

**BREAST CANCER, FEMININITY, EMBODIMENT, AND THE SPORT OF  
DRAGON BOAT RACING**

BREAST CANCER, FEMININITY, EMBODIMENT, AND THE SPORT OF  
DRAGON BOAT RACING

By

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## **ABSTRACT:**

In this dissertation the author provides an analysis of three separate but interrelated aspects of the experiences of women who have been treated for breast cancer and who participate in survivor dragon boat racing.

In the first analysis the author addresses the multiple meanings and functions that this physically intense competitive team sport has for the women. The paper explores some of the reasons why this activity appealed to them and the kinds of impacts and effects that participation in this activity had on their lives. The second analysis offers a critical look at the ways in which breast amputation has been characterised within the medical and breast cancer literature as a threat to women's self identity as female or feminine. The data from this study however demonstrates that women's experiences of breast amputation is much more complex and nuanced than characterised. Also included is an examination of women's own perspectives on this experience, as well as the mediating role that dragon boat racing had on this aspect of self identity. The third analysis focusses on a major theme that emerged from the data which was the transformative effect that competitive dragon boat racing had on women's bodies and on their sense of self. Discussed here are the impacts and effects that participation in competitive dragon boat racing had on women's self identities and bodies and that enabled the women to see themselves as strong, fitter, healthier and "better" than what they were prior to their breast cancer illness experience. Finally, the author concludes with a discussion of how regular participation sport, and especially for women living with a critical illness, can empower women at the individual, group and societal levels.

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## **Introduction: Dragon boat racing among women living with breast cancer.**

A relatively recent and fast-growing phenomenon is emerging all across Canada that involves women living with breast cancer as some of its most avid participants. This phenomenon is the sport of dragon boating. Originating in China more than 2000 years ago, this physically intense and gruelling water sport involves 22 individuals in total, and consists of 20 paddlers, a drummer who sits at the bow of the boat and a steers-person in the stern. The boat itself is 13.5 metres long, weighs anywhere between 800 and 1360 kilograms (Mitchell and Nielsen, 2002) and sports a dragons head at the front.

All-female groups of predominantly middle aged breast cancer survivor teams with names like Abreast in a Boat, Chemo-Savy, Breasts Ahoy and Bosom Buddies are participating in dragon boat competitions across Canada, the US and internationally. They do so with commitment and often with a sense of humour that belies that fact that they are living under the spectre of breast cancer. These women compete not only against each other in breast cancer cups and challenges, but also against co-ed teams consisting of both men and women (for co-ed teams there must be a minimum of eight women in the body). Many of these breast cancer teams are and have remained recreational while others have become or now start out as competitive.

The impetus for dragon boat racing for women living with breast cancer began as the initiative of a Canadian sports medicine practitioner and exercise physiologist Dr. Don McKenzie. Along with 24 women in Vancouver BC in 1996, Dr. McKenzie set out to challenge the prevailing medical opinion that women recovering from treatment for breast cancer should refrain from strenuous physical activity. It was believed at the time that strenuous activity would lead to the development of lymphedema, a painful and persistent swelling of the hand, arm and torso regions. (Harris et al., 2001: Harris & Niesen-Vertommen, 2000)

Formed in 1996 and located in Vancouver BC, “Abreast in a Boat” was the first known team of dragon boat racers consisting of women living with breast cancer (Unruh & Elvin, 2004). After completion of the research study participants were so enthusiastic about their participation in this activity that they decided to continue to paddle and talked to others about their involvement with dragon boat racing (Parry, 2008). Word soon spread throughout the breast cancer community and a social movement was born as participation rates for women living with breast cancer rose steadily (Parry, 2008). According to Parry, “...what started as a small, empirical study has grown to include 93 dragon boat racing teams for breast cancer survivors worldwide, including Canada, the United States, Australia, China, England, Italy, Malaysia, New Zealand, Poland, Singapore and South Africa” (2008: 223).



This dissertation presents an in-depth analysis of the experiences of the women on one of these teams. The team, called “Knot-A-Breast” is located in Hamilton, Ontario, but draws women from across the Golden Horseshoe area (St. Catharines, Niagara Falls, Burlington, Oakville) including communities as far as Orangeville (northwest of Toronto) and Alliston, (in south central Ontario). The team was founded in 1997 by a woman who for the purposes of this study chose the name Mighty Mouse for herself. Mighty Mouse had read about Dr. McKenzie’s study and Abreast in a Boat in an article in *Chatelaine* magazine while recovering from a bilateral mastectomy. A girlfriend had given Mighty Mouse the article because she thought it was something that Mighty Mouse was ready for and capable of doing. Along with having breast cancer, Mighty Mouse also suffered from Lupus erythematosus, a serious and sometimes fatal immune disorder. Looking for an alternative to medically modelled forms of after care support that did not involve sitting and talking about one’s negative illness experiences, Mighty Mouse saw dragon boat racing as an alternative form of self-help that was positive, life affirming and physically oriented.

Under the auspices of her husband’s office (her husband, like Dr. McKenzie, is also a sports medicine doctor) Mighty Mouse contacted Dr. McKenzie by phone and discussed with him her desire to start a dragon boat team. Shortly thereafter she flew out to Vancouver and met with Dr. McKenzie and the women of Abreast in a Boat. Upon her return home, Mighty Mouse began the process of putting a team together. She approached the local television station and a breast cancer support organisation and gave them her name and phone numbers. Within one month 22 women had signed up to paddle.

Practices were held Tuesday evenings and Saturday mornings. The team’s first boat was on loan from the Chinese Business Men’s Association until its fourth year when the women had sufficient funds (from garage and bake sales, BBQs, dance fund-raisers) to purchase their own boat. One of the local yacht clubs allowed the women to use their facilities at no cost. This included a place to dock and store the boat as well as their own clubhouse that served as a change room and storage for their paddles, life jackets and eventually their trophies.

Initially the intent was to get a group of women living with breast cancer together to train for one race, in order to prove to themselves that “we could do this dragon boating thing.” It was at a party that they threw for themselves a week later to celebrate their achievement that several women approached Mighty Mouse about entering other races because of how much they enjoyed paddling and competing. Soon thereafter “Knot-A-Breast” was born.

In its early years the team functioned primarily as a source of recreation and emotional, physical, social and in certain circumstances financial support for its members.

Over the last several years, however, there has been a shift in the team's focus. While the purpose of the team is to continue to support each other, particularly when a team member is re-diagnosed or is facing a crisis, the competitive aspect of the sport has emerged as an important and organising feature. Many team members will describe their team as "a support group on land but a competitive dragon boat team on the water". The decision to become competitive occurred during the team's fourth year and came from the women themselves. After a "disastrous" race (in a high profile venue) in which the boat veered off course and careened into nearby rocks, team members resolved to take this activity more seriously and to improve their racing skills. To do this the team brought in experienced coaches and steerspersons to teach them proper paddling technique and strategy. They began working out regularly, engaging in weight training and conditioning sessions to improve their stamina and over each season the team has increased the physical intensity and duration of their paddling work outs.

At present (season of 2008) there are approximately 50 active paddlers. A second boat was purchased, this time through a government grant, in 2004 in order to accommodate the increasing number of active paddlers. Mighty Mouse continues to act as both the team's president and head coach, and plays a critical role in keeping the team together. Another team member has recently taken on the role of coach for the second boat.

This study is based on five years of intense involvement with the team, starting in the summer of 2002 and ending in the summer of 2007. I began by conducting a series of interviews with individual team members. The interviews were initially semi-structured rather than open-ended because I was interested in exploring specific questions concerning women's experiences of breast cancer and their effects on embodied identity. I encouraged participants, however, to tell their own story. They did, with remarkable openness and frankness. It was through the course of the initial interviews that my focus quickly shifted to include not only the women's experiences of breast cancer, but also their experiences as members of a dragon boat racing team made up of women living with breast cancer.

The individual interviews eventually led, in January of 2003, to participant observation and to my joining the team as a member of the "Support Section" [for a discussion of my first experience in a dragon boat race, see Appendix D.] In the methods section at the end of this introduction, I explain in a much more detailed way what being a member of the "Support Section" entailed. The opportunity to move beyond interviews to actually spending time with the women as a team, practising with them, accompanying them to their races, unwinding and celebrating with them afterwards, and on occasion even paddling with them gave me more intimate access to the group and a much fuller understanding of their experiences. This dissertation is the product of that involvement

and understanding.

### **Structure of the dissertation**

The dissertation takes the shape of a “sandwich thesis.” It consists of three papers, each of which is written as a stand-alone piece. This accounts for some of the repetition that runs through the three papers. Details about the prevalence of breast cancer, for example, the history of dragon boat racing and the methodology I employed in doing the study are replicated in each paper. I have tended to reserve my discussion of some of the relevant theoretical, conceptual and substantive literatures for each of the separate papers.

The first paper addresses the multiple meanings and functions that dragon boat racing had for the women. The paper explores some of the reasons why this activity appealed to the women and the kinds of impacts and effects that participation in this activity had on their lives. The paper represents my initial effort simply to grasp what the experience was like from the women’s perspective. There is an analytical dimension to the paper in the sense that the decision about how to thematically organize what the women had to say was mine. Also throughout the paper I relate what the women had to say to broader issues having to do with their place as women in society. However, a central goal of the paper was to let the women “speak” in their own voices.

The second paper takes a deeper and more critical look at the ways in which the loss of, or changes to, women’s breasts due to treatment for breast cancer have been characterised within the medical and breast cancer literature as a threat to women’s sense of self as feminine or female, and the mediating role and effect that dragon boat racing plays in this experience. Although the paper is less essentially about dragon boat racing and more about gender identity and breast cancer, women’s experiences of dragon boat racing were not irrelevant to this experience. Rather, they play an important role in women’s experiences of femininity post-treatment.

The third paper addresses a major theme that emerged from the data and explores in detail the positive and transformative effects that competitive dragon boat racing had on women’s bodies and their sense of self such that they found themselves feeling “better” than they did prior to their illness experience.

Finally, in the conclusion, I look at a common theme that links the three papers together - the transformative and empowering effects of competitive and team sport for women living with breast cancer.

## **Theoretical Framing**

Each of the three papers in the dissertation is informed by a critical interactionism, a theoretical perspective that emphasises human agency and the interpretive processes through which meanings are constructed, but also attends to the structural inequalities that mediate these processes, including gender inequalities. Critical interactionism blends symbolic interactionism and critical feminist theory.

Symbolic interactionism is based on the foundational work of George Herbert Mead (1934). However, it was Herbert Blumer (1969) who actually coined the term and re-formulated Mead's ideas in the form of three tenets that made symbolic interactionism more accessible to sociologists and other researchers. The three tenets are: 1. Human beings act towards things on the basis of the meanings that those things have for them. 2. These meanings arise out of social interaction. 3. These meanings are handled in, and modified through, an interpretive process.

According to symbolic interactionists, the world is not imbued with intrinsic meaning. Individuals give meaning to, or interpret, the objects, situations and people around them, and then respond not automatically, but on the basis of these meanings. They form these meanings in the context of interaction. The meanings are social products, created in and through the defining or interpretive activities of individuals as they interact and try to fit their lines of action to each other. Moreover, these meanings are not fixed. People are constantly adjusting, revising and modifying the meanings that they attribute to the actions of others. Interaction becomes a constant process of interpreting, negotiating and re-negotiating meaning.

