"If the Dishes Don't Get Done Today, They'll Get Done Tomorrow": A Breast Cancer Experience as a Catalyst for Changes to Women's Leisure

Charlene S. Shannon University of New Brunswick Susan M. Shaw University of Waterloo

Breast cancer is a life threatening illness experienced by many women. Although research is being conducted in various disciplines, the effect of breast cancer on the role of leisure throughout the illness experience has not been considered. The purpose of this study was to understand in what ways a breast cancer diagnosis and treatment alters women's experience and choice of leisure activities post-treatment. Eight women with breast cancer experiences participated. The findings indicated women's leisure changed by their making leisure a priority, seeking more meaningful leisure, and engaging in health promoting leisure. The research has implications for furthering our understanding of leisure entitlement, purposive leisure, and the ethic of care.

KEYWORDS: Cancer, women's leisure, negative life event, illness.

Introduction

Breast cancer is the most prevalent form of cancer among women (Meyerowitz & Hart, 1995). Recent statistics show that in 2000, over 202,000 women in North America were diagnosed with breast cancer and approximately 51,200 women died from the disease (Ferlay, Bray, Pisani, & Parkin, 2001). This report also estimated that more than 1.2 million women would be diagnosed with breast cancer worldwide in 2001. These statistics demonstrate first, that this disease is a serious health concern for many women and second, that there are many women in North America and around the world whose lives are shaped by a breast cancer experience.

Treatment can include various combinations of procedures—surgery, radiation, or chemotherapy. Each procedure has side effects that impact a woman's ability to function as she normally would (Love, 2000). In this regard, breast cancer is a disease that disrupts a woman's life and has the potential to effect many aspects of her everyday life including her physical abilities, her family, her career, her social world, and her leisure.

The most significant body of research on women and breast cancer has focused on the medical aspects of the illness—diagnosis, treatment, understanding causes, and prevention. The development of non-medical research

Address correspondence to: Charlene Shannon, Faculty of Kinesiology, University of New Brunswick, P.O. Box 4400, Fredericton, New Brunswick, Canada E3B 5A3. Telephone: (506) 458-7533. Email: cshannon@unb.ca.

has given consideration to the psychological and social ramifications of breast cancer. Such studies have devoted attention to understanding how family relationships and support systems influence adjustment to and recovery from breast cancer (e.g., Roberts, Cox, Shannon, & Wells, 1994), how family members and spouses are effected by a breast cancer experience (e.g., O'Mahoney & Carroll, 1997), and how body image and identity are effected by breast cancer surgery and treatment (e.g., Langellier & Sullivan, 1998). There have also been efforts to understand the effect of a breast cancer experience on other aspects of a woman's life. For example, the psychological effects of a breast cancer experience (e.g., Glanz & Lerman, 1992), changes in women's family and occupational roles during treatment (e.g., Bloom & Kessler, 1994), changes in levels of physical activity (e.g., Bloom et al., 1990) and changes within the lifestyle choices women make following diagnosis and treatment (e.g., Reardon & Aydin, 1993) have all been examined.

While some of the research on the social psychological outcomes of cancer experiences makes passing reference to changes that relate to leisure (Bloom et al., 1990; Mustian, Katula, & Gill, 2002; Zemore, Rinholm, Shepel, & Richards, 1990), these studies do not focus on or provide a clear understanding of the leisure experiences or choices of women living with breast cancer, and these women's perceptions of how the diagnoses and treatment has affected their leisure. The attention leisure does receive in such research relates mainly to social, psychological, and physical constraints that breast cancer patients and survivors experience following surgery or during treatment. The concentration is related to the effect on leisure activities while discussions about the effect on the attitude toward, experience of, or valuation of leisure are not included. This provides a very limited perspective on how a breast cancer experience could effect, influence, or interact with a woman's leisure. The purpose of this study, therefore, was to understand whether and in what ways a breast cancer diagnosis and treatment alters women's experience and choice of leisure activities post-treatment.

Literature Review

The leisure studies literature does not include much empirical research dealing specifically with cancer or the issues facing individuals with cancer or who have survived cancer. However, leisure researchers have investigated chronic illnesses and acquired disabilities as well as life events and transitions. These are related bodies of knowledge that contribute to an understanding of the possible inter-relationships between leisure and women's breast cancer experiences.

Chronic Illness and Acquired Disabilities

Within the field of therapeutic recreation, a number of studies have provided insight into how various illness experiences and acquired disabilities alter leisure experiences and activities. These studies have identified ways in which an acquired disability can effect one's continued participation in activities that were previously enjoyed (e.g., Hutchinson & Kleiber, 2000), how one can negotiate constraints that result from the illness so as to allow satisfying leisure experiences to continue (e.g., Henderson, Bendini, Hecht, & Shuler, 1995), and how leisure can serve as a strategy for maintaining health and function while living with an illness or disability (e.g., Mobily & Verburg, 2001).

While these studies are useful in developing an understanding of the types of challenges and issues that individuals who have or have survived cancer may face and how a cancer experience may interact with leisure, breast cancer has some characteristics that makes it unique from many of the chronic illnesses and physical disabilities that have received attention through leisure research. First, breast cancer is a life threatening illness and has the potential to be more than a temporary disruption to women's lives. The threat that cancer could end one's life can cause fear, anxiety, stress, and depression for extended periods of time (Bloom & Kessler 1994; Glanz & Lerman, 1992). Although this uncertainty exists throughout the treatment process, the health of some women with breast cancer is eventually restored with the physical effects being minor or, in some cases, temporary (Bricker-Jenkins, 1994). The women who are fortunate in this regard can resume performing the roles and engaging in the activities that they did prior to diagnosis. This recommencement of roles and activities, however, is not without change. The intensity of this life threatening experience can prompt changes in attitudes and behaviors following recovery. For example, patients often begin taking responsibility for their own health by paying attention to diet, exercise, and stress levels (Reardon & Aydin, 1993). Little is known, however, about leisure changes. There is a gap in both the breast cancer literature and leisure studies literature in the understanding how the leisure of an individual whose life is temporarily disrupted by a life threatening illness is affected and experienced once the individual is able to resume living a healthy life.

