts of a physician with an interest in breast cancer. McKenzie (1998) wanted to demonstrate that exercise was beneficial and to promote public awareness of breast cancer. In preparation for racing, the 24 women completed a progressive training program consisting of strengthening and stretching exercises, and 20 minutes continuous aerobic exercise.

No woman on this team experienced a new episode of lymphedema over a two-year period. A few minor musculoskeletal injuries occurred due to unaccustomed exercise (McKenzie, 1998). The women themselves reported positive physical results including improved shoulder range of motion, and for one woman, a resolution of chronic reflex sympathetic dystrophy. McKenzie (1998) claimed that there were no adverse effects and marked improvement in the physical and mental health of the women.

Harris and Niesen-Vertommen (2000), two physiotherapists who were involved in the first dragon boat team, went on to investigate what they described as the myth of exercise-induced lymphedema in a before-after study with 20 of the 24 women involved in the "Abreast In A Boat" team. The investigators measured arm circumference at the beginning of training, the beginning of the racing season, and at the completion of the racing season. Two of the 24 women had a measurable difference in arm circumference (< 0.5 inch), but no one had a clinically significant difference (< 1.0 inch). Harris and Niesen-Vertommen (2000) concluded that there was no increased risk of lymphedema with strenuous, repetitive upper extremity activity for the women in this sample.

Mitchell and Nielsen (2002) examined the meaning and psychosocial impact of dragon boat racing and women with breast cancer in a qualitative study with teams from Thunder Bay and Toronto. They reported nine themes (hopeful mission, common base, paddling and the environment, camaraderie, regaining control, embracing life, facing the disease, having fun, being focused and moving on) that emphasized the strong positive influence of dragon boat racing on psychological recovery from the fear associated with diagnosis and treatment for breast cancer.

Summary of the existing literature

As yet, there is little existing literature or research about dragon boat racing and breast cancer, or the impact of vigorous upper extremity activity on the risk of incurring lymphedema. The two existing studies by McKenzie (1998), and, Harris and Niesen-Vertommen (2000) challenge the expectation that a strenuous physical activity, such as

dragon boat racing, will increase the risk. Nevertheless, the absence of a control group in both studies limits drawing a firm conclusion about the relationship between physical activity and lymphedema.

The experience of breast cancer has substantial impact on physical and psychological well-being. Finding ways to live meaningfully in the face of cancer is difficult and challenges most people's inner resources. McKenzie (1998), and, Harris and Niesen-Vertommen (2000) were concerned with the physical impact of dragon boat racing and the risk of lymphedema. However, McKenzie (1998) noted, "The impact of this experience on these women has been overwhelming, the physical changes barely keeping pace with the changes in psyche" (p. 377). His impressions were further supported by Mitchell and Nielsen's (2002) study of a similar group of women in Ontario. Dragon boat racing challenges cautionary restrictive advice about physical activity to reduce lymphedema, and demonstrates the critical role of meaningful occupations in enabling an individual to live with stressful life experiences such as breast cancer.

Objective

The objective of this pilot study was to explore the impact of dragon boat racing on psychological well-being from the point of view of women who have experienced breast cancer. This study contributes to the work by Mitchell and Nielsen (2002) and examined dragon boat racing in a group of Maritime women.

The researchers had no personal experience with dragon boat racing or breast cancer. Interest in dragon boat racing occurred through discussion with other women with breast cancer who were participating in an ongoing study about the meaning of gardening in daily life and also spoke about their interest in dragon boat racing.

Methodology

Study participants

Three participants were accessed for this study from a brochure for their dragon boat team. Abbie, Anna, and Alice were in their early 50's and had been diagnosed with cancer 2 to 4 years before the study occurred. Anna and Alice were married; Abbie separated 6 months before receiving her diagnosis. Abbie and Alice had surgery. Anna and Alice were given chemotherapy and all three women were treated with radiation. At the time of the study, the women had completed their treatment, and no one had experienced a re-occurrence of cancer.

These women became involved with dragon boat racing within 6 months to 3 years following their diagnosis. Anna and Alice first heard about dragon boat racing from a col-

league or friend. Abbie read about it in a newspaper article and persuaded another friend to go with her to a meeting.