As a perspective, symbolic interactionism focuses on the emergent, multiple and complex ways in which people create and make sense of their life-worlds in tandem with others, including the ways in which they conduct themselves on a day to day basis (Prus, 1996). Society, its institution, habits and 'ways of being' are seen as socially constituted, reproduced and maintained through the collective actions and meaning-making activities of social actors. Human society is seen as the result of collectivities of people engaging in purposive action (Blumer, 1969).

Though symbolic interactionism has influenced a generation of sociologists to focus on meaning-making and interpretive processes, it has also generated critics. Among the most persistent of the arguments that have been made against the perspective is the charge that it is astructural and does not take sufficient account of the constraints on individuals. Missing from symbolic interactionism's conceptualisation of social life is an analysis of the ways in which social structure and the relationships and practices of power shape and inform the interactive and meaning-making activities of individuals. According

to Bilton, et al., (2002: 362) “interactionism offers neither a theory of power nor a theory of patterns of inequality.”

Feminists in particular have been critical of symbolic interactionism’s indifference to the conditions of women’s material and daily lives and the gendered social relationships and practices of power that constitute and shape their life worlds. While feminist scholarship shares with symbolic interactionism an interest in the lived experiences of social actors, particularly women, many feminists argue that what is needed is an approach that makes visible “the structures, practices, and inequities of the gendered social order” (Lorber, 2005: 11).

Out of these criticisms has come a more critical interactionism that marries feminist perspectives, and their concern for the gendered nature of social life, with the traditional concerns of symbolic interactionism. What distinguishes this more feminist and critical interactionism is the focus on how everyday practices sustain or disrupt gender inequalities. An example of how this perspective has been used is offered in the work of West and Zimmerman (1987) who use both feminist and interactionist insights to explain how people “do gender” through their routine conversations and interactions. Similarly, in a series of papers edited by Deegan and Hill (1987) titled *Women and Symbolic Interactionism*, while the concern is on women’s issues and women’s perspectives, these are considered always through the lens of women’s disadvantaged place in a fundamentally patriarchal society. In this study as well, my goal is to prioritize and highlight the women’s own experiences. However, I argue that it is impossible to fully understand these experiences without taking gendered practices and relations into account.

Each of the three papers is also informed by a large body of literature on Western’s medicine’s relationship with women and their health care concerns which has itself been influenced by feminist perspectives. Western medicine’s history of ignoring, dismissing and neglecting the health care claims and needs of particular groups of women has been well documented (Alexanderson, 1999; Ehrenreich & English, 1978; Eichler et al., 1992; Randsall, 2001; Zimmerman, 2000). As a powerful and key definer of social reality, medicine has played and continues to play an instrumental role in constructing and representing women’s bodies and physiological processes as deviant and pathological, and their physical capabilities as limited and inferior. These representations can be found throughout numerous medical texts and discursive practices, including popular, quasi and pseudo-scientific texts and representations of female biology and physiology (Fausto-Sterling, 1992; Findlay & Miller, 1994; Giacomini, et al., 1986; Martin, 1992; Riessman, 1983). Based on beliefs and assumptions about the natural inferiority of the female body (in comparison to the male body), the medical profession continues to represent women as a complicated “other”, subjugated to, and overdetermined by, physiological, biological

and reproductive processes that are perceived as naturally limiting women's full participation in social life. Naturally occurring biological events in women lives, such as menstruation, pregnancy, childbirth and menopause (Kohler-Reissman, 1983; Walters, 1991) have been medicalised to varying degrees and conceptualised as medical problems in need of intervention (Graham & Oakley, 1981; Kohler-Reissman, 1989; Griffiths, 1999; Eichler et al., 1992; Blum & Stracuzzi, 2001). They have also been constructed as damaging and potentially dangerous to women's physical and mental health and well-being (Hanson, 2001; Culpepper, 1978; Meyer, 2001).

The assumptions often made about women by those who take a Western medicine perspective are reflected in the roots of the dragon boat racing phenomenon among women with breast cancer. Dragon boat racing among this group originated largely in response to an approach to breast cancer after-care that was prevalent at the time and that to some extent still exists today.<sup>1</sup> The first challenge to conventional medical wisdom came out of medicine itself, with studies such as Harris and Niesen-Vertimmen (2000: 95) who argued that the usual advice given to women was "wholly unsubstantiated by research" and that it compromised the "quality of life of women living with breast cancer by limiting their participation in many competitive or recreational activities." Harris and Niesen-Vertimmen found that women who underwent axillary dissection (including radiation) for breast cancer and who participated in an upper extremity strengthening and aerobic conditioning program in preparation for dragon boat racing, were able to safely participate in strenuous upper extremity exercise without incurring the side effects of lymphedema. They found as well that these women experienced a whole series of other health improvements including increased flexibility and range of motion, increased physical fitness, and enhanced feelings of psychological well-being (McKenzie, 1998; Harris and Niesen-Vertimmen, 2000).

As significant as this challenge was, however, it was limited in its critique because it framed the failure on the part of the medical profession to substantiate its recommended

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<sup>1</sup> Guidelines for the on-going management of women's after treatment care for breast cancer are limited (i.e. guideline for the management of lymphedema, 2001) and treatment protocols depend on where one lives and which health care professionals oversee the care provided (Gillham, 1994). Thus it is no wonder that physical therapists, surgeons and other health care professionals continue to encourage women who have had axillary dissection (the removal of lymph nodes as a means of inferring whether or not cancer cells are elsewhere in the body) to avoid using the affected arm to lift anything more than 10 pounds (Radina and Armer, 2001), and to refrain from engaging in "vigorous, repetitive or excessive upper body exercise" (Harris and Neisen-Vertimmen, 2000: 95).

courses of treatment as simply outdated “dogmas entrenched from the 1950s and ‘60s”, or as the result of the conservatism of individual physicians who “tend to err on the side of caution” (Kent, 1996: 969). Missing from the critique was any recognition of the larger context for the relationship between the medical profession and women’s health care concerns. A consideration of this larger context raises the issue of whether the absence of standardised follow-up and the unsubstantiated claims about women’s physical capabilities and limits after treatment for breast cancer is yet another example of the indifference and neglect that often characterises Western medicine’s attitudes towards women and their health problems. That there is still uncertainty about how best to deal with women recovering from breast cancer may in part be a reflection of cultural beliefs and values that continue to shape and permeate medical discourses and practices concerning women and their health needs.

The rise and increasing popularity of dragon boat racing among women living with breast cancer needs to be located within a complex articulation of medical discursive practices and gendered social relations. Although this activity began as a reaction against unsubstantiated medical claims and as a way to promote the idea of “getting women back to normal activity following breast cancer treatment without fear” (Kent, 1996: 969), the increasing popularity of this activity suggests that it has become much more than this. The practice of dragon boat racing for women living with breast cancer has taken on a whole series of other meanings, and has given rise to a number of positive and transformative effects, which are reflected in the experiences of the particular group of women who are the focus of this study.

## **Related Studies**

There are now several studies that have looked at the experience of dragon boating among women living with breast cancer. Some of these studies have addressed the impact of this activity on women’s lives with a focus on understanding the mechanisms of psychosocial support and post-treatment needs of women living with breast cancer (Mitchell & Neilsen, 2002; Mitchell et al., 2007), women’s psychological well-being (Unruh & Elvin, 2004), and on the role of dragon boat racing in breast cancer survivorship as a life long dynamic process (Parry, 2007). Other studies that have addressed the experience of dragon boating have done so through a physiological-rehabilitative lens. These include a study on exercise adherence within a theoretical model of exercise promotion (centring around issues of non-compliance behaviours) (Courneya et al. 2001), health related quality of life measures with a focus on team cohesiveness (Culos-Reed et al. 2005), and the minimising and management of risk of lymphedema (Harris & Neisen-Vertommen, 2000; Lane et al., 2005; McKenzie, 1998).

Of particular relevance are the qualitative studies on breast cancer survivors' experiences of dragon boat racing. Two initial qualitative pilot studies by Mitchell & Nielsen (2002) and Unruh & Elvin (2004) also focus on the experiences, meanings and psychosocial impacts of this activity on women living with breast cancer. Several of the themes that emerged in those studies are similar to themes found in this research initiative. However, there were other themes that were noted in this study that were not found in the others. Although important initial forays into the experience of dragon boat racing among women living with breast cancer, the focus of these other studies are 'health measures and quality of life assessment' perspectives in which the experience and significance of dragon boating is framed within the context of its rehabilitative, ameliorative and coping effects. These studies are for the most part descriptive and tend not to locate the experience of dragon boating for this group of women within the larger context and complexities of women's daily lives. Although my study also addresses the meanings that dragon boat racing has for women living with breast cancer, I offer a more in-depth analysis of this experience and link it to more broader issues having to do with gender.

## **Methodology**

In the remainder of this chapter I describe how this study was conducted. I begin by explaining how I became involved with this dragon boat team and how they became the focus of my research. I go on to describe the ways in which I collected data that were relevant to my analysis. I include a discussion of the interviews I conducted and my role as a participant observer. I end with a detailed description of the women who participated in the study.

### **Entry into the group**

This dissertation did not initially begin as a study of a women's breast cancer dragon boat team but more generally as a study of women with breast cancer. I wanted to study the effects of mastectomy on embodied femininity. However, when I mentioned to someone I knew that I was having difficulties figuring out how I was going to recruit participants, the suggestion was made that I might want to approach the members of a dragon boat racing team nearby. As our conversation about the team continued, I discovered that I knew the woman who had founded it.

Shortly thereafter, I contacted the founder of the team, told her who I was, informed her about my study and asked her if she would be willing to let me talk to the women on the team about participating. There was tremendous enthusiasm for the study from the start. The team's founder was elated that I had thought of the team and that I had contacted her. The woman, whom I will refer to here on in by the pseudonym she



eventually chose for herself as a participant in this study<sup>2</sup> -“Mighty Mouse” - responded positively and agreed to facilitate my access to the team. I explained to her that there would be a lag while I went through the process of obtaining ethics clearance for my study. When, after several months, she had not heard back from me, she contacted me to see if I was still interested. By that point the ethics review process was close to coming to an end.

Gaining access or entry into the field is a central problem facing all researchers. This often involves processes of negotiation and renegotiation which takes place throughout the research experience and can shape the type of research that can be conducted (Geer, 1970 in Shaffir et al., 1994). Access to the field can also be impeded or controlled by ‘gatekeepers’, individuals within the organisation who have the power to grant or deny access to people or situations that are integral to the research process (Shaffir et al., 1994; Taylor & Bogan, 1984). However, for this study, from the point I made contact with Mighty Mouse, my entry into the field and sustained access to the group was unproblematic. As a gatekeeper, Mighty Mouse was as enthusiastic about my research project as I was and keen on having the team members’ individuals stories told.

Once my ethics clearance came through, Mighty Mouse and I made arrangements for me to meet the women on the team. At Mighty Mouse’s suggestion I joined the team at a Saturday morning practice in August 2002 at a local marina that allowed the team to use their facilities (docks, clubhouse and mainhouse) at no charge. I cannot recall what I was expecting prior to arriving except that I know that I was focussed on the opportunity I would have to recruit interviewees for my study as I had originally conceived it. I do recall, however, being struck by the sight of 30+ women preparing themselves to get into a large boat with an imposing dragon’s head carved out at the front of it.

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<sup>2</sup> I asked the women formally interviewed for the study to provide me with a pseudonym that they would like used if I made reference to something they said or quoted them in the dissertation. Some had names at their fingertips to suggest. Many explained that they were selecting names that they liked or names that had symbolic significance for them. Other women had difficulty coming up with a pseudonym and told me to select one for them. I chose names of celebrities I connected with the women. “Meryl” was named after Meryl Streep because she worked part-time as a movie extra. “Sophia” was Italian and wore large sunglasses similar to those worn by Sophia Loren. An advantage of having on-going contact with the groups was that I was able to ask these women if they liked the names or preferred another. All of the women stayed with the names chosen.