Life Events and Transitions

Developing or being diagnosed with a serious illness is a significant and stressful life event (Holmes & Rahe, 1967). Leisure researchers have examined both positive and negative life events, such as motherhood, retirement, and the death of a spouse, in an effort to understand the effects that such events have on individuals' leisure behaviors and experiences. For example, retirement often provides individuals with more discretionary time to pursue activities of interest (Rosenkoetter, Garris, & Engdahl, 2001); the demands of motherhood can constrain a woman's time and can influence the types of activities in which she engages (Bialeschki & Michener, 1994); and the death of a spouse can mean the loss of a leisure partner (Patterson, 1996). In addition to the changes in behavior patterns, roles, and identities that

occur as a result of such life events, the transitions associated with these and other life events frequently cause individuals to engage in a process of self-reflection (Kiecolt, 1994). One of the outcomes of this reflective process is typically a restructuring of leisure time and activities (Kleiber, 1999).

The manner in which leisure is structured in women's lives is often a function of their roles. For many women, work and family roles and the obligations or responsibilities associated with those roles take priority over other pursuits (Henderson, Bialeschki, Shaw, & Freysinger, 1989). The sense of responsibility and commitment that women feel to others is referred to as an "ethic of care" (Gilligan, 1982) and serves as a constraint to women engaging in leisure (Searle & Jackson, 1985). When leisure does take priority. women who experience a lack of entitlement feel guilty for engaging in leisure activities (Henderson, 1991). Some research has given attention to how women's leisure experiences and constraints are affected by life transitions. For example, Bialeschki and Michener (1994) found that some mothers were able to transfer their ethic of care to themselves after their children had left home which provided opportunities for leisure and time for self. This research suggests that shifts in the role of leisure are possible as women move into a new stage of life (i.e., empty nest). Little is known, however, about how a life threatening illness or other life event affects women's constraints to leisure or how the role of leisure may change as a result of a life transition. If leisure restructuring occurs as a result of a breast cancer experience, there may be implications for the constraints these women would experience related to leisure.

An illness experience is different from life transitions that are a part of one's regular development such as parenthood or retirement in that a serious illness is very seldom anticipated. The changes caused by the life event itself might demand that an individual make changes in many aspects of his/ her life (i.e., individuals with cancer undergoing radiation therapy are more sensitive to sun exposure) and this may mean changes in the types of leisure activities or behaviors in which the individual engages. It is important, however, not to overlook the process of self-reflection that is prompted by a life threatening illness and the role that it can play in altering one's life. The awareness that results from facing death often causes an honest reflection of what is important and a reorganization of priorities (Kinnier, Tribbensee, Rose, & Vaughan, 2001; Stensrud, 1993), influencing leisure choices and behaviors. Individuals have also identified illness experiences and other negative life events as being a positive force in their lives and contributing to personal transformations (Tedeschi, Park, & Calhoun, 1998). It is this personally transformative aspect of a negative life event that is often neglected by researchers (Hutchinson & Kleiber, 2000), suggesting the need for research into whether and in what ways leisure restructuring occurs through a process of self-reflection and/or transformation during or following an illness experience.

Clearly, there is a need for more research into the role and meaning of leisure in the lives of individuals with life threatening illnesses. Given the

prevalence of breast cancer among women in North America and the fact that leisure has not been investigated to any great extent within the context of a breast cancer experience, there is a need to begin exploring the role of leisure in the lives of women who had a breast cancer experience. The emphasis on experiences and choices led to two specific research questions. First, what leisure choices/experiences do women who have had a breast cancer experience make/have, and how do they feel about these choices/experiences? Second, how do the women think their leisure experiences, choices, valuations, and attitudes have changed since their breast cancer diagnosis and treatment? This research is significant in that it serves as a starting point for understanding how breast cancer, and perhaps other life threatening illnesses, can effect a women's leisure. It also provides insight into how cancer experiences can influence the valuation of and attitudes toward leisure.

Methodology

Phenomenology was the broad theoretical perspective that guided the inquiry. According to Patton (1990):

Phenomenological inquiry focuses on the question: "what is the structure and essence of the experience of this phenomenon for these people?" Phenomenologists focus on how we put together the phenomena we experience in such a way as to make sense of the world and, in doing so, develop a worldview. (p. 69)

This approach provides a way of gaining access to the lived experiences related to leisure (Harper, 1981) and understanding the changing meanings of leisure for women following a breast cancer experience. Given that the focus of this study is on meanings and experiences, phenomenology was well suited with an exploratory approach and the use of an interpretive framework to guide the research.

A purposeful sample was used to identify potential participants who were at least one year post-treatment and had been or currently were part of a formal support network. Women were considered to be one year post-treatment if, 12 months prior to the commencement of the study, they had completed any surgery, radiation, or chemotherapy that had been part of either an initial treatment plan upon diagnosis or a revised plan following initial treatment procedures. It was believed that women who had at least one year distance from active treatment would have be in a good position to reflect on how their leisure, and their lives in general, had changed since their breast cancer diagnosis and treatment.

Two issues were taken into consideration when developing a strategy for recruiting women to be participants in the study. First, the stigmatized nature of cancer often causes individuals to be very private about their illness (Bloom & Kessler, 1994). There was concern about the willingness of participants to voluntarily identify themselves as individuals who had experienced breast cancer to a researcher with whom they were not familiar. Second,

consideration was given to how comfortable the women would be divulging very personal information to someone they did not know. The authors felt that women who seek out and become part of a support group do so with a willingness to identify themselves as an individual with cancer to other individuals who in many cases are strangers. Women in support groups also have experience in telling their story to others (Avery & Nyhof-Young, 2003). Both of these factors contributed to the decision to recruit women who had made the choice to become part of a formal support network.

Henderson (1990) suggests that gaining the support of an individual who may serve as a link to the group of people one wishes to study is a useful step toward gaining access to potential participants. In order to identify women for the study, two key informants were utilized.

The first author had been involved with the Canadian Cancer Society's Living With Cancer support group as a volunteer between 1994 and 1996 in a rural community in Nova Scotia, Canada. She had come to know two individuals who were survivors of breast cancer and these women had trained as facilitators for this particular support group. These two individuals agreed to act as key informants, and compiled a list of individuals who they believed met the basic criteria for the study. One of the informants then delivered recruitment letters to eight women. The recruitment letters explained the purpose of the research, the procedures that would be used in collecting the information, and the ways in which confidentiality would be protected. The letters also provided instructions on how to contact the researcher if they were interested in being participants. All eight of the women who were approached contacted the first author within a very short period of time after receiving the letters and expressed interest in being involved in the process.