Procedures

Each woman was interviewed twice. The first interview was face-to-face and 1 1/2 to 3 hours in length. This interview was semi-structured with the questions designed as conversational prompts about: 1) the attraction of dragon boat racing; 2) the organization of the dragon boat team and the extent of the participant's involvement; 3) the benefits and risks of involvement; and, 4) the overall meaningfulness of dragon boat racing to the participant's daily life. The questions were derived from informal conversations with other women breast cancer survivors who were involved in racing and the literature in this area. The second interview provided an opportunity for the interviewer to clarify information and for the participant to add any new information or expand on her earlier comments. The second interview was 1/2 to 1 hour and was conducted by telephone. Both interviews were recorded and transcribed.

Field notes were taken by the interviewer (the second author) at the end of each interview to summarize the topics of discussion, consider emotions expressed by the participant, reflect on the interview process, and note any insights immediately apparent from the interview.

Data analysis

Both authors read the transcripts. A content analysis was used to organize an initial understanding of the respondents' comments in response to the open-ended questions that guided the interviews. A thematic analysis was then used to search for and identify the common and recurring threads across questions in an individual interview and among the interviews of the participants (Morse & Field, 1995). Themes and sub-themes were identified if statements from at least 2 of the participants supported them. The second author created the initial thematic framework and initial analysis together with the first author. The framework and analysis were then later reviewed and expanded upon by the first author with advice from an expert in qualitative data analysis. The themes and sub-themes as they emerged from the data are discussed as the findings. An interpretation of the findings in relationship to stress, appraisal and coping research is given in the discussion.

Findings

Involvement in dragon boat racing required a considerable time commitment. Some women traveled long distances to attend practices and meetings. During the racing season, they had practices 3 times a week and attended various festivals across Canada. Throughout the year, they

participated in regular physical activity and monthly meetings. One participant began paddling too soon after her breast cancer treatment and developed a frozen shoulder. She had extensive therapy to regain range of motion in the shoulder before returning to dragon boat racing.

The women generally received enthusiastic support to participate in dragon boat racing from their partners and their children. One woman did report unsupportive comments from a parent suggesting that participation was inappropriate for a woman of her age and a waste of time and money. These comments did not change her decision to participate.

Although the participation of women with breast cancer in dragon boat racing in 1996 (McKenzie, 1998) first occurred as a challenge to the cautionary recommendations given to women, the women in this study participated for other reasons. They had heard about the dragon boat teams in Vancouver and were aware of the studies by Harris and Niesen-Vertommen (2000), and McKenzie (1998). They believed that it had been shown that lymphedema was not affected by strenuous activity. Only one of the women was cautioned about the possible association of strenuous activity with the onset of lymphedema. One participant developed lymphedema following breast cancer treatment, but believed that her lymphedema was unaffected by dragon boat racing. She used massage to treat it and avoided carrying heavy loads with the affected arm.

The women's conversations about the meaning of dragon boat racing to them illustrated the appeal of dragon boat racing, the benefits and challenges of participation, the tension between meeting competition and support goals, and the difficulty in coming to terms with fears about re-occurrence and possible death. Their interviews also reveal the evolution of a support group that is occupation-based in its efforts to meet its goals.

Theme 1: The attraction of dragon boat racing

The participants were asked about their attraction to dragon boat racing but their responses were also directly related to several other themes pertaining to well-being and support. They were attracted to racing for two reasons: a) the active nature of the support, and b) the enthusiasm and positive energy of the other women.

a) Active support

The women in this study became involved in dragon boat racing because the team was a group of women who were breast cancer survivors. In other words, the attraction was not initially racing but the support inherent in being with other women who shared this cancer experience.

Two of the women were quite explicit about their preference for a support group whose primary focus was to

pursue an activity rather than to talk about breast cancer. Anna liked the active quality of racing. It helped her to become physically fit, and have fun, "... sitting around talking or learning how serious this disease can be for some, it injects fear in me, and it takes me down a road I don't want to go." Alice commented:

... I wasn't that interested in forming my identity around having had breast cancer and while that is the reason that we are all on this team, what's out there, that we are all relating to is living well. It's not about having had breast cancer, although it's because of the breast cancer that we're really wanting to live well.

The women felt supported not by talking at length about breast cancer as might occur in a support group, but by working together as competitors. Alice's comment highlighted her perception that by participation in this occupation she would find a way to live well despite cancer because she saw other women living well.

b) Enthusiasm and positive energy

Anna described the spirit of the women on the team as contagious. As Alice's comments illustrate, they had a positive energy that was apparent to each of them at their first meeting with the team:

... even though I was wrecked physically from the treatment ... I could have floated home. I just felt high as a kite. And I just wanted to get back to that energy ... immediately when somebody comes ... people speak about the energy ... It is very enlivening, uplifting, positive, renewing energy.