Within moments of my arrival Mighty Mouse introduced me to the team. I briefly explained to them why I was there, letting them know that I would be interested in talking to anyone who felt comfortable talking about their breast cancer experiences. Mighty Mouse suggested that I hang around so that if anyone had questions or wanted to know more about the study they could approach me over the course of the morning. As the boat holds only 20 paddlers at a time, I walked with the remaining team members over to the site where the boat docks as the second set of paddlers wait to take their turn at paddling. Conversation about my study continued. I circulated a sign-up sheet so that those who were interested in being interviewed could provide me with their contact information. When the first set of paddlers returned, I did the same with that group. I left that first morning with twenty-eight names.

Not long after that I met with my dissertation committee. Sensing my excitement about dragon boat racing, my committee raised the question of whether I wanted to alter the focus of the study so that rather than looking at the breast cancer experience more broadly, I would be looking at it in relation to the participation of these women in dragon boat racing. The shift was one that I welcomed since I felt even at the early stage that what the women had to say about their breast cancer experiences would be integrally tied with their decision to pursue dragon boat racing.

### **Data Collection**

The shift in focus brought with it a shift in my methodology. In addition to the interviews, I incorporated participant observation in my data gathering strategy.

**Interviews:** Interviewing began almost as soon as I made contact with the women in the summer of 2002. The formal interviews ended the fall of that same year. However my more casual conversations continued until I began to pull away from the group. Interviews were semi-structured rather than completely open-ended because I was interested in exploring specific aspects of the women's experiences of breast cancer, including its impacts if any on their embodied identity. Nevertheless, I encouraged participants to speak openly and to tell their own stories. I used prompts and follow-up questions to elicit a breadth and depth in responses (Breakwell, 1995), and to allow women the opportunity to "reveal in their own words their view of their entire life, or part of it, or some aspect of themselves" (Bogdan & Taylor, 1975:6). Of the 31 formal interviews, 26 were transcribed (this owing to time and financial constraints) and were used in this study. Most interviews lasted between one and one-half hours, although there were a few that lasted longer, the longest lasting five hours.

At the time of the interviews there were two men who were members of the team. Mighty Mouse asked me to interview them if they wished; it appeared important to her

that the men not be made to feel excluded. Not wanting to jeopardise my access to the women in the group, I agreed. However, the men's responses were not included in my analysis since the question of men's experiences of breast cancer was beyond the scope of my study. Having said this, the two interviews with the men were rich in interesting insights and generated a myriad of questions to which I hope one day to return.

All of the women who initially put their contact information on the sign-up sheet were interviewed but one.<sup>3</sup> The interviews were conducted in a location of the interviewee's choice. Most women chose to be interviewed in their homes, but a few interviews were done at the clubhouse after either evening or early morning practices. One interview was conducted at the university. The interviews were audio-taped and transcribed with participants' permission.

**Participant Observation:** Participant observation has been defined "as a period of intense social interaction between the researcher and the subjects, in the milieu of the latter" (Bogdan and Taylor, 1975:5). By the time the scope of my project had broadened to include the dragon boat racing dimensions of the women's experiences, I was already spending more time with the women as a team. During the initial period of observation, in January of 2003, I participated in the evening paddling sessions at a local pool and joined several women afterwards for drinks at a local pub. I also regularly participated in the Saturday morning weight training sessions with the team. When the summer paddling season began I attended the bi-weekly paddling practices but usually observed the team from the safety boat that followed the team when they were out on the water. During the first two years of observation, I was on occasion allowed to paddle with the team when they were short of members. Later in 2004, when the team purchased a second boat in order to accommodate an increase in membership, I was invited to paddle regularly with the team in order to help fill the boat.

Participant observation throughout these years also included helping out with fundraising events, attending team general meetings, holiday parties and travelling with

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Recently, in a conversation with this woman, I discovered why she declined to be interviewed after initially putting her name down. She said that she was shy and unsure of herself at the time, and that she had second thoughts about her ability to talk to someone about her breast cancer. Over the course of the study, however, we got to know each other much better and had numerous occasions to talk. This woman had just competed in an Ironman competition at the age of 64 and who, until the age of 60, was a non-swimmer and terrified of the water. She attributes her dragon boat experience with giving her the courage to challenge herself physically and emotionally.

the team to racing events. Apart from getting together for team-related activities, the women also supported those among them who were experiencing a recurrence of their cancer or who were dying. I joined them in these activities as well - cleaning the women's houses, running errands, driving them to medical appointments, minding children and preparing meals. In the spring of 2003 I travelled with the team to Vancouver to attend a breast cancer survivor festival that included breast cancer teams from across Canada, the United States and other parts of the world.

The nature of my participation was such that I took on a "active membership role" from the outset and became "more involved in the setting's central activities, assuming responsibilities that advance the group, but without fully committing [to] the members' values and goals" (Adler and Adler, 1994: 380). My separation from the rest of the group was not necessarily the result of any reluctance on my part to become a full member or a decision on my part to remain aloof from the group for the sake of "assuming a professional stance" (Haas & Shaffir, 1994). Rather, the separation came out of not having breast cancer. Full membership was simply unavailable to me. Having breast cancer was a necessary condition for membership; my interest in, and willingness to connect myself as much as possible with the team made it possible for me to achieve the status of an "support member"<sup>4</sup> among them, but not having experienced breast cancer I was never able to become fully "one of the group". I was embraced by the team, but my status as a peripheral or support member - an 'outsider' - was always clear. Indeed, my relationship to the group was openly reiterated each time a potential new member was introduced. I was usually introduced with some variation on the following script: "And this is our Rhona. She is a Ph.D. student who is studying us. She doesn't have breast cancer." Although I was allowed to race with "newbees" (new recruits to the team) or as part of a "fun-boat" team in non-breast cancer cup races, there was never any question of my participating in any of the breast cancer competitive races, since the rules would not have allowed it.

A persistent issue for those who do ethnographic research is the extent to which the researcher comes to identify with the group and loses objectivity. The danger of "going native" is considered by some to be one of the pitfalls of qualitative research (Fontana & Frey, 1994: 367). In my case, I never hesitated to take advantage of any opportunity that presented itself to get closer to the group and to become involved in any

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<sup>4</sup> As well as myself, other "support members" included "Clint" who drove the safety boat and who was married to Gabby, "Chip" the husband of Mighty Mouse and "team physician" and "HT", Mighty Mouse's mother who attended many races and who would often recite a poem as part of the breast cancer ceremonies that were held at the venues where there were breast cancer challenges.

of the activities that were open to me. In part I felt an obligation to “give back” (Scanlon, 1993) to the team as a way of thanking them for their willingness to participate in my research.

However, I also feel strongly that my “going native” or at least as far “native” as I possibly could go as a woman not living with breast cancer, benefited the study. After all, the goal of my study was precisely to capture the perspectives of those I was studying. While I could not fully experience what it is like to be a breast cancer survivor nor to face one’s own mortality in the way that these women do, I could at least feel what it was like to be a member of a dragon boat racing team.<sup>5</sup> In my view this experience was critical. It contextualised for me what the women were saying; it gave me first hand understanding of the dragon boat experience; it also allowed me to ‘connect’ with the women in ways that established trust relationships and invited them to be more open about their experiences. Like them, I had gone through the rigours and pain of learning how to dragon boat race and was now a “dragon boat survivor”. Like them, I experienced the intense throe and exhilaration of dragon boat racing.

### **Leaving the group**

According to Maines, Shaffir & Throwetz et al., (1980) leaving the field is related to the structures of commitment that are created during the period of research. The leaving process, they state, “is an aspect of an ongoing interplay between field circumstances and the way in which the researcher negotiates social relationships and a workable identity”(1980: 273 in Shaffir & Stebbins, 1994: 2007). In the discussion above, I highlighted the ‘upside’ of the kind of the closeness I was able to establish with the team. For all of the benefits connected with this closeness, however, there were ‘downsides’ as well, the most significant of which was the challenge involved in leaving the setting.

Withdrawal from the dragon boat team after several years of regular and frequent contact was difficult for me because of the many close relationships and friendships that I had established. These relationships had been forged in deeply intense and emotionally charged experiences, both positive and negative. There had been euphoric moments of victory and triumph connected with the winning of big races; there had also been the dark moments of seeing team members die. “Drifting off” (Glaser & Strauss, 1967) - a common strategy for exiting the field - was not going to work in this particular context.

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<sup>5</sup> Attached in the appendices is a short paper detailing my first-hand and harrowing experience of competitive dragon boat racing.

Instead, I opted to pursue a strategy of “easing out” (Junker, 1960). In September of 2005 I began to participate less in the groups’ activities, and I was careful to explain why I was less available. The team members knew that after three years I was under pressure to produce my dissertation and that I had entered a phase in my study where most of my time was spent writing. I kept in touch with a few of the women to whom I felt closest. They relayed news about the team to me and brought me news of how I was doing back to the team. Through this process of gradual disengagement I would from time to time ‘check in’ with the team, participating in a paddling practice or attending a race to cheer the group on. A clearer break with the group occurred in the fall of 2007 when I decided to take up a research position at the University of Saskatchewan. This meant a geographical separation from the team. However, I remain in email contact with several members, talk to others from time to time by phone and get together with team members with I return to Ontario.

## **Analysis**

In keeping with the interpretive approach I take in this dissertation, the focus in relation to both the interviews and participant observation was on “people’s own written or spoken words and observable behaviour” (Bogdan & Taylor, 1975:4). The collection and analysis of the data was informed by the inductive grounded methodology of Glaser and Strauss (1967) and Strauss and Corbin (1990). Grounded theory is a general approach to research that emphasises the need to develop theory that is grounded in data which has been systematically gathered and comparatively analysed. Also known as the constant comparative method, grounded theory rejects the notion of working with pre-conceived hypotheses and gathering data only for the purposes of verifying or confirming these hypotheses. Instead, the object is to start with data, to generate theory on the basis of the data and, through a process of constantly comparing additional instances of the same phenomenon, to elaborate on and modify theory to increasingly higher levels of abstraction (Strauss & Corbin, 1994).

While I started my study with a loose set of questions related to women, their bodies and breast cancer, I was open to what the data had to say. My initial set of interviews and observations yielded a wide set of themes and categories. As the study progressed I made decisions about which of these themes seemed most promising or significant. I would incorporate more focussed questions around those themes into subsequent interviews and concentrate my observations in ways that elaborated on these themes. For example, early in the interviews it became clear that the women were experiencing positive changes to both their selves and to embodiment as a result of their participation in dragon boat racing so I began to ask the women questions that explored these aspects of their experiences in greater detail.

## **The group**

As a group, this team of dragon boat racers was fairly homogenous, including the group of women that I interviewed. During the five years that I was with the team membership grew from approximately fifty members (including approximately ten women who no longer paddled but remained as associates), to over seventy members, forty-nine of which are active paddlers. Associate members usually are women who once paddled but no longer do because of physical limitations or because they have moved onto other interests in their lives but wish to maintain some contact or association with the team. Often these women will attend or help out with fund-raisers and from time to time will come out to watch the team compete.