Data Collection

Data were collected from women living in rural Nova Scotia, Canada. The eight women involved in the study ranged in age from 36 to 55 years. Seven of the women were Caucasian and one was Asian. Six women were married and two women were widowed. All but one woman had children. Two of these women had children who were younger than 5 years of age at the time of diagnosis and three had children in high school. The remaining mothers had children who were grown and no longer living at home when they were undergoing treatment. Seven of the women had careers (e.g., three teachers, lawyer, accountant, financial advisor, administrative assistant) prior to being diagnosed with breast cancer. Three of the women were six years post-treatment, two were four years, two were three years, and one woman was a year post-treatment.

Interviews

In-depth, face-to-face interviews were conducted with each participant. The interviews were semi-structured and served as the primary data collec-

tion strategy. The length of the audio-taped interviews averaged 90 minutes, ranging between 65 and 100 minutes. Seven of the women invited the first author into their homes for the interview. One particularly busy woman asked to be interviewed at her place of work. The interview questions were designed to develop an understanding of individual leisure needs, life priorities, current leisure patterns, and constraints to leisure, as well as to have participants reflect on whether and in what ways their experience with breast cancer had changed their lives. Some of the interview questions were as follows: Tell me about your breast cancer experience. Tell me about your leisure time and activities prior to being diagnosed with cancer. Tell me about your leisure activities now? How has your life changed since your cancer diagnosis? What did you learn about yourself, relationships, or life in general as a result of your experience with breast cancer?

Prior to each interview, participants were explained the purpose of the study and that the findings would be presented at conferences and may be published in academic journals. Each of the women was asked to choose a pseudonym that would be used in any cases where findings were being reported.

After each interview was transcribed, the transcripts were mailed to the participants. Each participant was asked to read her transcript and make any corrections, additions, or comments that they wished. A few women made corrections in their descriptions of the sequencing of events or added more information about side effects from treatment. In some cases, the investigator needed clarification on one or more aspects of the interview and this process provided an opportunity to secure this clarification. For example, clarification was sought related to medications. After all interviews were complete, it appeared that some of the women were taking the same medications but for different reasons. The purposes were not clearly described in every case. Therefore, to gain an accurate understanding of each woman's treatment plan participants were asked for more information about the medications they discussed during the interviews.

Focus Group

Eight months following the interviews, a focus group was conducted with six of the eight participants. The purpose of the focus group was to present preliminary findings to participants. The length of time that elapsed between the interview and focus group was a result of the time necessary to transcribe, code, and analyze the interview data. There were also difficulties in scheduling a time when the participants were available. All eight women were invited to participate. After the focus group date was finally set, two of the women developed conflicts with the meeting time and were unable to attend.

In the time between the interviews and the planning for this session, the women in the study came to learn, for themselves, who else was involved in the study. The participants seemed to take pride in their involvement in this study and chose to share with other women who had cancer that they had participated. Some of the women were friends with one or two other women in the study, and everyone was connected to at least one other person in the sample. When the first participant was contacted about the focus group, she indicated that the others wished to turn the focus group into an evening gathering that involved the focus group session, a potluck dinner, and spending the remainder of the evening socializing. The focus group was held at the home of one of the participants. Each of the participants was asked about their comfort with this arrangement. All were enthusiastic about getting together as a group and participating in all aspects of the evening. Participants made a familiar commitment to each other to protect confidentiality. The women decided at the beginning of the session that "support group rules" would apply. This meant that, with the exception of what would be reported as research findings, what was said within the group was to stay within the group.

This stage of the research was a confirmatory process. The preliminary findings and analyses were presented to participants, and each of the women provided feedback on the interpretations. This allowed for a better understanding of individual experiences as some of the women explained how they felt their experiences fit with or differed from the findings. While the purpose was not to collect new data from the participants, their feedback did produce some new insights.

The three-hour focus group was audio taped. The tapes were reviewed, and a rough transcript of the participants' comments and reactions to the preliminary analysis was produced. Feedback that contributed new data and comments that were to be used in the reporting of findings were later transcribed verbatim.

Reflective Journal

The first author maintained a reflective journal throughout the data collection and data analysis processes. The journal provided a context for further data collection and analysis. It was used to acknowledge the expectations that existed first, as a result of prior conversations and experiences with individuals with cancer, and second, as a result of reviewing the literature on breast cancer prior to beginning data collection. The memos from the reflective journal were used to help create an awareness of how values, personal experiences, and personal knowledge (e.g., the belief that leisure is important) may have influenced aspects of the research and data analysis. The reflective journal allowed the first author to evaluate and process perceptions and emerging thoughts throughout the analysis of the data.

Analysis

Open, axial, and selective coding (Strauss & Corbin, 1990) were used to categorize the data and to identify patterns and links between those categories. Open coding was done with descriptive categories related to the types of side effects reported, the influence the cancer diagnosis and treat-

ment had on women's lives, and the changes that occurred in their lives as a result of their cancer diagnosis. Axial coding helped in the development of themes that focused on the ways in which the women spoke about their cancer experiences and the types of influences and changes that resulted—their emotions, attitudes, values, and perceptions. Selective coding was used to compare and contrast initial themes and to further develop major themes, sub-themes, and to make comparisons within and between the participants.

The constant comparison method (Glaser & Strauss, 1967) assisted in the identification and clarification of themes as the codes, categories, and groups of data were continually compared with the data and the themes that developed out of the data. Comparisons were made between data from the interviews and data from the follow-up focus group. Finally, data were compared with the developing conceptualizations that were recorded in the first author's reflective journal.

As indicated above, the transcript that was developed based on the follow-up group session was also coded. Particular attention was paid to determining the extent to which the women felt the main themes that were presented reflected their experiences. In a few cases, the women were uncertain about the labeling of a theme (e.g., leisure as more meaningful versus leisure as being purposeful). They generally felt, however, that the concept or central ideas that were captured by the various themes did correspond with those aspects of their experience. In this way, the focus group instilled confidence that the themes that had been developed did in fact represent the women's experiences.