The energizing effect of dragon boat racing was particularly motivating because it was in such sharp contrast to the negative psychological and physical effects of diagnosis and treatment. The women had a need for a different kind of experience, an energy that would take them beyond the negativity. As Alice had said, she wanted to get back to that positive energy because it made it possible for her to go on.

Theme 2: Physical and emotional well-being

The benefits of dragon boat racing to the physical and emotional well-being of each woman was commented on repeatedly by the women in their interviews. They spoke more often about emotional well-being but it was evident that emotional well-being grew out of physical achievement and the camaraderie of being with each other.

a) Physical well-being

Racing required increased stamina and physical fitness for each woman within her own abilities and limitations. The physical achievements were easily visible and helped the women to measure their progress. Anna and Alice spoke about the initially harrowing experience of being in a boat and then seeing real physical achievements in their ability to paddle, to paddle together, and to paddle for longer

periods of time without exhaustion. Anna said that she had never been in as good physical shape in ten years. Anna thought that dragon boat racing improved one's overall physical health because it drew attention to the body, the need to eat well and to stay fit in order to race. Abbie felt that she had more physical energy. All three women became more physically fit and they perceived it to be as a result of dragon boat racing.

b) Emotional well-being

There were some aspects of emotional well-being that were common to all three women. Dragon boat racing helped them: i) to put a positive interpretation on a negative experience; ii) to rebuild self-confidence and regain control, and iii) to make personal changes that affected their personal well-being.

i) A positive interpretation on a negative experience

Dragon boat racing was an opportunity to make something positive out of a very difficult experience. As Anna said: "I think it's a positive spin on something that could be interpreted as something very negative ... that's what I like about it because it is a positive aspect." Feeling more positive was important in attracting women to this occupation. They were facing an overwhelmingly negative experience in which they were confronted with fears, intrusive and painful procedures, disturbing side-effects, and guarded information about their prognosis. Dragon boat racing was an opportunity to move towards a more positive interpretation that gave them more optimism and hope for the future.

ii) Rebuild self-confidence and regain control

The cancer diagnosis and the treatment changed the way the women saw themselves. They had experienced many losses that challenged their self-confidence, and even perceptions of their own individual spirit. Anna said:

... I lost the way I saw myself, and the way I saw myself was sort of, and this is the way I am by nature, a happy, energetic, capable and confident woman. And I know I felt ... about myself, because I thought, well I guess I cancer the fact of being diagnosed with cancer, it sort of eats into your spirit of who you are... it's very difficult to explain. And I felt very frightened by the diagnosis ... you look in the mirror and you see this chemo patient, right, with pale skin and physically getting weaker. So I felt I was in this long tunnel, black tunnel and I couldn't wait to get out of it.

Alice had a similar perception of loss adding, "I think for many women there's a sense of maybe life is over and in a certain way it is. Life as it was on the inside, it's changed." These perceptions of loss eroded self-confidence.

Dragon boat racing enabled each woman to rebuild self-confidence and feelings of control. Anna explained this benefit quite clearly:

... that's why I think dragon boating is so important to women because it starts to build their confidence back that they can do something, taking control of their lives and puts them in fantastic physical shape ... through all of the accomplishments you have a feeling of control back and of confidence back. Then you start feeling great from a physical aspect ... comes the confidence and from the confidence comes the control, it's all weaved together.

Anna links these emotional benefits of dragon boat racing first to the impact of racing on physical health. The physical benefits were tangible and were a measure of recovery from cancer. When they started to feel better physically, they also felt more confident and in better control over their health. Dragon boat racing challenged the physical and psychological travesty of the disease.

iii) Personal well-being

In addition to these common experiences, each woman also had her own unique experience of the disease. Anna wanted to get through the experience of diagnosis and treatment, and have it behind her. Changing the verb tense from present to past in relationship to the way that she spoke about breast cancer was an important part of her emotional recovery. She said, "... I think of it as a cancer that I had, not a cancer that I have", and later, "... the thing is that I had breast surgery, but I don't have breast cancer right now." Anna referred to herself as a breast cancer survivor. Participating in dragon boat racing may have helped her to move forward and distance herself from diagnosis and treatment by giving her a challenging occupation with goals in the future related to competition.

Abbie's comments were focused on loss and the need to regain what was lost. Unfortunately, the diagnosis of cancer coincided with her marriage break-up thus intensifying her own experience of loss. She felt isolated by her disease and had difficulty finding support from family and friends. In addition to the treatment side-effects, Abbie struggled with depression. She said:

... I had lost interest in everything. I came to work but once I left work, I would go home and I would go to bed. In my depression, I just wanted to sleep, and I didn't care what was going on around me at all. It didn't matter any more ... That is a very hard attitude to get over too. It is a struggle because you get so depressed that you just can't see any reason for still being around.