Of the 26 women whose interviews were used for this study, 22 were married; 4 were either single or never married. All of the women but one identified as heterosexual. One woman stated that she was neither heterosexual or homosexual, (the explanation offered was that she was not sexually active). At the time of the interviews, the ages ranged between 29 and 73 years. All of the women were Christians (Roman Catholic, Anglican or Protestant); one woman described herself as agnostic. In terms of ethnic identity, all of the participants but two identified as Canadian. The two exceptions identified themselves as Italian. Further probing about ethnic backgrounds led to the women describing themselves as having either European or Anglo-Saxon roots. There were no women of colour involved with this group at the time of the interviews. With regards to education, 13 of the 26 women had attended or completed university, 9 had attended or completed college and 4 women had completed high school. Eight women were retired, one was on short term disability as a result of recurrence of her cancer, two were self employed, 13 worked full-time, one worked part-time and one described herself as a "domestic goddess" who engaged in volunteer activity from time to time. Teaching and nursing were the most popular occupations; the rest of the women were in banking, retail, clerical, real estate, television, printing and cosmetics. The annual combined family incomes ranged between CAN\$ 20,000 and CAN\$ 100,000+. Five women had family incomes between CAN\$ 60,000 - 80,000, seven were in the range of CAN\$ 80,000 - 100,000, another seven had family incomes over CAN\$ 100,000 and five were in the range of CAN\$ 20,000 - 60,000. Among the lowest earners were those who were single and a few who were retired. One women refused to disclose financial information; another said that she had no idea about her family income. In sum, the women tended to be white, well educated, relatively affluent and professional. This is a demographic that is characteristic of most breast cancer support and self help groups (Gray, et al., 1997) and is also characteristic of most women's amateur athletic teams (Deem, 1987; Sternfeld et al., 1999).

At the time of writing, three of the women interviewed have died as a result of

their cancer metastasising, and another four have been treated for localised recurrences. The average age of the women interviewed was 50, the average age at cancer diagnosis was 43, and the average age since diagnosis was seven years. With regards to type of breast cancer treatments, two women had bilateral mastectomies, four had lumpectomies, nine had segmental mastectomies and 10 had total mastectomies.

The medical treatments that the women had received varied depending on their diagnosis - the type of cancer they had (ductual, lobular, inflammatory, etc.), the stage it had reached (size of the tumour, if there is lymph node involvement and if the cancer has spread beyond the lymph glands), and its grade (growth rate (slow or fast) of cancer cells).<sup>6</sup> Seven women received radiation therapy, nine received chemotherapy and six women received both. Nine women were taking Tamoxifen, a drug used to treat and manage women's breast cancer if it is estrogen fed. Five of the women had reconstructive surgery. Several women had a range of other conditions they were dealing with besides cancer, including fibromyalgia, lupus, scoliosis, arthritis, bad backs; some had been treated for other cancers such as ovarian, uterine and thyroid cancer. Five of the women interviewed were unable to paddle regularly because of health conditions; the remaining 21 were symptom free through the time I was with them.

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<sup>6</sup> [Http://www.cancerbackup.org.uk/Cancertype/Breast/Causesdiagnosis/Staginggrading#5542](http://www.cancerbackup.org.uk/Cancertype/Breast/Causesdiagnosis/Staginggrading#5542)



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## **Paper 1: “It Means Everything To Me:” Breast Cancer And Dragon Boat Racing.**

Breast cancer remains the most common cancer among Canadian women. Although one in nine women is expected to develop breast cancer during her lifetime, and the breast cancer incidence rate in Canada is among the highest in the world,<sup>7</sup> treatment protocols depend on where one lives and which health care professionals oversee one's care (Gillham, 1994).

A growing number of women dealing with the experience of having been diagnosed with and treated for breast cancer are turning to the sport of dragon boat racing. The dragon boat racing phenomenon among women with breast cancer started in the Vancouver BC and was a research initiative of a Canadian sports medicine practitioner and exercise physiologist Dr. Don McKenzie. The intention was to challenge the predominant medical opinion that women recovering from treatment for breast cancer should abstain from repetitive and strenuous physical activity. Popular at the time was the belief that intensive upper body physicality would lead to the development of lymphedema, a painful and persistent swelling of the hand, arm and torso regions (Harris et al., 200; Harris & Niesen-Vertommen, 2000).

So popular was this activity among the women research participants that they decided to form a team and continue to paddle. Thus it was in 1996 in Vancouver BC, that the first known team of dragon boat racers consisting of women living with breast cancer was formed. The women called themselves “Abreast in a Boat” (Unruh & Elvin, 2004). Soon thereafter word spread throughout the breast cancer community and a social movement was born and participation rates for women living with breast cancer continue to rise to date (Parry, 2008). At present, it is estimated that there are over 93 dragon breast cancer survivor boat racing teams worldwide, and can be found across Canada and the United States, as well as in Australia, China, England, Italy, Malaysia, New Zealand, Poland, Singapore and South Africa (Parry, 2008).

The growth of the dragon boat racing phenomenon among women living with breast cancer has generated some scholarly interest in recent years. There are now several studies that have looked at the experience of dragon boating among this group of women. Some of these studies have examined the role of dragon boat racing in breast cancer survivorship as a life long dynamic process (Parry, 2007). Other studies have looked at the experience of dragon boating through a physiological-rehabilitative lens. These include a study on adherence and compliance with dragon-boat racing as a part of an exercise promotion program for women living with breast cancer (Courneya et al., 2001),

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<sup>7</sup> Canadian Cancer Society ([www.cancer.ca](http://www.cancer.ca))

a study on health-related quality of life measures with a focus on team cohesiveness (Culos-Reed et al. 2005), and studies on minimizing and managing the risk of lymphedema among women who participate in dragon boat racing (Harris and Neisen-Vertommen, 2000; Laneet al., 2005; McKenzie, 1998).

Of particular interest are two qualitative studies on breast cancer survivors' experiences of dragon boat racing. Mitchell and Nielsen (2002) and Unruh and Elvin (2004) focus on the psycho-social impact of dragon boat racing on women living with breast cancer. Both studies emphasize health-related quality of life assessments in the approach that they take; the significance of dragon boating is framed within the context of its rehabilitative, ameliorative and coping benefits. Neither study really emphasizes the larger context of women's daily lives including the gendered social relations and practices that shape their experiences.

In this paper I present the findings of a qualitative study conducted between July 2002 and September 2007 among women who make up a dragon boat racing team located in a mid-sized urban centre in Ontario, Canada. My concern is to lay out the multiple meanings that dragon boat racing had for this group. I begin by presenting, as far as possible in the women's own voices, their ways of thinking about dragon boat racing and its relevance in their lives. What this presentation of predominant themes in the women's talk will show, however, is that two important contexts come together to play a critical role in mediating and shaping their experiences. These include the fact that they are living with breast cancer and that they are women in a world where gendered social relations and practices shape women's experiences of sport and leisure. The latter part of the paper turns to a discussion of these two contexts and their significance in understanding the women's experiences.

## **Methods**

Two data collection techniques were utilized in this study. The first consisted of in-depth interviews that became more open-ended as they proceeded. Participants were encouraged to tell their own stories, and unscheduled prompts and follow up questions were utilised in order to elicit a breadth and depth in responses (Breakwell, 1995). This was to allow women to "reveal in their own words their view of their entire life, or part of it, or some aspect of themselves" (Bogdon and Taylor, 1975:6). Of the thirty one women interviewed, twenty-six tapes were transcribed (this owing to time and financial constraints) and were used in this study. Most of the interviews lasted between one and one-half hours, although there were a few that lasted longer, the longest taking five hours. Interviews were conducted, and audio-taped after consent was obtained, in a place of the interviewee's choice, which was usually in her home. Some interviews were conducted at the team clubhouse after practices and one interview was conducted at the university. The

interviews were transcribed verbatim and were read and reread in order to identify recurrent themes and sub-themes both within and between participants accounts.

Like other qualitative approaches the focus here was on the interpretive, on “people’s own written or spoken words and observable behaviour” (Bogden and Taylor, 4). In keeping with the spirit of this research tradition, there was no intent to quantify the experiences of these women but rather to capture the subtleties and complexities of their lives as women living with breast cancer who dragon boat. The collection and analysis of the data was informed by the inductive grounded methodology of Glaser and Strauss (1967) and Strauss and Corbin (1990) which is a general methodology for developing theory that is grounded in data that is systematically gathered and comparatively analysed. Also known as the constant comparative method, theory is generated initially from the data, or if an existing grounded theory, is elaborated on and modified as new data is carefully compared against it (Strauss and Corbin, 1990). At the beginning of the interview process I was sensitive to the themes and analytical categories that were initiated by the respondents themselves and incorporated them, when appropriate, into the list of questions for subsequent interviews. I conducted an analysis of the first 15 transcribed interviews in order to get a sense of the data and to discern the predominant themes and categories. This informed the analysis of the 11 remaining interviews.

A second technique, participant observation, which is “characterised by a period of intense social interaction between the researcher and the subjects, in the milieu of the latter” (Bogdon and Taylor, 1975:5) was also employed and continued for five years. The decision to engage in participant observation was a secondary consideration and emerged as I became involved with the group as a “support member”. As a result of my participation, I took on a “active membership role” and became “more involved in the setting’s central activities, assuming responsibilities that advance the group, but without fully committing [to] the members’ values and goals” (Adler and Adler, 1994: 380). Regular contact and interaction with the group as a whole began in January 2003 when the team began their winter training for the racing season. These training sessions consisted of weekly weight work outs and paddling sessions at a local swimming pool. I also joined the team for the bi-weekly on-water paddling practices that began mid-May of that same year when they were able to safely take to the water. I participated in these activities with the team regularly and joined the small but regular group of women for drinks at a local pub after pool and paddling practices. I also attended various team activities and travelled with the team to many of their regular season dragon boat competitions. I was invited to and attended the 10<sup>th</sup> year anniversary celebration of the first breast cancer dragon boat team in Vancouver BC in June of 2003 with the team. Participant observation ended after the 2007 season.



## The group

As a group, this team of dragon boat racers was fairly homogenous (similar in social class, ethnicity, sexual orientation, marital status, most had children) including the group of 26 women that I interviewed. During the five years that I was with the team, membership grew from approximately fifty members in 2002 (including approximately ten women who no longer paddled but remained as associates), to over seventy members by the end of the summer of 2007. Of those seventy members forty-nine were active paddlers. Associate members were usually women who once paddled but no longer could due to physical limitations or because they had moved onto other interests but wished to maintain some contact or association with the team. Often these women would attend or help out with fund-raisers and from time to time would come out to watch the team compete.

Of the 26 women whose interviews were used for this study, 22 were married; 4 were either single or never married. All of the women but one identified as heterosexual, and one woman stated that she was neither hetero or homosexual. At the time of the interviews, the women's ages ranged between 29 and 73 years. All of the women were of the Christian faith except one woman who said that she was agnostic. All of the interviewees but two identified as Canadian, and with further probing identified as either European or Anglo-Saxon. There were no women of colour involved with this group at the time of the interviews. Half of the women had attended or completed university, while 9 women had attended or completed college and 4 had completed high school. The annual combined family incomes ranged between CAN\$ 20,000 and CAN\$ 100,000+. One woman refused to disclose financial information and another said that she had no idea what her family income was. This particular group of women were white, well educated, affluent and professional, a demographic that appears to be characteristic of most breast cancer support and self help groups (Gray, et al., 1997) and women's athletic teams (Deem, 1987; Sternfeld et al., 1999).