Findings

Analysis of the interview and focus group data resulted in the development of three main themes that helped to explain the changes in leisure that the women experienced following diagnosis and treatment. These three themes were related to key changes in the women's lives following treatment: making leisure a priority, desire for meaningful leisure, and focus on health promoting leisure behaviors.

Making Leisure a Priority

The breast cancer diagnosis was a life event that contributed to the women developing a greater appreciation of time. The recognition or awareness that "life is short" inspired the women to consider how they were spending their time and led them to make changes. Paid work and housework became less of a priority, and leisure and family became a higher priority. The women were asked to define leisure and gave similar descriptions—that leisure was as an activity that was not associated with paid work or housework; something that they enjoyed; something they did for fun.

There were a number of different choices that the women made related to paid work. A couple of women moved from full-time to part-time work. Muriel, a woman who was self-employed, indicated that she simply worked fewer hours. Other women indicated working less by lowering their standards slightly and learning to let things go without expecting perfection. Two women retired. And finally, Susan left her profession and career entirely, and found employment that was more flexible and did not spill over into her home life. She explained,

I didn't want the busy, hectic lifestyle anymore. Because of this happening, I think I really. . . I was a teacher before, now I don't want to go back and teach full time. I don't want to have the obligation and demands of that full time job. I want to have my life, some freedom, some time, you know? Now, sometimes I'm home during the day, sometimes I'm home at night. I work part-time. I waitress a couple of nights a week and then I substitute teach during the winter. I go and I do the job. I don't bring it home, you know? I don't have to work at home all night after working all day. I have my weekend free. You know? My life is very different. (Susan, 36 year-old married mother of eight-year-old daughter)

Many of the women also described changes in their priorities related to housework. Previous to their breast cancer experiences, getting housework done had been a relatively high priority for most of the women. Those tasks had come first, while time for self and leisure were enjoyed afterward. In some cases, the women described that their leisure had been a reward for completing obligatory tasks. However, after their cancer diagnosis and treatment, a shift occurred. Completing housework was no longer a prerequisite to having time for themselves or engaging in leisure activities. Many of the women indicated feeling comfortable leaving their housework until "later" if and when they had the opportunity to engage in an enjoyable leisure activity. As Sandy explained,

This cancer diagnosis has given me a whole new look at what's important. And, today's what I've got. . .seize the moment. If the dishes don't get done today, they'll get done tomorrow. If something comes up that would give me a chance to go bird watching this afternoon, well, that's what I'll do. Now, I realize that every minute counts, and because of that, I take more time for those things that bring me joy. . .mostly leisure things and family time. (Sandy, 49 year-old retired married mother of two adult children)

Similar to Sandy, many of the women expressed having an intensified awareness that time was finite and that this awareness contributed to a desire to spend as much time with family as possible. This priority was often expressed and represented by the women spending time engaged in leisure activities with their family members—their spouse, their children, and the whole family together.

The changes toward making leisure as priority tended to be both attitudinal and behavioral. The negative life event prompted a shift in thinking for all women—a change in attitude towards leisure, a motivation to engage in leisure, and a conscious valuation of leisure. However, while the *desire* to spend time at leisure along with the *recognition* that leisure and time for self were important existed, a few women were less able to accompany this change in attitude with change in behavior. These women indicated that they

were still constrained by feelings of guilt associated with making leisure a priority over their household tasks, family, or work.

Leisure is more important. I don't do it, but it's more important.

I'm not clear. . .it's more important, but you don't do it? Right.

I'm sorry, can you elaborate a bit. I don't understand what you mean exactly.

I mean, I know it's more important. Like, what the. . .why are we doing. . .you know, why are we knocking ourselves out? You know what I mean? Like. . .we don't know what. . .tomorrow we might be dead. And what was the last thing you did? Well, let's see. . .today I cleaned my windows. Whoop di do. You know? Who cared when you died if your windows were clean. But that's what I'd probably do. You know? Probably I'd mow the lawn so my lawns wouldn't look bad. (Michelle, 54 year-old widowed homemaker and mother of grown children)

The intensified appreciation of the limits of time caused the women to consider what things they wished to accomplish and what needed to be done in order to achieve those life goals. The women viewed this outcome as a positive aspect of their breast cancer experience. Each of these stimuli encouraged the women to open their minds to possibilities and ways of life that they had not previously considered. Each woman took action and reorganized her priorities including, self, family, work, and leisure. The extent to which women were able to do this, however, did vary.

Desire for Meaningful Leisure

With leisure becoming a more significant priority in their lives, the women in this study also became much more thoughtful about the type of leisure in which they wanted to participate. Consideration was given to the reasons why they were engaging in certain leisure activities. A few of the women indicated they valued leisure for the sense of escape and pleasure that it provided them. For example, reading fiction was considered by one woman to be an excellent opportunity for her to escape; for another woman, going to the beach was her great escape. Other women engaged in activities simply because they enjoyed them and experienced joy through their participation. However, facilitating escape and enjoyment was not the typical role that leisure had in these women's lives following their breast cancer experience. In conjunction with gaining a greater appreciation of time, examining their values, and re-evaluating their priorities, most of the women described how their lives became more meaningful. They described leisure in terms of "not wasting time" and "making the most of time." The women's attitudes about time resulted first, in an evaluation of their leisure time behaviors and choices, and second, in a quest for activities that were more purposeful or meaningful to them. Leisure was viewed as an opportunity and avenue for making meaning in their lives.

Meaningfulness took a variety of forms in the women's lives. What was a priority and considered to be "meaningful" was not the same for everyone. For some women, emphasis was placed on being productive.

I manage my time more wisely now, even my leisure time, and try to do things that are worthwhile, constructive.

For example?

Things that yield good results: furthering my education or for leisure it might be baking cookies or raking the yard or planting flowers or having lunch and catching up with a friend. At the end of the day I can feel like I was productive and did not waste the day. (Snowflower, 54 year-old married mother of two grown sons)

Engaging in various learning activities was also an important way for the women to experience their leisure as meaningful. In some cases, this meant reading and learning about cancer. It also involved learning about different types of birds, gardening, or how to do certain crafts that a few of the women had always wanted to do. Finally, volunteer work, mainly through cancer support and breast cancer advocacy groups, was another way that many of the women made their leisure, and therefore their lives, meaningful.