Abbie found a social support network that decreased her sense of isolation, and gave her an interest in something that counter-balanced her depression: "Something that I believe quite strongly is that if this dragon boating thing hadn't come along, I would still be in a state of depression. I'm sure I would be."

Alice wanted to hold on to the positive aspects of what she had experienced by having cancer. She explained:

One of the things ... that I feel ... is important ... is saying to myself 'I hope I never forget' because there are a lot of lessons or gifts in remembering that we're not here forever. There's a certain way that being in the group keeps that in the center with me, to not lapse into a state of complacency, kind of taking everything for granted ...

Although Anna's and Abbie's comments emphasized the ways in which dragon boat racing took them away from thinking about breast cancer, for Alice, racing kept breast cancer more present in her life in part because Alice also changed in other ways. She often took on organizational responsibilities and public relations activities within the team. Alice said dragon boat racing had helped her to develop new abilities, to become more extroverted, and to build new friendships.

Theme 3: Competition as positive energy

It was apparent throughout the interviews that competition was the impetus for change for the participants. Competition also provided an opportunity to experience individual and team pride.

a) Impetus for change

Competition was the reason for the enthusiasm, and positive energy of the team. Competing provided the underlying motivation that facilitated the physical and emotional benefits that the women experienced even though the opportunity to race and compete did not appear to be the initial attraction of dragon boat racing. Support without competition would not have been meaningful or sufficient.

Alice spoke at length about why competition was vital to her experience of dragon boat racing:

I did paddle in a boat that ... didn't have enough paddlers ... and the coach of that team was a survivor. There was very much a sense of support in that team and looking after one another and so on, but the shadow side of that is a certain complacency, not pushing yourself, ... kind of a tendency to sink into this 'Let's just have a good time, let's not really tax ourselves, let's be nice to one another'. And really it's about both. Both energies are really necessary ... (you) can feel the oneness in the boat ... competition allows for a certain experience that you can't have otherwise.

Alice's comments suggested that when there is less emphasis on competition, the women have less incentive to develop their full potential and less opportunity to experience the emotional benefits of striving to excel. Competition provided the push to expect more from oneself and each other. Alice believed:

The ground is the caring and support. The path is racing as a competitive team. The fruition is enhancing self-esteem and physical well-being ... So it's not like

one is more important than another, they each have their place and they work together towards the goal of building physical and emotional health.

The focus on competition might discourage women who do not perceive themselves as naturally athletic. The women noted that the expectation of the team was to achieve according to each person's abilities or one's personal best rather than to compete with one another.

b) Individual and team pride

The women enjoyed telling stories about their racing successes. They were middle-aged women who might not normally be expected to be involved with such vigorous physical activity. They were women who had experienced a very serious, life-threatening disease. Two of the women did not even have a prior history of vigorous physical exercise before taking up dragon boat racing. Anna related, with enthusiasm and pride, her story about winning the women's challenge trophy against a team of 20-year-old women who did not have breast cancer.

Theme 4: Dragon boat racing as social support

The women's attraction to dragon boat racing as an active form of support meant that much of the support given to each other was implicit and informal but it did also have tangible and practical dimensions. A key challenge for the team was balancing support and competition needs.

a) Implicit and informal, tangible and practical

Support for each other was implicit because of the women's shared understanding about the experience of breast cancer, and by a need to do something positive about their physical and emotional health without focusing on the disease itself. As Anna said:

... literally, we're all in the same boat ...we all have the same feeling, like we all come from the same place. And we all understand each other ... the benefit is being with women, who - the unspoken word is we're all here together for the same reason ...

They knew without much discussion or explanation what they were feeling. Team members were also sources of information about cancer treatment. Women heard about treatment options from their doctors but they also talked to other women on the team about treatments, tests and new advancements. As Abbie said, if she had questions about a treatment there was a good chance that one of the team had already been through it. When team members were not doing well, the women found ways to send food through other members even when they lived some distance away from each other. The team met once a month to have lunch, go for a walk or do another social activity. Some women developed friendships within the team.

b) Balancing support and competition

The attraction to participate in dragon boat racing was the shared experience of breast cancer, but the focus of the women's activity together was competition. Almost inevitably, there was tension between the competitive goals and the support goals. In fact the tension between these goals was present at the outset of the formation of this team when some women wanted to introduce themselves to the group by talking about their cancer experience when other women preferred to talk about other matters related to organizing a dragon boat team.