The medical treatments that the women had received varied depending on their diagnosis - the type of cancer they had (ductal, lobular, inflammatory, etc., ), the stage it had reached (size of the tumour, if there is lymph node involvement and if the cancer has spread beyond the lymph glands), and its grade (growth rate (slow or fast) of cancer cells).<sup>8</sup> Seven women received radiation therapy, nine received chemotherapy and six women received both. Nine women were taking Tamoxifen, a drug used to treat and manage women's breast cancer if it is estrogen fed. Five of the women had reconstructive

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<sup>8</sup> <http://www.cancerbackup.org.uk/Cancertype/Breast/Causesdiagnosis/Staginggrading#5542>

surgery. Several women had a range of other conditions they were dealing with besides cancer, including fibromyalgia, lupus, scoliosis, arthritis, bad backs; some had been treated for other cancers such as ovarian, uterine and thyroid cancer. Five of the women interviewed were unable to paddle regularly because of health conditions; the remaining 21 were symptom free through the time I was with them.

## **Findings**

What attracts women who are facing the threat that breast cancer represents to an activity such as dragon boat racing? Dragon boating is an intense physical activity that involves the development of upper body strength and cardio-vascular stamina. Practices involve long hours of endurance training as well as sets of exercises that develop physical (upper body) power and speed. Dragon boating is not for the faint hearted and not everyone returns after their first encounter with the team. Through the time that I spent with the team and participated in the paddling practices there were many occasions where women would come out either to observe or even begin practising with the team only to decide that dragon boating was not for them. Some offered explanations for their departure, suggesting that they found the activity too strenuous or that the connection of the team to breast cancer was too much of a reminder of their own breast cancer; others just simply never returned.

While it is difficult to discuss in any detailed way why women did not come back, the appeal of dragon boat racing for those who continued with it was easily discernible in the ways the women talked about their involvement with the sport. The majority of those who ultimately joined the dragon boat team were women who had been physically active intermittently throughout their adults lives or those who had enjoyed physical activity early in their lives but whose involvement with physical and recreational endeavours had been interrupted by the demands of work, marriage and children. They were, for the most part, women who enjoyed physical activity for its own sake and not simply as a means of keeping body weight down and keeping slim. Many of them had prior experience more specifically with water sports such as canoeing, kayaking and water skiing and described themselves as "water people". Part of the appeal of dragon boating for many of them had to do with the fact that it was a water-based recreational activity.

For all of the women dragon boating came to represent so much more than merely the opportunity to participate in an exciting and challenging sport. There were a number of recurrent and overlapping themes that emerged in the women's discussions of dragon boat racing and its significance in their lives. Among them were the dragon boat racing team as: a) an alternative to traditional forms of breast cancer support; b) a source of friendship; c) a source of pride, achievement and empowerment; d) a transformative personal experience; e) life affirming; f) a safe place, and g) a time to oneself.

## **An alternative to traditional forms of breast cancer support**

Many of the women had come to count on their fellow team members for social and emotional support and thought of the team as a support group.

We call ourselves a floating support group. (Lola)

However, in several of the women's responses it was evident that they did not regard all support groups as 'created equally' and that the dragon boat team offered them support of a different sort. Several women had been a part of conventional support groups for many years and benefited from their association with such groups, but found themselves wanting something different. Their participation in dragon boat racing did not necessarily represent a rejection of traditional forms of support but rather that they were seeking out an alternative. Others, however, had difficulty with conventional groups from the start, finding them "heavy" and "depressing" and felt in need of something else. Macaulay, for example, admitted that she was put off by what she saw as the "poor me" atmosphere that permeated the traditional peer support group she had once tried:

I went to one of those (support groups). They were awful. A lot of the girls in the group went to another one and hated it. [*Did they say why?*] They were so down. I went to one and it was like poor me. It was awful. Oh, and I'm like why are we here? .....Oh, the room was dark and every body was sad and it was all horror stories. I'm thinking eww, yuck, how could you sit through here? Isn't this depressing? Why would you come back? (Macaulay)

Similarly, Mighty Mouse recounted her previous experience with a support group:

We just come to it at a different angle than sitting in a group. [*And just talking?*] Yeah, well, just sitting and I went to some of the support groups for Lupus and it really turned me off. You know as far as they are concerned you should be lying in your house just waiting to die type of deal and "Oh I can't do this and I can't do that..." And it was that, that made me stay away from regular breast cancer support groups too because I didn't want to sit and just hear the sad stories... And still dealing with it, but in a really positive, very upbeat sort of way. (Mighty Mouse)

The difference the women experienced in the dragon boat team as a source of support was in the activity-oriented premise and focus of the group. They saw the team as being about "doing" rather than "talking," and about getting on with life in spite of having breast cancer. They also emphasized the fun they had as a team as well as the hard work they put into their training and the laughs they shared with one another.

It's just a wonderful group of women who love to laugh. (Lola)

Some women were impatient with those who preferred to see themselves as victims or who exhibited a "why me God?" attitude. Talking about one's breast cancer experiences in a woeful or self-pitying manner was not tolerated nor was it indulged. The attitude among some was that "You've got 5 minutes to get over it" (Bette). The ethos of the group was to "get on with it," to stay focussed on the positive and to live life to the fullest because one is never sure how much time one has left.

People will often say "Why me?" I never did. Why not me? Why should I be any different from anybody else? Why should I be special? (Babs)

There's also a whole group of people who need to be pulled up by just what this dragon boat does, and to be there for each other. We're not talking breast cancer; lots of times it's never mentioned in a night, in any night. But you also know that there's somebody there to give you a hug if the hug is needed or to say to you, hey. (Gabby)

Get on with it, get over it and make light of it. We've been given another opportunity here because some of our colleagues haven't. (Gabby)

This is not to say that the women were not compassionate nor understanding; they were. In fact, it is ironic given the pains that some of the women take to distinguish the team from conventional peer support groups, that in important ways the team serves precisely the same functions as other types of support groups, including information exchange and emotional support. Regarding themselves as a "competitive breast cancer team on the water but a support group on land"<sup>9</sup>, the support group/self-help role comes into play whenever someone requests information about treatment protocols or procedures, is diagnosed with recurrence of their cancer or is facing death. Support takes many forms and ranges from cards and emails of encouragement to nursing care (several women on the team are nurses) to running errands, minding children, cleaning houses and preparing meals.

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<sup>9</sup> Helgeson et al., (2000) distinguishes between support groups and self help groups. They define support groups as groups that contain group discussion or information exchange that is led by a trained facilitator, while self groups are those which do not have an expert leader. However, many of the same functions of self help are the same as support groups (Rootes and Aanes, 1992).

Information exchange is done informally with requests for information usually made via email or through announcements at the beginning of practices. Often women will approach each other or the team's founder, who happens to be a nurse and is married to a sports medicine doctor<sup>10</sup>, before going to see their own doctors. Several women spoke of the difficulties they had talking candidly and openly to their doctors about their illness and treatment experiences. Thus, the team provides its members with information, resources, care and alternative approaches and perspectives concerning their illness experience that they feel they cannot get from their own cancer care practitioners.

No, no, you don't get much from doctors. (Lady Di)

They don't know how to deal with it. So it's the first place we go when we've got questions before we make that final decision to go to the doctor. A lot of time, they'll come and say "I've got this what do you think?" And we'll say, whatever. And that way we're not going out there and they're labelling us as nuts [*Or as hypochondriacs.*] Yeah because that's not fun either. And it gives us a little more self worth. (Mighty Mouse)

Mighty Mouse's comment speaks to the uneasy relationships that many women have with their doctors and the need this creates to have one's concerns legitimated. The comments also speak to the appreciation many women have for the opportunity to rehearse their questions and requests before posing them directly to health care providers. The dragon boat team functioned in many ways to meet women's needs in this area.

It is important to emphasize, however, that the support function of the group expresses itself in the context of the physical *raison d'être* of the team and that the dragon boat racing in fact becomes the means through which support, when it is needed, is delivered. In the following quotation, Martha and Esther express it well:

I like the physical aspect of it rather than if it had been just a social group with people who were dragon boaters, but the fact that I could go every week and work on the exercise and I didn't even have to talk to anyone or I didn't have to be part of this, like I ended up being part of the team and I'm very happy to be part of the team. But I wasn't like, I wasn't interested in the touchy feely and I would have run the other way. (Martha)

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<sup>10</sup> Many of the women also consult the founder's husband directly for various other health and illness related concerns and arrange through him to get referrals to other health care specialists, bypassing their own family physicians, so that they can get treatment and care sooner.

It sounded exciting to me physically... I could see all these other pluses and now its such a turn on, of course the paddling is still a turn on, I love that, but you go there and you talk to people and you find out if somebody is having a bad day or a good day. You get involved in their lives. The caring starts as you get to know people and then it really becomes so much more. (Esther)

The dragon boat team as a physically orientated support/self-help organisation offered women positive alternatives and choices. They could participate in the group and receive emotional support from others that aided in their adaptation to life with breast cancer or they could participate in the group for the physical activity and for the physical and health benefits that the strenuous exercise provides.

### **A source of friendship**

Friendships are voluntary relationships that are characterized by intimacy and self disclosure. Relative to romantic-sexual relationships, friendships are considered to be less formally scripted and less institutionalized (Rose, 2000). However, there are still expectations and rules governing the interpersonal dynamic between friends. Although friendships may vary in levels of intimacy, expectation and involvement, at a minimum, friends are expected to stand up for each other, show emotional support, trust and confide in each other, provide help in times of need, share news of success, and more generally to strive to contribute to each other's happiness (Argyle and Henderson in Rose, 2000). A whole series of mediating factors come into play in bringing and keeping individuals together as friends including similarities in world view, a similar sense of humour, similarities in individual dispositions, ethnicity, social class, age, sexual orientation, and marital status. Looking more specifically at friendships between women, the care-giving and emotion work that women are generally socialized to provide, their tendency to be cooperative and accommodating and to put others' needs ahead of one's own (Hochschild, 1983: 164) facilitate the process of creating friendships.

Many of these general observations about friendship were found in the friendships that developed among the women on the dragon boat racing team. Apart from the many demographic characteristics they share in common, their common interest in physical activity and in taking a proactive approach to the problems they face in life, there is the shared trauma of living with breast cancer. The team dimensions of the women's involvement in dragon boat racing also contribute to the strong bonds of friendship that develop. Team sport has the capacity to facilitate female bonding, friendship and a sense of sisterhood through the sharing of a similar interest in physical activity and through the goal orientated context of competition that emphasizes support and cooperation (Blinde et al., 1994; Theberge, 1987; Young, 1997). It is not surprising under these circumstances to find that the women bond and pursue deep and meaningful friendships with each other:

The friendship bond gets better and deeper with every year and with every changing health situation that involves giving of oneself emotionally to one another. (Esther)

I've made a lot of friends who do the dragon boating, it's been fun.... Even if it got to the part where I couldn't paddle, I think I would still be part of the team. (Lucille)

The camaraderie, laughter, tears, fooling around, other people, not me, sweating, feeling like a piece of shit, nausea, heart burn, accomplishments, fulfilment, and about all the friendships, love. Where else can we feel that in one hour? (Esmeralda)

Oh I just have a good time. I just enjoy it. It's like an extended family. Again it's a thing that I don't have, sisters. It's just, I love it! (Meryl)

In describing their friendships the women stress the base of understanding and shared experiences that make these relationships so powerful. Bette points out that this base, at least in terms of their breast cancer, is there whether it is openly talked about or not.

It's nice to be among women who've had breast cancer so you're all coming from the same spot, but they don't talk about breast cancer. It's like friends you went to university with. You all knew you were from the same university with the same experience.... And I know that if I ever needed to talk about anything, that there are women that I could go to, that I could discuss it with. And it's a nice feeling. (Bette)

The women feel that they do not have to maintain any pretences with each other, either in terms of what they say or how they look. There may be a reluctance to talk to "outsiders," even if they are significant and caring others, for fear of alarming them or of not being understood. It is much easier to talk to each other. There is also a reluctance in relation to the outside world to reveal the scars of their surgeries or other side-effects of their treatments. Among themselves, however, the women feel they can be who they are. Each of the following quotations illustrates the level of openness in their friendships.