During the interviews, most of the women explained that being entertained—particularly in terms of television watching and reading fiction—was no longer something they considered important. However, when the women discussed this issue at the focus group, it was evident that not everyone felt this way. Monica, a 40-year old mother of two small children, explained that at times "escaping into fiction" was meaningful to her and therefore, was an important form of entertainment that she incorporated into her life. As the focus group discussion ensued, it became evident that for some of the women, what was meaningful to them was closely linked to what they perceived society might view or define as meaningful. Volunteer work, supporting and helping others with cancer, learning new things, creating things (e.g., knitting mittens for grandchildren), and spending time with family were all things they felt were valued by society and were considered to be meaningful. By engaging in these activities, many of the women perceived themselves as doing something meaningful with their lives.

Relationships were seen by many of the women as having elevated importance, and family relationships in particular were seen as having high priority. There was an emphasis placed on social leisure, and leisure with family was expressed as more meaningful than individual leisure. Consistent with this attitude, some of the women indicated that leisure activities with family took priority over individual leisure activities.

The leisure activities that are shared activities. . .those are the ones I'll make time for. You know, if something has got to go, I have to say it would be the leisure activities by myself—the ones I do on my own. If I don't have time for something today, it will be my personal leisure. I guess it's the family ones that. . .family leisure has the biggest priority. (Monica, 40 year-old teacher; married mother of two pre-school children)

The goal of participating in more meaningful activities often produced negative feelings about activities that the women did not perceive as "meaningful". Guilt was one of the predominant negative feelings.

I started feeling guilty when I found myself lying around reading a book by the fire.

Why?

I'm not being productive.

What about your other leisure pursuits? Did engaging in those make you feel guilty as well?

Well, being involved in politics was meaningful. It serves a purpose because government is a part of life and someone needs to help with the process. Volunteering is important.

What about gardening?

That's therapeutic. And I'm exercising at the same time which serves a very important purpose. Maybe if I was reading a textbook, I wouldn't feel guilty. Because?

Learning. . .I'd be learning. But if I'm just reading a Dick Francis novel, I'm being entertained which is not a meaningful or purposeful existence and so I feel guilty. Maybe if being entertained was a priority. . .but it's not. (Ann, 55 year-old accountant; married mother of grown children)

Similar to Ann, a number of the women put considerable pressure on themselves to make their lives more meaningful almost to the point of causing them distress when they perceived themselves as not being productive or engaging in activities they considered to be meaningful. Engaging in meaningful leisure activities served to relieve the guilt that some of the women associated with having or taking time for themselves or taking time for leisure. These women, similar to Ann, were more comfortable participating in leisure that they deemed to be productive or socially valuable. This was not, however, the case for all the women: For some, the search for meaningfulness was more closely related to the re-evaluation of work and leisure in their lives, and did not seem to be linked to feelings of guilt.

Making a contribution to society, to their families, or to their own personal growth and well being was important to the women. They were no longer interested in being entertained, but rather wanted to be actively living and making the most of life. This attracted them to activities and pursuits that had a purpose and/or would feel meaningful to them. Each of the women examined leisure activities and experiences in terms of the benefits that could result and then evaluated whether these were benefits or outcomes they valued.

Focus on Health Promoting Leisure Behaviors

Another meaningful pursuit for the women in this study involved health-promoting leisure. In this case, the conscious decision to focus on health promoting leisure activities was viewed not as an avenue for making meaning, but rather as a means of achieving positive health outcomes and a number of indirect benefits/opportunities that they believed were associated with good health.

Throughout the breast cancer treatment process, restoring health was the main objective for each of the women. Once the treatment was complete and normal functioning resumed, the women shifted their focus to maintaining health, and in some cases, improving it beyond the level it had been at prior to their cancer diagnosis. The women valued health more and felt entitled to be healthy.

When you are healthy, you don't think about your health much. Being in bad health for almost a year kind of pissed me off. I wanted to be healthy like everyone else. That's where it started with me taking the time to walk, enjoy myself more, and work the fewest hours possible. I thought all those things were important to my health. Forget having a clean house. I deserve to be healthy and whatever that takes. . .me going for a walk while the laundry piles up. Fine. I still do laundry but it isn't more important than my health. I think of it that way more, so in that way, my focus has changed. (Muriel, 55 year-old widow, no children)

The outcome of this change in focus was that the women were more committed to engaging in behaviors that would promote both their physical and mental health.

Various strategies were used in an effort to maintain physical health and the behaviors associated with these strategies became integrated into the women's lives. For example, diet changes and hormone level adjustment strategies (e.g., tamoxifen) were two strategies among many that were recommended or imposed by the medical profession. Many of the women, however, also incorporated leisure activities into their daily routine and experienced this as having a direct effect on their physical well-being.

You have to have leisure. It's a part of good health. . .mentally and physically. It's as important [as the medical strategies] because it gives me less stress and it makes me feel good. (Snowflower, 54 year-old, married, working mother of two grown sons)

Each of the women had experienced a variety of negative psychological effects following diagnosis and during treatment—anxiety, stress, fear, anger, guilt, and feelings of uselessness. Leisure was described as an important coping strategy during treatment. For example, a couple of the woman began walking as a way of releasing stress and anger during treatment. In other cases, the women became aware of the therapeutic benefits of activities that they were already participating in and used those activities as a way of coping. The positive outcomes that the women experienced with leisure activities during treatment encouraged them to continue to engage in those activities following treatment. Interestingly, their activities took on different meanings than they had before the women had cancer—many women now evaluated their leisure activities based on the positive outcomes or benefits that resulted from engaging in them.

The women described journal writing and working in the garden as "therapeutic" leisure activities that helped maintain good mental health. Physical activity also became an important component of most of the women's leisure repertoires. Each woman had become very aware of the ways in which she benefited from engaging in particular activities.

I started meditating after diagnosis. Now, if I find myself agitated, upset about something, I try to do it. I have some beautiful tapes and I use them and I listen very carefully. . . I'll take more or less time depending on the situation. If it's a normal day, two meditations will do. But, if I'm distressed, I will take more time than that. (Sandy, 49 year-old retired married mother of two adult children)

Fear of recurrence was an issue for many of the women in the study and their fear was independent of the number of years post-treatment. Their awareness was heightened in some cases because of their involvement with support networks. They had fairly regular contact with other women with breast cancer and knew of women whose cancer had recurred. As many of the women discussed changes they had made to their lives since their diagnosis, it became evident that fear of recurrence was an issue even five years or more after treatment. The fear of recurrence served as a motivating factor in some of the women developing and maintaining a healthier lifestyle. For a couple of women, meditation and walking programs were among the activities considered to be important for reducing stress and "jacking up the immune system." Another woman indicated that the "innocence about life [was] gone" and she was more aware of the consequences—both positive and negative—of her actions.