Alice felt that competition was critical to achieving the physical and emotional benefits possible through dragon boat racing, but recognized that competition could overwhelm the support goals of the team, and cause divisions within the team. She referred to this problem as "... the shadowed side of that kind of competitive energy."

When tensions between competitive and support goals risked causing divisions, the team formed a caring committee. Later they held a one-day workshop to come to some agreement about these issues. The outcome was a more explicit and joint commitment to competition based on achieving one's personal best and meeting mutual support goals. Support goals were given priority.

Women who participate in dragon boat racing have diverse support needs that are influenced by their own personal experience and their support networks outside of the team. For some women, the need for support was met primarily through the dragon boat team. Other women who were involved with the team also participated in a monthly cancer support group through the cancer society.

Working out a balance between competition and support needs had to emerge over time in response to the evolution of the group itself. As Alice said: "... to a certain degree bad things had to happen in the whole group so that the consciousness of the value and the danger had to be known in the whole group. And that as a whole group, people said this is what we must do ..." In other words, in order to achieve what the team wanted for itself with respect to support and competition, the team needed first to experience the difficulties and come to a group resolution rather than a solution proposed by one or two people.

Theme 5: Transcendence/connectedness/oneness

Transcendence over the cancer experience, connectedness with other women, and oneness with all women who struggle against breast cancer was also a recurrent theme in these interviews. Abbie said that dragon boat racing transcended the negativeness of cancer. Before a race the team visualized together to ensure that they were all thinking positively. Abbie said this visualization reinforced for her a perception

of belonging. The experience of transcendence and connectedness within the team was also supported by the symbolism of their paddles. To raise funds in their first year, donors to the team could have their own name, or the name of someone they wanted to remember, written on the blade of a paddle. As Alice explained:

... all the signatures were on the blade of the paddle and it's the blade of the paddle that moves the boat ... there's the point where it's paddles up and you're just waiting, waiting. And you look down and you see all these names, and it's like the spirit of all those people are with us ... it's almost impossible to convey what that experience is, because it's the sense of oneness with the women in the boat, it's the sense of oneness in spirit of those people whose names are on the paddles.

The women were conscious that when they raced, they were racing for themselves, for their team and for the many women whose names were represented on their paddles.

Theme 6: Reoccurrence of breast cancer and death of team members: Fear, identification and coping

Each of the participants spoke of the recurrence of breast cancer in team members, or the death of other members. Reoccurrence of breast cancer renewed fears that one's own experience of cancer might not yet be finished, in addition to feeling worried and concerned for the women to whom it had occurred. Anna said:

Well we do have women right now who have been through a recurrence and ... it can be a very disconcerting, discouraging 'Is-this-going-to-happen-to-me?' feeling among the women ... part of our mission as is to be supportive of those women who have had a recurrence, and to understand how to deal with that when it does occur.

Abbie commented:

The hardest part about being (name of team omitted) is finding out when a teammate has had a reoccurrence ... two of our team members have died since we started and about five have had a reoccurrence since before Christmas. So it is something that is very hard to deal with ... That is the hardest part about being a (name of team omitted). Everything else is good.

It is evident from Abbie's comment that reoccurrence, or death of members was not uncommon; it occurred to 7 of the 30 to 40 women on their team (not all of the women were currently paddling). Nevertheless, the team appeared to be caught off guard and unprepared particularly when a team member died. As Alice said:

We lost two people since we formed the team, and we didn't really have much of a ritual around that for people to deal with their feelings ... we need some skills

for that and we need to have some kind of a forum in which we can attend to some of those things.

At the time of the interviews, Abbie indicated that the team leaders had organized a workshop with professional facilitators to help them to develop more skills to support each other through the grief process. The grief process had much to do with grief for their teammates and grief for a life that had been free of a worry about cancer and one's own mortality.

Theme 7: Increasing public awareness and perceptions of breast cancer

All three women spoke about the way in which dragon boat racing gave them an opportunity to change people's understanding and perceptions of cancer. Abbie emphasized the opportunity to promote public awareness and positive health behaviours by providing information about risk factors, screening, and preventative health behaviours.