What keeps me coming back is the friendships, the workout, the people who don't care how I look. Just that I am there week after week to share a smile, a hug and a story with someone who can relate to whatever I am going through. (Charlie)

My girlfriends, the Ya-Ya's we'll call them, they know me. I can be myself. In fact you know I am more open to some girls than I would my husband because there

are things in life that, I don't know why, he wouldn't probably be sympathetic. (Morgan)

You can talk to them about anything because they've been through it, they've been through the major thing like you have. You go on and whine but you know that if you really need to speak to someone there's always somebody there. (Lola)

### **A source of pride, achievement and physical empowerment**

Besides offering a source of support and friendship, dragon boat racing gave the women a sense of pride and achievement, and in doing so it empowered them. There were several aspects to these benefits. One benefit derived from the effects of dragon boat racing on their bodies. For those who stayed with the team and committed themselves to the training, there was an almost immediate impact on the appearance of their bodies and their sense of physical well-being.

Physically it has made me stronger and healthier. I have been exercising more and working harder at keeping myself in shape. (Sophia)

I like the way it looks (her body) when I'm in good physical shape especially with the dragon boating now and doing the heavier upper body stuff. I've got a "V" to my back and when you work with athletes and you see that "V". (Mighty Mouse)

The women experienced their bodies in ways that went beyond the feminine concern for physical appearance and attractiveness, although this to varying degrees remained important to them. Instead they saw their bodies as muscular, powerful and strong. They were proud of their bodies, not simply because they had slimmed down and perhaps now conformed to the dominant cultural ideal of thin and feminine, but because their bodies felt and looked strong, and their shoulders and arms were toned, defined and muscular. This sense of pride was heightened by their knowledge of the fact that these muscles and fit bodies were so hard won.

When we first started getting down to our tee shirts, somebody said to me 'how old are you?' and I said I was 56, and they said 'God I hope I have your body when I'm your age'. And I said thank you. This isn't all god-given, some of this is worked for. (Martha)

Like now I have pipes. That's what the guys call them. Bette, you've got pipes. And my clothes..., some of my shirts are a little bit tighter around my arms... [*And how do you like having pipes?*] It's kind of neat. (Bette)



For some of the women dragon boat racing allowed them to demonstrate their physical capabilities and competence, especially in light of their experiences with breast cancer, not only to themselves but to others. In the following, Mighty Mouse alludes to the reservations those around her, namely her sister-in-law, had about her decision to pursue dragon boat racing after her cancer diagnosis and the sense of satisfaction it gave her to be able to show what she could do.

And [her husband's] sister is just overly protective and she still thinks I shouldn't be lifting stuff. I keep reminding her that I'm doing this dragon boating, I'm doing more stuff than ever before. (Mighty Mouse)

Beyond the changes in their bodies, there was the pride that came from being a member of the team and sharing in its successes. Many women had engaged in individual sports and activities such as tennis, racquetball, squash, aerobics, skiing, swimming, and jogging, but few had participated in team sports past high school. Even fewer were involved in physical activities that were competitive and which required that they train regularly and achieve a competitive level of fitness.

I never was a member of a sports team before. (Esmeralda)

I've never been much for team sports before, like I didn't need to be on a team. I liked tennis and scuba diving, swimming and stuff. (Princess Margaret)

As a kid I hated exercise and in high school I could hardly wait to get out of gym. I think in grade 10 you could drop it as an elective and I could hardly wait to get out of it. I took swimming lessons as a kid and basically after I got out of high school that was it. I just didn't exercise. (Didi)

I wasn't into sports or anything like that when I was younger. (Babs)

Many of the women expressed surprise at finding themselves involved in such a demanding sport. They regarded their very membership on the team as an accomplishment in itself.

It takes serious energy and serious strength and I can do this. I shocked myself. But hey, I can actually do this. (Didi)

I wasn't into anything and I never joined clubs. I never went to the Y. No, this has got me doing more strenuous things, and I figure I'm better, good at my age. (Morgan)

A more poignant example is offered by Lady Di whose only experience with sports as a child involved always being picked last for the team. Yet she became one of the strongest members of the dragon boat racing team:

I was one of the ones, if you were on the baseball team, [Lady Di] was last to be picked. And now, if you've talked to Charmaine, she introduces me to new people as one of the star paddlers and I think are you making fun of me or do you mean this? Because for me, I would think they were making fun of me because I've never been in this position. But I really work, I'm very serious (Lady Di)

That they were able to involve themselves in dragon boat racing at all was remarkable in their eyes given that they were women living with breast cancer, women with mutilated breasts and compromised and problematised bodies, women continuing to adjust to and manage treatment side effects, women coping with the anxiety of the very real possibility of recurrence. That as a team they were able to compete in races and win made the accomplishment all the more remarkable. The magnitude of their sense of achievement was captured by one woman who rated her successful participation in dragon boat racing as second only to the birth of her only child, a child she had later in life and thought that she might not ever have.

Yeah, so it's a real accomplishment, it's the biggest accomplishment actually that I have ever had, other than having my daughter, you know I have to say. Going to university all that stuff, yeah, they're all important but this to me is my greatest achievement. (Emma)

The women often shared among themselves tales of their glories and victories, especially those involving races in which they were competing against non-illness based dragon boat racing teams. This sense of accomplishment was affirmed in the team's interactions with other competitive and non-breast cancer dragon boat teams who related to the women as serious contenders and not "just" a group of predominately middle aged women who wanted to "paddle for a laugh."

A particular event that figured prominently in the lore of the group was a competition in which the team was invited to compete as the only breast cancer team in the last race of the day among a group of elite women's teams. While they did not win the race, the team put in an impressive performance. Esmeralda recalls this pivotal and defining moment for the team.

And then the accomplishments. Look at us, look at what we've been through, look at what has taken place and the recognition as well, ... when we were able to keep up with all those women's teams and the other teams... These excellent, elite

teams and we were going to be a part of this group. Being right up with the rest of them and the women's cup in the afternoon, the last race of that day when they invited us into the 250m challenge. That was a gruelling day because we didn't have any extra left. So when we were able to keep up with everybody in that lady's challenge, that was an accomplishment. (Esmeralda)

With each new victory the team challenged itself to reach for new goals. As the women began to improve their race times and win competitions, they set the bar higher for themselves. They began to see themselves as a force to be reckoned with. Towards the end of my connection with the team the focus was no longer on simply participating or even finishing first in their lane, but on winning every race and taking home the "hardware" (trophies).

Stratford was the capper. It was 5 years of hard work that really came together. And yeah, I started out by saying "we come first every time we're out there, we come first in our lane". Well it's gone beyond that because they are working so hard at it. (Mighty Mouse)

### **A transformative personal experience**

There is a sizeable literature on the transformative effects of serious illness. Serious illness has the capacity to change one's sense of priorities, one's orientation to life and one's sense of self. Many people who have faced either a life limiting or a life ending illness claim that ultimately they come to regard their illness as positive in that it made them realize how precarious and precious life is (Aldwin, 1994; Csikszentmihalyi, 1990; Tedeschi et al., 1998; Van Tigham, 2001 in Kleider et al., 2002). People living with HIV/AIDS have talked about the opportunity their HIV/AIDS gave them to search for meaning in their lives and to grow as individuals (Barroso and Powell-Cope: 2000). Women living with breast cancer have discussed the unforeseen benefits and affirmative experiences that their diagnoses generated, including opportunities for self growth and understanding (Arman and Rehnsfeldt, 2003; Caldwell, 2005; Exley and Lathery, 2001; Paillasse, 1997; Tedeschi et al., 1998; Utley, 1999). A diagnosis of breast cancer can act as a catalyst, this literature suggests, for greater awareness and development of self (Kleider, et al., 2002; Paillasse, 1997; Shannon and Shaw, 2005). However, the mechanisms by which these transformative effects are generated are not often explored.

It is certainly the case that the women on the dragon boat racing team experienced dramatic growth and change in how they thought and felt about themselves. They too talked about transformations. Mighty Mouse, for example, reflected:

[Breast cancer] has really changed everything around for me. I look at life very

differently now. And it's changed my whole idea of where my life is going to be going. What I'm more focussed on and everything. (Mighty Mouse)

However, the women attributed their transformations as much, and in many cases more, to their participation on the dragon boat race team as to their breast cancer. There were many references to a new-found strength and assertiveness.

Yeah [the dragon boat racing] changed my personality too. I was probably, hey you probably won't believe me but I was always shy and very quiet. I would never speak up. In a restaurant if the food was cold I would have eaten it cold and that's changed. That's been a total reversal. I don't put up with any crap now. (Veronica)

Didi talked about becoming a better person as a result of her experiences:

I'm certainly more assertive in saying what my needs are and making sure that I meet my own needs. But yeah, certainly (pause) ah, it sounds simple but I think I'm a better person. (Didi)

Another woman, Babs, described herself as having become more compassionate. In doing so, she weighs the relative impact of breast cancer and her participation in the dragon boat racing in this transformation:

I think it's been more the dragon boat team that's had the impact than the actual breast cancer. I'm more aware of what other people have gone through. I think it's all very easy to be isolated and just to see what you and your family are doing. But when you get out there and you talk to people and realize what they've been through, it's made me more compassionate to other people. (Babs)

Sophia spoke of being happier:

It [the dragon boat racing] has just given me a whole different outlook on life. It's just lifted me, it's given me a lift on how I feel about myself. Just, it's made me feel happier. (Sophia)

The impact of their involvement with the dragon boat racing team is so powerful for the women that many of them re-framed their cancer experiences in more positive terms. Had it not been for their breast cancer diagnosis, many of them argue, they would not have discovered dragon boat racing and the profound changes that they have experienced in their lives might not have occurred. Perhaps the most dramatic statement in relation to this point came from Lola who compared what it might have been like never to have had the dragon boat racing experience to the loss of her breast.

If I didn't dragon boat race, physically I would miss something. It would be a real, it would be losing, missing something almost like a mastectomy again, a loss. (Lola)

Others spoke in the same way of the paths their breast cancer diagnoses had cleared for them:

I think getting breast cancer opened up a lot of other avenues that I might not have had. I might have been someone just sitting back and not maybe getting involved as (pause). Breast cancer got me involved in a support group, dragon boating and there were little chances of that [happening]. I'm not thankful for getting it, but I'm not regretting that. (Morgan)

And you know it's funny, we talk about this sometimes with other women there. The best thing that came from having breast cancer was being in a group like that, it was. Such negative stuff and that turned out positive in many ways. (Sophia)

In a way its opened some doors like the dragon boat and meeting a lot of other fabulous women, really exceptional women and its just amazing. Probably more positive than negative. (Meryl)

### **Life affirming**

Related to the idea of the dragon boat racing as transformative is the women's experience of their participation in the sport as life affirming. At a point in their lives when they were dealing with a life threatening disease and were subject to a series of treatment side effects that problematised their bodies and sense of well-being, dragon boat racing gave them the opportunity to participate in something that made them feel vital, alive and capable of doing whatever they wanted or needed to do.