It would be nice to just. . . to like, you know, do whatever I wanted to do without thinking about the consequences which is what I did before. I was like. . .I never thought, oh God, I drank too much. I'd think, darn, I'm going to have a hangover tomorrow. Now, I guess I'm more scared what drinking will do to my body and that like. . .doing things that might, you know, hurt me later. I became. . .exercising every day, and just very, very health conscious, you know, and food conscious and taking vitamins. (Susan, 36 year-old married mother of eight-year-old daughter)

For a few of the women, engaging in leisure behaviors that they believed would promote their health was actually a strategy for coping with the fear of recurrence.

I feel better mentally knowing that I'm out walking and that I'm taking time to relax, to get out and enjoy my life, and that I'm more committed to the idea that, you know, leisure as an important part of life. Some people worry that their cancer will come back and taking these measures makes it less of an issue for me. I would probably worry more about it coming back if I hadn't made these positive changes in my life. And you have to realize that there are other advantages besides warding off another bout of cancer, right? (Ruth, 54 year-old teacher; married mother of a teenager)

It is important to note that while the women began to see caring for themselves as an important health-promoting behavior, this did not interfere with their ability or desire to care for others. Sandy spoke about how difficult it was for her to change from being focused on her family, which was something she grew up learning was her role as a wife and mother, to focusing on herself. She explained that sometimes she feels guilty for putting herself

first, but she does it anyway because "my health depends on me doing this." Later, she added that, "I need to be healthy in order to take care of [my family]." Like Sandy, a couple of the other women saw caring for themselves as an important step in helping them continue to take care of their family.

Most of the women in this study believed that they could influence their own physical and mental health by achieving certain outcomes such as lower stress levels or improved levels of fitness. It was a desire to achieve these outcomes that motivated their focus on health promoting leisure behaviors.

Discussion and Conclusions

The breast cancer experience of each of the women in this study did influence aspects of her leisure. Being diagnosed with a life-threatening illness stimulated the women's self-awareness as well as a process of self-reflection. The meaning and valuation of various components of each woman's life were affected and this contributed to changes in each of the women's leisure attitudes, choice of leisure activities, and/or leisure patterns.

Many of the women, in discussing how their lives have changed following treatment, indicated the changes they made as a result of their experience were indeed positive. It may be difficult to conceptualize a breast cancer experience as positive. Generally, this type of illness experience is seen as a negative and highly stressful life event, particularly at the time of diagnosis and during treatment (Glanz & Lerman, 1992). The women's stories, however, suggest that a breast cancer experience provides opportunities for reflection that can result in positive outcomes in many aspects of life including those aspects related to leisure and leisure choices. Despite some of the negative outcomes that resulted for some of the woman (i.e., loss of a breast, fear of recurrence), the women's attitudes toward and perspectives on their illness experience are consistent with other findings in which individuals have indicated that various traumatic events (i.e., injury, illness) have turned out to be a positive force in their lives (Tedeschi et al., 1998). Similar to other life events and transitions such as retirement (Rosenkoetter et al., 2001) or the death of a spouse (Patterson, 1996), these women's breast cancer experiences served as a catalyst to leisure restructuring.

The meanings that the women attached to leisure differed from traditional definitions of leisure. The emphasis that the women placed on the importance of leisure following their breast cancer experiences was not based on thinking about "pure leisure". The women did not describe their leisure as freely chosen, intrinsically motivated, or engaging in it for the sake of the activity—characteristics which are often associated with "pure leisure" (Neulinger, 1981). Rather, their leisure was "purposive"—a concept which has been introduced in a recent family leisure study. Shaw and Dawson (2001) found that parents participated in family leisure for the benefits and positive outcomes that would result. In many cases, family leisure was not freely chosen, but was a means to an end. These researchers suggested that purposive leisure might be a form of leisure that exists in other contexts. A

breast cancer experience is clearly one such context and therefore, the results of this study have the potential to take purposive leisure beyond the confines of family leisure and suggest that leisure can be purposive in other ways as well. As with the parents in the family leisure study, many of the women engaged in leisure that was goal-oriented. The women did express obtaining benefits in addition to achieving their goals of maintaining their health, avoiding recurrence, spending time with family, helping others, and making a contribution to society. Social interaction, having fun, and experiencing enjoyment were all described as outcomes of their participation in various leisure activities. However, it was clear that for these women, leisure became an avenue in which they could achieve a number of important goals. It is also important to note that while the women may have been motivated to engage in leisure for purposes other than enjoyment, this did not mean that they did not experience activities as leisure or that they did not enjoy themselves.

The findings in this study also raise a number of interesting issues related to women's leisure. There was a shift in the role and valuation of leisure among other components of the women's lives. Prior to diagnosis and treatment, many of the women took time for leisure and for themselves only after their obligatory tasks were complete and the needs of their family were met. The descriptions of their lives prior to diagnosis are consistent with the constraints that women traditionally experience (Henderson et al., 1989). However, these women emerged from their breast cancer experience structuring leisure into their lives. Leisure in various forms and contexts was being included as part of their daily routines as a priority rather than a reward.

Closer consideration of why leisure and certain leisure activities suddenly became included as an important part of these women's lives raises some interesting issues about their sense of entitlement to leisure. The reflection and psychological effects described by the women as part of their breast cancer experiences were both enabling and constraining in terms of the leisure changes that the women made to their lives.