The positive interpretation on the negative experience of breast cancer was an important part of their public stance. These comments from Alice and Anna illustrate their intention to project a more positive and hopeful image for other women:

My message is more for women who are in the midst of a crisis of breast cancer. To see a kind of picture of afterwards, that isn't so debilitated. To see that really ... your life is not over ... the strongest message of support is to live well. To live well even if you're in the middle of a re-occurrence to do that well. To live well. (Alice)

I think the message is that breast cancer is not a death sentence, that breast cancer survivors are living and you can live a fit, fulfilling life after that diagnosis ... We're saying 'Come on women, just don't take this, don't just shrivel up and think something awful is going to happen to you. Get out there and show the world that you can do this' ... I'm helping other women, and just to say 'Hey, it's ok, you're gonna be alright. Join this team and see what you can do, get physically fit, and we care and support one another'. (Anna)

The women's racing activities in provincial and national competitions publicly challenged the impression of a woman with breast cancer as someone who was ill and limited in her ability to do things. Dragon boat racing had challenged their own self-perceptions; they saw themselves as strong women who were survivors with renewed hopefulness about life, and they wanted to share this vision with other women. They understood what a woman who was newly diagnosed was likely to feel and wanted to reach out to her.

Discussion

The substantial changes in physical and emotional well-being that the women in this study experienced due to breast cancer produced a deeply negative perception of life with breast cancer. It was apparent throughout these interviews that dragon boat racing enabled them to reconstruct their perceptions of themselves as breast cancer survivors.

Vrkljan and Miller-Polgar (2001) found that the participants in their study (also women with breast cancer) reconstructed their self-perceptions through their engagement in meaningful occupations. The diagnosis of cancer initially led to a deconstruction of occupational self because the diagnosis disrupted previous occupational routines. Occupations were by necessity reconstructed about the activities associated with treatment. In time, the women adapted their occupational routines taking into account their occupational self before the diagnosis as well as those activities now associated with treatment and recovery. Through continued engagement in familiar occupations, especially those that were most meaningful to them, the women reconstructed their identities to move ahead. The occupations that were particularly important to the women were paid work, caring for their families, and leisure occupations such as walking and gardening. Continuing with these occupations reinforced perceptions that they were healthy, normal, and capable, and that life would still go on despite the threatening nature of cancer.

In an earlier study, active engagement in meaningful occupation (gardening) was also found to help women with breast cancer to counterbalance some of the negative psychological effects of the disease (Unruh et al., 2000). Gardening was familiar and restored women's perceptions of being normal and healthy. It provided continuity in occupational routine.

Women in this pilot study about dragon boat racing were attracted to an occupation that was very new to them and possible only because of their experience with breast cancer. It is not known how these women, and the women in the Mitchell and Nielsen (2002) study, might have differed from the women in the previous studies of Unruh et al. (2000), or Vrkljan and Miller-Polgar (2001). Their ages, life circumstances, and treatments for breast cancer were similar. The women in this study may have had different occupational preferences and different needs for social support. They may have had a greater need for a demanding occupation that would challenge both personal and public stereotypes about breast cancer. They may simply have had more opportunity to become involved in dragon boat racing.

The findings of this study parallel the findings from Mitchell and Nielsen (2002). Finding a way to challenge cancer and embrace life were important aspects of both studies. Support and regaining control had an important

role in the women's motivations to participate. Finding ways to face reoccurrence and death among team members was a significant concern. The most significant theme in both studies may be the emphasis on finding hopefulness about life and a positive interpretation about the cancer experience. The women in these studies and those by Unruh et al. (2000), and Vrkljan and Miller-Polgar (2001) used engagement in occupation to reconstruct the meaning of their experience with breast cancer. In this sense, occupations become important coping strategies that reduce stress, shift the meaning of stressful experiences, and rebuild individual spirit. In stress and coping research, meaning is considered as an individual's appraisal or perception of the potential significance of an experience (Fife, 1994). One of the most influential models in coping research is the stress, appraisal and coping model (Lazarus & Folkman, 1984). Lazarus and Folkman maintained that a stressful experience initiates a circular process of appraisal and coping behaviours. Coping behaviours are a response to the initial or primary appraisal but coping behaviours also promote re-appraisal or secondary appraisals that may be quite different. They conceptualized appraisal as a cognitive process in which characteristics of the person and of the situation contribute to the perception of a stressful event as a challenging, harmful, or threatening experience. Past and current beliefs and values, commitments and responsibilities, as well as perceived predictability and controllability of the stressful experience are important influences on the perceived meaning (Croyle, 1992; Moos & Swindle, 1990). Harmful, threatening, or challenging appraisals are not mutually exclusive; they may co-exist in a stressful experience (Unruh & Ritchie, 1998). For example, a woman in labour may perceive her experience as threatening especially if she has had no previous childbirth experience; she may also perceive labour as highly challenging. Similarly, the experience of breast cancer may be perceived as highly threatening because of the treatment and uncertain prognosis, as well as challenging because of other beliefs, commitments and resources.