Oh, it just, it's life affirming you know, I can't imagine not doing it, like every time I go out I just, again reinforcing the fact that I am a survivor and I can do this and I can do whatever I need to do, and want to do. (Emma)

It has given me my life. A focus and it has done so much good. (Suzanna)

As the earlier discussion of dragon boat racing as an activity-oriented support group established, the women wanted an activity that they could throw themselves into completely instead of dwelling on their cancer experiences. The intensity and potentially all-consuming dimensions of their involvement gave them moments of respite from the always at hand awareness of breast cancer in their lives. However, there were also

moments where they did not want to forget, and in fact, juxtaposed the “lows” of their cancer with the life-affirming “highs” of their experiences on the dragon-boat racing team. The dragon boat racing took on a symbolic meaning for them. It came to represent their drive to survive. For example, one woman had been given a 50/50 chance of surviving surgery in order to remove a large tumour that had spread to her liver. Another was so ill from her chemotherapy treatments that she had to be hospitalized for several weeks. These women explained that they will never forget how they looked (bald, pale, unlike themselves) and felt (tired, nauseous, in pain) while undergoing treatment. They brought to their experiences of dragon boating traumatic and painful embodied memories associated with their diagnosis and treatment experiences.

I remember throwing up. I can remember distinctly my husband and I laughing at certain times or coming home from the hospital. Pain, I remember painful things. Like they say if you remember giving birth you'd never have another child.  
(Charlie)

Chemo knocked me for a loop. I came home and I needed help to get off the toilet, I couldn't get into the bathtub on my own. I couldn't do very much. I got control of the vomiting to a certain degree because they give you pretty powerful stuff, but I used to refer to it as my Alice in Wonderland hole and I'd fall into it. So I come home pretty high on the Tuesday, having not looked at the nurse. (Gabby)

Thomas-MacLean (2004: 639) has argued that among women with breast cancer “memories of suffering remain vivid and powerful” and that the mere anticipation of chemotherapy can evoke strong emotions. Dragon boating allowed these women to “reclaim” their bodies, to once again feel good, healthy, vital and capable both in and through their bodies.

That I could be so sick on a death bed, literally, on a death bed last August. To get out of a boat a year after having chemotherapy and knowing that was my last chemo. The first day I got into a boat and looked at Sweet Pea and I start to cry. That I'm here, I can do this. Isn't it beautiful out on the water? Oh my god, my body can do this. (Charlie)

### **A safe space**

Another critical function the dragon boat team serves has to do with the “safe space” it provides for team members, in both a literal and figurative sense. The previous section on friendship touched on the possibilities that the strong bonds between the women create for them to “be themselves,” to share their experiences, hopes, dreams, fears, and terrors with each other with the expectation that they will be understood. In this

section I want to elaborate on this function and also to draw attention to other ways in which the team functioned to create safe spaces for the women.

According to McKenzie and Crouch “cancer survivors most profound feelings lie outside the acceptable limits of practical consciousness and will largely be debarred from expression in ordinary social intercourse which is constrained by routines of the natural attitude.” (2004: 143). Women are aware that talking about their breast cancer can disrupt and problematise social interaction. They must also contend with others’ lack of knowledge and understanding of what it is like to live with a life threatening disease, and how life does not unproblematically return to normal after diagnosis and treatment (McKenzie and Crouch, 2004). Esmeralda put it like this:

So it was really weird how people looked at you, you know? They felt sorry for me. You just sort of have that label whether you like to admit it or not, you’re labelled. *[And people don’t know what to do or say to you.]* Yeah and that’s what so comfortable about (the team) they take the stigma away and you can laugh and joke about your families. There’s a bond I never thought I would have.  
(Esmeralda)

Suzanna, who at the time of her interview was dying, talked about how difficult it was for her to express herself to her family. She explained that they would not allow her to discuss her imminent death or to share with them her feelings about dying. The fact that she understood why this might be the case and that she did not doubt their love for her, however, did not make the situation easier for her to bear.

My family...expects me to be the same as I was. They don’t give me a lot of leeway which is sometimes hurtful, but mostly, but at least they love me.  
(Suzanna)

Turning to another dimension in which the team offers the women a safe space, in much of the popular and medical discourse about the loss of the female breast there is an emphasis on the damaging consequences of this experience both in terms of self-esteem and body image (Anderson, et. al., 1994; Braddon, 1999; Klaus, 1999; Times et. al., 1994; Wilmot, 2001). The societal view of this experience puts women who have lost a breast to cancer in a position where it is expected, even demanded, that they feel anxiety about the loss and further, that they exhibit this anxiety either by wearing a prosthesis or undergoing breast reconstructive surgery. In other words, women are expected to take the necessary measures to reproduce and represent to others a normalized feminine body that masks and denies the telltale signs of difference in general and of breast cancer in particular (Lords, 1980; Yadlon, 1997; Young, 1990).

These expectations and the consequences of transgressing them are part of women's breast cancer experiences. Both Macaulay and Mighty Mouse recalled how female patrons at the fitness club where the team used to work out responded to the sight of the "breastlessness" of some of the team members. Several of the patrons were so disturbed by the sight of team members' disfigured bodies that they went to the club's management and complained about the team changing their clothes in front of them.

Like we used to go to [name of the club] racket ball club but some of the ladies were upset that we got undressed in the locker room, we upset them. [*And they communicated that to you?*] They said that to the manager and we're no longer there. The disfigurement, it upset them, that we were disfigured and we were disrobing in front of them. (Macaulay)

We didn't change with them [other fitness club patrons] but the other women had to go through and I guess it scares them and we weren't being show-offish or anything, but they just happened to see it. And I think it would scare other women that aren't going through it because, god forbid that happens to them. And they probably see the disfiguration that way. We don't. (Mighty Mouse)

When they are exclusively in each other's company, however, the women experience the freedom to "be who they are" in how they look as well as in how they behave or express themselves. They can be women living with breast cancer, women whose bodies may be marked or scarred. In this space, breast prostheses and other devices used to mask their breast cancer and normalize their bodies are not necessary. Many of the women experienced this as a weight or burden from which they had been liberated. Gabby, for example, talked about being able to express herself as a woman who was now single breasted. She did not feel the normative pressures to hide her 'lack.'

So now the only place I go without it [her prosthesis] is the dragon boat. Because I tried to. First of all I had to express myself, myself was nothing there. But then when Clint would say to me "Gabby". That's all he does. That means there's nothing there. (Gabby)

Similarly, Lucille drew attention to the team as a refuge.

The supportive people on the team and the feeling of sanctuary. (Lucille)

The women did not have to worry about embarrassing, offending or upsetting others with their difference, (as bald, single breasted or breastless women, or as disfigured) or with the fact that they have breast cancer. In these safe and protected spaces the women are not only sheltered from, but can also challenge and resist, the critical gazes



and comments of others. This aspect of their participation in the team is reflected clearly in an insightful comment made by Mimi. Mimi describes the team as providing the women with a “power base”, a position of both authority and solidarity among a group of women who all share a similar lived understanding of what it means to have breast cancer and who know what it is like to lose a breast(s).

All of this might have been a totally, or would have been a totally different experience without the dragon boat because it has given you a power base to work from. If you were going through all of this as an isolated individual it would have been totally different. But being a part of this group where the joke is you can’t wear your prosthesis on the boat because it weighs too much, it has to go overboard, it’s a totally liberating thing. It allows you to be who you are, not who you’re expected to be and that has been a huge bonus. (Mimi)

The safe place that the dragon boat racing team offers the women can be thought of in terms of “therapeutic landscapes of healing”. Therapeutic landscapes of healing have been defined as situations or locales where “physical and built environments, social conditions and human perceptions combine to produce an atmosphere which is conducive to healing” (Geissler, 1996; English et al., 2008: 69). There are two types of such landscapes: the extraordinary, which involves domains that are situated within places that are outside of peoples’ everyday lives (i.e. travel, the hospital, nature, camps, etc.), and everyday, which are located within the home and the community. Although landscapes of extraordinary healing are important to peoples’ experiences of healing, they are sites where people experience a high quality of life for only a short period of time, and as a result, the relationship to health and healing is a short term one. English et al., (2008) suggest that the combination of everyday and extraordinary landscapes may play a critical role for long term healing, especially for those who have a chronic or critical illness condition, such as women living with breast cancer.

Based on this description, the dragon boat racing team, the clubhouse, the boat, and the team itself in all of the locations where it meets provides such an experience. The team offers everyday and extraordinary moments of healing. Through their participation in dragon boat racing and as a result of regular (often daily) contact with team members (via emails), the women receive psychological, emotional and social support. The surrounding bay area and the lake on which the women paddle serve as natural and extraordinary landscapes of healing which can play an important role in restoring and improving one’s health when one is immersed in or viewing natural environments. Being on the water and surrounded by natural beauty and wildlife, these natural locales can inspire and provoke feelings of calmness, tranquillity, relaxation and rejuvenation (Kaplan, 2001 in English et al., 2008: 75) and can also lead to psychological well being and healing as it did for Charlie.

Love it !!! To do something that makes you free so alive! To be on the water. To see the sun sets. To say my prayers of thanksgiving. To be a part of something that was so terrible. Just having the "Cancer" and then to be in remission and doing something that brings attention to the fact that I am ALIVE !!! (Charlie)

### **A time for oneself**

Considering the impact that the women feel their participation in the dragon boat racing has in their lives, it is not surprising that they come to commit themselves wholeheartedly to the team and its activities. These activities included not only training, paddling and racing, but also a myriad of other things - organising and participating in fundraising events, breast cancer advocacy and community outreach, organising and managing races, hosting barbeques, dances, ad hoc committees and caring for each other. These activities become a priority for them and the women are prepared to make significant personal and professional sacrifices in order to participate in them.

I make this a priority in my life and therefore decline invitations on team function days. (Lucille)

My garden is now a little wilder, my house not as clean, my entertaining not as lavish. My family friends and church work still get attention. Is this a sacrifice? I think not. (Honeybun)

We have this beautiful sail boat that's crying to go away on weekends. Jim is committed to sailing, but we don't use the boat as much as we had hoped. (Didi)

The sacrifices can be significant. In Esmeralda's case they involved tensions in her relationship with her husband who felt that her time away interfered with her home and family responsibilities.

I have to admit that there have been times when Bob has been ticked because I'm away and things around home are neglected. (Esmeralda)

Babs too encountered trouble on the home front. Her husband, although supportive of her being active, had difficulties with her being on the dragon boat team because he thought the team was too focussed on breast cancer and that the team was too "in your face". For her husband, breast cancer was something that you had, got treated for and got over; he resented the way that dragon boat racing and his wife's breast cancer had become the focus of her life.

He doesn't actually agree with the dragon boat team. He thinks we're too out,

we're too in your face about it. Like he supports me in that type of thing but he very rarely will come to any of the races especially even in the beginning when it was all exciting and everything. I think it was a little bit overwhelming for him. See his mum had it [breast cancer] a long time ago and it wasn't spoken about. It happened, get over it don't talk about it and I don't think he could quite understand that I was going to be right out and into people's faces. You know in the newspapers and this sort of thing. (Babs)

Lady Di talked about the financial sacrifices involved:

I give up working Tuesday evenings and Saturdays, as well as the weekends that we race which will probably make a difference in my pension as this will be my 6th year and that is considerable income loss. (Lady Di)

A particularly dramatic example of the lengths to which the women will go was offered by Didi. Didi had several surgeries, some related to her breast cancer and others not, that had left her badly scarred and with a body that sometimes made her feel "monstrous". "I describe myself as the bride of Frankenstein" she said. She was planning to have plastic surgery to repair some of the scar damage to her breasts, but kept deferring the scheduling because she did not want it interfering with any of her dragon boat racing activity.