Living in the shadow of recurrent illness created some unique motivations for lifestyle changes in the women who participated in this study. Each of the women in this study regained her health following treatment and resumed normal functioning—an outcome that is similar for many of the women who receive a breast cancer diagnosis and pursue treatment. These women were all aware, however, that their cancer could recur, and that awareness motivated some of the changes that they made in their lives. For many the women in this study, justifying leisure as a positive health outcome was significant in its being included as an important part of their lives. Being able to justify time for leisure seemed to alleviate some of the women's feelings of guilt—one of the characteristics of lack of entitlement (Henderson, 1991). They felt they were entitled to be healthy, and therefore felt entitled to make choices and pursue activities that would assist them in maintaining their health. Reardon and Aydin (1993) indicated that following a cancer experience, individuals pay greater attention to diet, exercise, and stress lev-

els in an effort to maintain health. For these women, engaging in leisure was a complementary strategy for maintaining both physical and mental health. While some feelings of guilt were still experienced, to a certain extent justifying leisure as necessary for good health indirectly lessened the lack of entitlement as a constraint to leisure and allowed the women to incorporate leisure into their daily structure.

This justification, however, also constrained the women's leisure. By using health and the threat of recurrence as a rationale for engaging in leisure or as a way of relieving guilt, the women may have limited themselves to leisure activities and pursuits which they perceived as health promoting or producing positive mental and physical health outcomes. The use of these justifications suggests that the women only felt entitled to certain forms of leisure. In this regard, restrictions on their sense of entitlement constrained their participation in forms of leisure that did not fit with the justifications being used. While the inclusion of leisure into the daily routine was not without justification for some of the women, it nonetheless represents a change in these women's lives and one that may not have come had it not been for their breast cancer experience.

The heightened awareness of death that accompanied the women's breast cancer diagnosis and treatment played an important role in clarifying values and altering some of the choices that the women made, including choices related to leisure. Strensrud (1993) explains that death awareness "offers us elements of heaviness that push us down and ground us and allow us to become directed towards the important elements of our lives" (p. 33). She argues that contemplating death is one of the strongest influences in living and one that leads to a new perspective being found. For the women in this study, an outcome of a new found perspective involved an awareness of the role and importance of leisure.

After surviving a life threatening illness, the women did not choose to put more effort into doing their jobs better or becoming more skilled at cleaning the house. They wanted instead to live healthy lives, spend time with and enjoy their families, and engage in meaningful activities. The socialization process experienced by many of the woman before having cancer contributed to their simply accepting the roles they had taken on in their lives without really contemplating them. Facing death and coming to appreciate time motivated the women to think about their behaviors/roles and the importance that had been assigned to those behaviors/roles. The women in this study were able to more clearly see what mattered most to them and would contribute to their quality of life. Having "things" was viewed as less important as was having a clean house. Having time to "experience" things became more important. As a result, the women's behaviors, in many cases, reflected a shift away from materialism. The behaviors that represented changes in priorities that involved more opportunities for "play" and advocated less materialism are consistent with other research involving individuals who have faced death (Kinnier et al., 2001). Leisure time and activities took on greater meaning, and the leisure restructuring in which these women engaged demonstrates one of the values or positive consequences that can be found in death awareness.

After assessing their priorities, some of the women specifically identified that engaging in family leisure took priority over their individual leisure. Spending more time with family was important to all of the women and for some, this was achieved through engaging in family leisure. Family leisure is not necessarily "leisure" for women as they often perform the planning and organizing tasks—the work—necessary for the leisure experience to be successful (Shaw, 1992). This raises some interesting questions about how women who face a life threatening illness come to perceive family leisure. Perhaps the "work" associated with family leisure is something that the women, at different points in their lives, enjoy or perceive as worthwhile given the outcomes that can result. Perhaps what women gain personally from engaging in family leisure following an illness experience, or even after other life transitions, is far greater than that which they would gain from individual leisure. Is it possible that at some point, family leisure becomes less about satisfying the needs of others, and more about a wife/mother meeting her own need to be with family? Or, are these women simply meeting a need to care for family—a need that perhaps intensifies after temporarily abandoning some of their caregiving roles or after enduring a process that involves facing the possibility of death? Clearly, more research is needed to better understand how women engage in and experience family leisure at different points in their lives.

For the women in this study, breast cancer was a life event through which lifestyle change was inspired and served as a catalyst to restructuring their leisure. The value and importance of leisure was realized in moments when an appreciation of time and life were intense. This suggests that processes that involve self-reflective and personal transformation have important implications for leisure. Further research is needed in order to understand whether and which other health events and life events may prompt women to restructure their leisure and restructure in a manner that allows it to emerge as a priority. More research is also needed to understand how a woman's entitlement to leisure and ethic of care interact with life events.

While this study has made a variety of contributions in understanding the affects that women's breast cancer experiences may have on leisure choices, the nature of the research process and the sample women who participated in the study were fairly homogeneous group may lead to the results having limited applicability. All but one of the women had a career prior to being diagnosed; all but one of the women had children; all were heterosexual; and there was little racial or ethnic diversity. Each of these women had also made a decision that they needed or wanted support outside their own social circles and apart from their own support resources. The similar characteristics among the women may have contributed to their sharing similar attitudes, impressions, and perspectives about their experiences. The findings, then, may have limited applicability to other settings and other women with a cancer diagnosis. Research that explores the experiences of

women who are more diverse is needed. Also, much that was positive came out of these women's breast cancer experiences. Certainly not all women's experiences with breast cancer are as positive as the women in this study described. Further research is necessary to understand the role leisure plays in the lives of women who do not perceive or experience their breast cancer diagnosis, treatment, and life following treatment as positively.