Lazarus and Folkman's (1984) work has been used to understand many health crises and life situations (e.g. Gass & Chang, 1989; Unruh, Ritchie & Merskey, 1999). Gage (1992) used this theoretical framework to develop an assessment and intervention model of coping for occupational therapy intervention. The harm/loss appraisal associated with cancer treatment is based on very real losses in physical health and psychological well-being. Sustained harm/loss and threat appraisals when the underlying stressful event is prolonged, as it is when a person is diagnosed with cancer, increases anxiety, depression, and perceptions of helplessness (Arathuzik, 1991). A primary appraisal of perceived life threat is associated with more difficult adjustment for people with cancer (Jenkins & Pargament, 1988).

The most prevalent theme throughout the conversations of the three women in this study was the way in which dragon boat racing enabled them to make a positive interpretation out of the negative experience of breast cancer. It was their personal experience; it was also a key element of the public message that they wanted to convey to other women. Their comments suggested that as they became involved with dragon boat racing they also began to re-appraise the cancer experience as a challenge, something that could be overcome. By improving their physical fitness and stamina, often well beyond pre-morbid levels, they increased their perceptions of control over their physical health, and thereby regained self-confidence and decreased helplessness. They were more hopeful and began to think of themselves and their situation quite differently.

Very little is known about the impact of challenge appraisals on the ability to cope with serious health crises. There is some evidence that challenge appraisals are associated with using positive self-statements (e.g., I can get through this, I am going to be okay) as well as using cognitive and behavioural distractions to cope with the stressful event (Unruh et al., 1999).

Reframing cancer as a challenge partially through dragon boat racing might indeed facilitate cognitive and behavioural distraction. It was demanding and time-consuming, and a direct challenge to cautionary advice about life with breast cancer. Anna said that she was attracted to dragon boat racing because it took her away from her fears about the cancer. Dragon boat racing was also an important cognitive and behavioural distraction for Abbie; it helped her to rethink her experience with cancer and gave her the means to reduce her depression. The experience of dragon boat racing in relationship to appraisal and coping may have been somewhat different for Alice. Another woman who had a reoccurrence of breast cancer 11 years after the woman's first diagnosis influenced Alice in her thinking about cancer. The re-occurrence had caught Alice's acquaintance off guard; she wasn't expecting it and had said, "I kind of forgot, I just didn't see myself that way." The story left its mark on Alice. Alice did not want to forget. Although Alice talked about wanting to remember the lessons and gifts associated with facing cancer, her comments were embedded in words about recognizing one's mortality and "... sucking the marrow out of life as best as we can." Alice's comments suggested an acceptance of a possibly higher threat appraisal of cancer, but she surrounded it in a context that was challenging and positive partially through her participation in dragon boat racing. She seemed prepared to live with a more conscious awareness of cancer possibly because it increased her perception of controllability over the fear of a reoccurrence.

The team did not know how to respond initially when a team member had a reoccurrence of breast cancer or had

died. By reframing the cancer experience in a more positive and challenging light through dragon boat racing, the team may have unwittingly repressed fears about cancer to the extent that team members felt protected from having to face these fears yet again. Dragon boat racing may have been perceived as something like an amulet that would keep cancer at bay.

Coping is defined as efforts to manage stressful experiences regardless of whether the outcome of these strategies is helpful (Lazarus & Folkman, 1984). These strategies are thought to serve two functions: problem-solving and regulating emotional response. Coping strategies themselves can be broadly classified as information seeking, direct action (e.g. taking medication), inhibition of action (e.g. rest), intrapsychic processes (e.g. denial, distraction, positive self-talk), and seeking social support (Cohen & Lazarus, 1983). The findings of Unruh et al. (2000), Vrkljan and Miller-Polgar (2001), and this study demonstrate that engagement in occupations that are meaningful to the individual, are also extremely beneficial as coping strategies. In these studies, engagement in meaningful occupations was the vehicle by which other critical changes in the perceptions of life with a serious health crisis could be made.

This study illustrated the potential advantages of occupations that combine competition with support. The competition redirects some of the focus of attention away from stressful experiences by setting future goals often combined with expectations to work to one's personal best. Competition may also encourage more optimistic and hopeful expectations. Nevertheless, competition can hinder support needs if competition and support are not balanced in a way that is appropriate to the particular group. The comments of women in the earlier studies suggest that the nature of occupations that enable coping in stressful life experiences (competitive or otherwise) is dependent on the individual woman's own needs and experiences.