References

- Avery, J., & Nyhof-Young, J. (2003). Like a cleansing fire: Exploring the impact of short-term support groups for women with breast cancer. *Journal of Psychosocial Oncology*, 21(1), 27-51.
- Bialeschki, M. D., & Michener, S. (1994). Re-entering leisure: Transition within the role of motherhood. *Journal of Leisure Research*, 26, 57-74.
- Bloom, J. R., Gorsky, R., Fobair, P., Hoppe, R., Cox, R., Varghese, A., & Spiegel, D. (1990). Psychological performance of work and leisure: Validation of a measure of biological energy in survivors of Hodgkin's disease. *Journal of Psychosocial Oncology*, 8(1), 49-63.
- Bloom, J. R. & Kessler, L. (1994). Emotional support following cancer: a test of the stigma and social activity hypothesis. *Journal of Health and Social Behavior*, 35, 118-133.
- Bricker-Jenkins, M. (1994). Feminist practice and breast cancer: "The patriarch has claimed my right breast. .." Social Work and Health Care, 19(3/4), 17-41.
- Ferlay, J., Bray, F., Pisani, P., & Parkin, D. M. (2001). GLOBOCAN 2000: Cancer incidence, mortality, and prevalence worldwide, Version 1.0. IARC CancerBase No. 5, Lyon, IARCPress.
- Freysinger, V. J., & Flannery, D. (1992). Women's leisure: Affiliation, self-determination, empowerment and resistance? *Society and Leisure*, 15, 303-322.
- Gilligan, C. (1982). In a different voice. Cambridge, MA: Harvard University Press.
- Glanz, K., & Lerman, C. (1992). Psychosocial impact of breast cancer: A critical review. Annals of behavioral medicine, 14(3), 204-212.
- Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory. Chicago: Aldine.
- Harper, W. (1981). The experience of leisure. Leisure Sciences, 4, 113-126.
- Henderson, K. A. (1990). Dimensions of choice: A qualitative approach to recreation, parks, and leisure research. State College, PA: Venture Publishing, Inc.
- Henderson, K. A. (1991). The contribution of feminism to an understanding of leisure constraints. *Journal of Leisure Research*, 23, 363-377.
- Henderson, K. A., & Allen, K. R. (1990). The ethic of care: Leisure possibilities and constraints for women. *Journal of Leisure Research*, 26, 119-137.
- Henderson, K. A., Bendini, L. A., Hecht, L., & Shuler, R. (1995). Women with physical disabilities and the negotiation of leisure constraints. *Leisure Studies*, 14, 17-31.
- Henderson, K. A., & Bialeschki, M. D. (1991). Sense of entitlement as constraint and empowerment of women. *Leisure Sciences*, 13, 51-65.
- Henderson, K. A., Bialeschki, M. D., Shaw, S. M., & Freysinger, V. J. (1989). Leisure of one's own: A feminist perspective on women's leisure. State College, PA: Venture Publishing.
- Holmes, T. H., & Rahe, R. H. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research*, 11, 213-218.
- Hutchinson, S. L., & Kleiber, D. A. (2000). Heroic masculinity following spinal cord injury: Implications for therapeutic recreation practice and research. *Therapeutic Recreation Journal*, 34, 42-54.
- Kiecolt, K. J. (1994). Stress and the decision to change oneself: A theoretical model. *Social Psychology Quarterly*, 57, 49-63.
- Kinnier, R. T., Tribbensee, N. E., Rose, C. A., & Vaughan, S. M. (2001). In the final analysis: More wisdom from people who have faced death. *Journal of Counseling & Development, 79*, 171-177.

- Kleiber, D. A. (1999). Leisure experience and human development. New York: Basic Books.
- Langellier, K. M., & Sullivan, C. F. (1998). Breast talk in breast cancer narratives. Qualitative Health Research, 8(1), 76-94.
- Love, S. D. (2000). Dr. Susan Love's breast book (3rd ed.). New York: Perseus Publishing.
- Meyerowitz, B. E., & Hart, S. (1995). Women and cancer. In A. L. Staton & S. L. Gallant (Eds.), The psychology of women's health, (pp. 51-86). Washington, DC: American Psychological Association.
- Mobily, K. E., & Verburg, M. D. (2001). Aquatic therapy in community-based therapeutic recreation: Pain management in a case of fibromyalgia. Therapeutic Recreation Journal, 35(1), 57-69.
- Mustian, K. M., Katula, J., & Gill, D. L. (2002). Exercise: Complementary therapy for breast cancer rehabilitation. Women and Therapy, 25(2), 105-118.
- Neulinger, J. (1981). To leisure: An introduction. Boston: Allyn and Bacon.
- O'Mahoney, J. M., & Carroll, R. A. (1997). The impact of breast cancer and its treatment on marital functioning. *Journal of Clinical Psychology in Medical Settings*, 4(4), 397-415.
- Patterson, I. (1996). Participation in leisure activities by older adults after a stressful life event: The loss of a spouse. *International Journal of Aging and Human Development*, 42, 123-142.
- Patton, M. Q. (1990). Qualitative evaluation and research methods. Newbury Park, CA: Sage Publications.
- Reardon, K. K., & Aydin, C. E. (1993). Changes in lifestyle initiated by breast cancer patients: Who does and who doesn't? *Health Communication*, 5, 263-282.
- Roberts, C. S., Cox, C. E., Shannon, V. J., & Wells, N. L. (1994). A closer look at social support as a moderator of stress in breast cancer. *Health and Social Work*, 19(3), 157-164.
- Rosenkoetter, M. M., Garris, J. M., & Engdahl, R. A. (2001). Postretirement use of time: Implications for preretirement planning and postretirement management. *Activities, Adaptation & Aging*, 25(3/4), 1-18.
- Searle, M. S., & Jackson, E. L. (1985). Socieconomic variations in perceived barriers to recreation participation. *Leisure Sciences*, 7, 227-249.
- Shaw, S. M. (1992). Dereifying family leisure: An examination of women's and men's everyday experiences and perceptions of family time. *Leisure Sciences*, 14, 271-286.
- Shaw, S. M. (1994). Gender, leisure, and constraint: Towards a framework for the analysis of women's leisure. *Journal of Leisure Research*, 26, 8-22.
- Shaw, S. M., & Dawson, D. (2001). Purposive leisure: Examining parental discourses on family activities. Leisure Sciences, 23, 217-231.
- Stensrud, C. (1993). Quality living until death: A fusion of death awareness into therapeutic recreation-leisure education. In M. P. Lahey, R. Kunstler, A. H. Grossman, F. Daly, S. Waldman, & F. Schwartz (Eds.), Recreation, leisure, and chronic illness: Therapeutic recreation as intervention in health care (pp. 31-38). New York: Haworth Press, Inc.
- Strauss, A., & Corbin, J. (1990). Grounded theory methodology—An overview. In N. K. Denzin and Y. S. Lincoln (Eds.), Handbook of Qualitative Research (pp. 273-285), Thousand Oaks, CA: Sage Publications.
- Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (Eds.) (1998). Posttraumatic growth: Positive changes in the aftermath of crisis. Mahwah, NJ: Lawerance Erlbaum.
- Zemore, R., Rinholdm, J., Shepel, L. F., & Richards, M. (1990). Some social and emotional consequences of breast cancer and mastectomy: A content analysis of 87 interviews. *Journal* of Psychosocial Oncology, 7(4), 33-44.