The women in this study did not comment about the symbol of the dragon and it may not have any particular meaning for them. From an outside view, the dragon head on a dragon boat of a team of women who have had a diagnosis of breast cancer, seems emblematic. As was discussed, in mythology, the dragon is often portrayed as having two sides, good and evil, depending on place and time. In this circumstance, the dragon on the one hand is like the menacing face of breast cancer, and yet on the other hand, the dragon is a powerful force setting out to challenge and triumph over the disease. This view of breast cancer as a dragon was the focus of a recent book by Tocher (2002). Tocher was captivated by the image of the dragon in response to her father's diagnosis with esophageal cancer. She wondered about the dragon image in other circumstances and eventually recruited 22 stories from dragon boat survivors of breast cancer from across Canada. Tocher wrote:

For breast cancer survivors, every race is a ritual battle with the dragon. They call it 'winning against Lane 11'. While 10 boats line up to race, they imagine Lane 11 to be occupied by the dragon of cancer. The women may appear to be racing against each other, but they are really racing against cancer, winning their lives back from the dragon. (p. 105)

Although interest in dragon boat racing for women who were breast cancer survivors originated as a challenge to precautionary advice about the prevention of lymphedema, the women in this study were not worried about whether their participation affected lymphedema; it had little to do with their experience of dragon boating. Only one of the three women had lymphedema and she believed it was unrelated to racing. The women had the perception that it had already been shown that strenuous activity did not increase the risk of lymphedema.

Unfortunately, it is still not known whether the risk of lymphedema is increased or even decreased by participation in dragon boat racing or other vigorous upper extremity activity. There was no apparent risk for the women in this small study or in the studies by McKenzie (1998), and, Harris and Niesen-Vertommen (2000), but without a randomized control study it is not possible to assess risk. Determining the risk is important since these studies illustrate the physical and psychosocial benefits of active participation in leisure occupations on coping with a serious health problem such as breast cancer.

At present, women are still advised to be cautious in their physical activity in the absence of strong research evidence to the contrary. Recently, Health Canada convened a steering committee to provide practice guidelines for the care and treatment of lymphedema (Harris et al., 2001). Following a detailed discussion about the research evidence pertaining to medical and rehabilitative treatments for lymphedema, the committee provided several practical tips based primarily on clinical common sense. The committee suggested that:

Exercise involving the affected arm may be beneficial in controlling lymphedema. Although some clinicians have recommended avoidance of rowing, tennis, golf, skiing, squash, racquetball or any vigorous, repetitive movements against resistance, there is no published evidence to suggest that these activities promote or worsen lymphedema ... Some experts have recommended that women with lymphedema wear a compression sleeve during arm exercises. (p. 195)

Occupational therapists who work with women who have been diagnosed with breast cancer should provide information about lymphedema and its treatment, particularly the use of pressure garments. Where appropriate, they should clarify for clients that dragon boat racing does challenge cautionary advice about strenuous upper extremity

activity but the research is inadequate thus far to conclude that such activity will influence the risk. Occupational therapists should be cognizant of the potential detrimental impact on physical and emotional well-being of restricting participation in meaningful occupations that are physically strenuous.

The participants in this study were actively involved with dragon boat racing. Their comments may not be representative of all women who participated, particularly the women on this team who were not active paddlers. Dragon boat racing may also have different meaning for women who experience a reoccurrence of cancer and for women of different ages. The participants in this pilot study came from one dragon boat team in the Atlantic provinces. Organizational and regional differences may affect the way women regard dragon boat racing. Lastly, the themes and sub-themes generated reflect the interpretations of the researchers about the information given by the participants. Although the authors have endeavoured to reflect the data as given by the participants, interpretation is also shaped by the underlying themes from one participant to another and the subjectivity of the researchers.

Conclusion

The results of this study demonstrated that the occupation of dragon boat racing holds meaning for women with breast cancer in many different ways. It enhanced the physical and emotional well-being of the women involved, and was a positive medium through which women promote an energizing approach to life after a diagnosis of breast cancer. This study illustrated the way in which engagement in a meaningful leisure occupation may enable people to shift the way a terrifying negative life experience is viewed to a framework that is a more positive and optimistic view of life. Further, leisure occupations may have an extremely valuable role as coping strategies that promote health and well-being in daily life. Future research in this area should explore more fully the relationship between engagement in meaningful occupations, appraisals and coping in experiences of serious health crises. A better understanding of occupation as a coping strategy and as a vehicle for social support is needed.

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