So I'm having trouble deciding when's the best time to go in for this surgery that isn't going to interfere with my dragon boating (laughter). (Didi)

The women's commitment to dragon boating and their involvement with the organizational aspects of the team is a powerful declaration to friends and families that this activity is important to them. The women are willing to do what they must to protect the time they spend with the team. They consider it "their time" and fight fiercely to preserve it.

It is just something I do for me. (Charlie)

### **Concluding Comments**

Reflecting on the women's experiences as part of the dragon boat racing team, it is impossible to ignore the centrality of the two overlapping threads that provide the context for these experiences – their breast cancer and the gendered contexts within which women live their lives.

First and foremost, these were women who were led to dragon boating as a result

of a diagnosis of breast cancer. They were not women who had simply found an engaging and challenging leisure activity to participate in, or even women participating in dragon boat racing after treatment for a disease. They were women who came to dragon boat racing as individuals who had been diagnosed with, treated for and were now living with, breast cancer. A diagnosis of breast cancer is the kind of experience that brings into stark relief the reality of one's mortality and the very real possibility of a premature death. Although not every woman diagnosed with breast cancer dies of the disease, one in three will. This means that even for those who ultimately survive, there is always the spectre of recurrence and death with all of the existential issues that these possibilities raise (Colyer, 1996; Payne et al., 1996). A diagnosis of breast cancer can disrupt assumptions about one's daily life including future expectations and for many initiates changes to one's sense of self (Arman and Rehnsfeldt, 2003).

Treatments for the disease can also assault and problematise physiological and biological processes both during and long after treatments have ended (Love, 2000; Thomas-MacLean, 2004). Most women who are diagnosed with breast cancer receive a range of treatments (Reigle, 2006), which involve more than the amputation (in part or in whole) of the breast and surrounding breast tissue. Local and systemic treatments for breast cancer can be intensive, invasive and toxic depending of the number and types of treatments used. Treatments for breast cancer can give rise to a series of iatrogenic, chronic and deleterious side effects (e.g. lymphedema, fatigue, limited mobility, pain, hot flashes, arthritis, compromised respiratory function, forgetfulness, etc.) and can have implications for women's embodiment in both the short and longer term (Mustin et al., 2002; Thomas-MacLean, 2005). Memories of these difficult and sometimes traumatic experiences of treatment linger and remain salient.

It is against this backdrop that the women experienced their participation on the dragon boat racing team as positive, supportive and life-affirming. The women felt vital, alive, strong, and empowered. They could scarcely believe what they were accomplishing both individually and as a team. In how their bodies looked and in what those bodies could do they found a reason to be proud. They could display those bodies among each other without worrying about offending or upsetting others. And when there was a need for support, they found it in the therapeutic landscapes their team members and activities provided them.

Also critical to an understanding of the participants' experiences is women's location within broader gendered social relations and practices, including women's experiences of sport. In a variety of ways the women were dealing with expectations about their appearance, their availability to perform their traditional roles in relation to their families and others around them, and particularly their physical capabilities or lack thereof. Women's circumscribed roles often lead to a lack of a sense of entitlement to

leisure and to time out for themselves and away from their families to pursue their own interests. There is a “feminine ethic of care” that women often internalize that holds that as women they should nurture and seek to meet the needs of others at the expense of their own needs (Harrington et al., 1992). For many women and girls, access to and participation in sport, especially activities that involve intense physicality is limited (Fasting, 1987; Sleep and Wormald, 2001). An indifference to sport begins early in the lives of many young girls and organised sport does not become an important part of the culture of girls and women in the same way it does for boys and men (Fasting, 1987; Sleep and Wormald, 2001). Medical and scientific discourses that typify women’s bodies as incapable of withstanding the rigours of intense physicality and strenuous sport further limit women’s access to and participation in sport (Hall, 2002). Thus women’s dragon boat racing experiences can be seen as acts of agency as well as resistance both as women living in a gender stratified and patriarchal society and as women living with a life threatening disease.

Only against this backdrop is it possible to appreciate the barriers that the women had to overcome to make the commitment to dragon boat racing that they did, the sense of achievement and empowerment they derived from their participation and their victories, and the sacrifices they were prepared to make to continue with dragon boating.

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## **Paper 2: "Breasts Do Not a Woman Make". Femininity, Breast Cancer, and the Competitive Sport of Dragon Boating.**

### **Introduction**

The medical and scientific professions have a long and problematic history regarding the ways in which women's health and health care concerns have been framed and constructed, and the ways in which women have and continue to be treated by these communities. As key institutions in the defining of social reality and as agents of social control, (Bordo; 1997; Ehrenreich and English, 1979; Foucault; 1977; Shilling, 1993) the medical and scientific communities have and continue to enjoy and exert a powerful influence on how the female body is conceptualised, understood and even experienced (Price and Shildrick, 1999).

Within medical and scientific discourses there is a tendency to emphasize the significance of biological and reproductive sex differences whereby women are often defined by and reduced to their biological, physiological and reproductive processes to an extent that is far greater than for men (Gannon; 1998; Todd, 1983). Not only has women's ontology been conceptualized as determined by the biological and reproductive, these processes are typified by the medical and scientific communities as diseased, anomalous and "other" (Hanson, 2001; Meyer, 2003; Weideger, 1975). Naturally occurring conditions in women, such as pregnancy, menstruation and menopause have been medicalized to varying degrees and conceptualized as medical problems in need of intervention (Blum and Stracuzzi, 2001; Eichler et al., 1992; Graham and Oakley, 1981; Griffiths, 1999; Kohler-Reissman, 1983) and as hazardous to women's physical health (Culpepper, 1978; Hanson, 2001; Meyer, 2001). Women's bodies have been considered to be volatile and dangerous by nature, potential breeding grounds for a variety of diseases and disorders (Hanson, 2001; Todd, 1983). Women have also been regarded as more likely to suffer from psychosomatic disorders rather than from organic disease, and physical symptoms have often been interpreted as psychiatric and have not been taken seriously (Ehrenreich and English, 1979; Fabrizio, 1991; Miles, 1991; Ussher, 1991). Explanations for moods and behaviour have also been reduced to biology. Ignored are complex social, cultural and political forces that shape and mediate women's embodied and lived experiences (Gannon, 1998).

Many of these same assumptions and practices can also be found throughout the literature on breast cancer, particularly in research that addresses the psycho-social effects of breast surgery and loss. Within this literature the focus has tended to be on four areas: 1) the psychological and psychiatric effects of breast loss (i.e. psychiatric morbidity due to breast loss); 2) the adverse impact on sexuality (with an emphasis on sexual dysfunction and loss of libido); 3) the negative effects on body image and self identity and 4) the benefits of both breast conserving surgery for psychological health and well being and

breast reconstruction as a means of maintaining as well as returning women to normative femininity.

Informing each of these areas of focus are certain beliefs about the nature of women which have shaped the tenor of the research conducted and have given rise to several claims concerning women's experiences of breast cancer. These claims include the following: that the loss of a breast is so traumatic and devastating to women that they inevitably suffer from a variety of psychiatric problems (Koh, 1999; Polivy, 1977); that breast amputation surgery is more anxiety provoking than other surgeries including those to the face, eye and leg (Polivy, 1977); women who have had mastectomies suffer more psychologically (Polivy, 1977; Yurek et al., 2000); and have more psychiatric problems than women who have had breast conserving surgery (Fallowfield et al., 1986; Kemeny et al., 1988; Pozo et al., 1992; Steinberg et al., 1985; Wellisch et al., 1989); women have greater difficulties coping and are more likely to go into denial than face up to the loss (Klaus, 1999; Polivy, 1977; Reaby, 1995) breast cancer is an attempt by women to rid themselves of essential aspects of their femininity (Liste, 1999); there is a feminine cancer personality or predisposition (Kiekcaldy and Kobylinska, 1988; Liste, 1999; Polivy, 1977; Renneker and Cutler, 1952; Margolis et al., 1989;); women are more concerned about the threat to their femininity than they are of death (Margolis et al., 1989; Polivy, 1977; Renneker and Cutler, 1952); the loss of a breast impacts or undermines a women's sense of self as feminine (Bruner and Boyd, 1999; Clifford, 1984; Koh, 1999; Kunkel et al., 2002; Margolis et al., 1989; Pikler and Winterowd, 2003; Reaby, 1998; Reaby and Hort, 1995; Renneker and Cutler, 1952; Steinberg et al., 1985; van der Riet, 1998; Wilmot, 2001) or as a woman (American Cancer Society, 1974; Lloyd et al., 2000; Wilmot, 2001); women who have mastectomies experience more negative body image concerns (Polivy, 1977; Renneker and Cutler, 1952; Renshaw, 1994; Schover, 1994; Steinberg et al., 1985) and impaired sexual function than women who have had breast conserving surgery (i.e. lumpectomies) (Bukovic et al., 2004; Fallowfield et al., 1986; Koh, 1999; Renneker and Cutler, 1952; Steinberg et al., 1985; Wilmot, 2001).

Although there is a growing body of literature that has taken issue with and refutes many of these claims, (Cohen et al., 1998; Crouch and McKenzie, 2000; Fallowfield et al., 1986; Frost et al., 2000; Hordern, 2000; 1990; Klaus, 1999; Langellier and Sullivan, 1998; Maunsell et al., 2001; Payne et al., 1996; Penman et al., 1986; Reaby and Hort, 1995; Shover, 1991, 2004; Spencer et al., 1999; Tait, 1996; Williams et al., 1995), implicit even within some of this critical literature are unchecked and normative assumptions about femininity and femaleness which continue to shape and inform research and after treatment care practices (Yadlon, 1997). Medical and popular assumptions about the nature of femininity and femaleness, and the tendency to define and reduce women to their biology and physiology have led to an predominant focus on

the importance and significance of the female breast in much of the psychosocial literature related to concerns around breast amputation.

“When the breast is the target of therapy, more than the physical tissue is affected. The breast is an important cultural symbol of femininity and an intimate part of the patient’s self-esteem.” (Williams, et al., 1995: 103)

“The removal of a breast should be understood as an amputation of a body part, a part that symbolizes sexuality, femininity, gender, and maternal issues.” (Kunkel et al, 2002:131)

“Therefore, breast amputation has potentially devastating effects on a woman’s feminine self-image, sexuality, and physical attractiveness that may ultimately affect her post-mastectomy attitudes regarding herself and her role as a woman.” (Reaby and Hort, 1995: 57)

The concept of femininity as it is used within the breast cancer literature is that of the ‘natural attitude’, it is ‘commonsensical’, taken-for-granted and is represented as obvious and unproblematic. The concept is neither defined nor operationalized and in some instances the concept of femininity is conflated with or is undifferentiated from the concepts of femaleness and womanhood. Often femininity is represented as the natural expression of biological femaleness and is sometimes used in conjunction with other concepts such as body image, self concept, self-esteem and sexuality. The links between these concepts tend not to be defined nor explained. There is little understanding of femininity as an aspect of self identity that is socially constructed, multiple, contradictory, and contextually situated, nor is it understood as mediated by other social practices and relationships such as social class, age, ethnicity and sexual orientation.

### **Emergence of the notion of threat to femininity**

Women’s breasts are imbued with a multiplicity of meanings (i.e. as a signifier of biological and ‘essential’ femaleness, female sexuality, motherhood, as objects of desire) which influence the ways in which women make sense of and experience themselves as “women” or as feminine”. When a woman is diagnosed with breast cancer it is not only assumed but expected that the loss of or changes to her breast will disrupt and threaten her sense of self as a woman or as feminine. This ‘natural attitude’ is pervasive and can be found mediated through a multiplicity of popular and medical discourses, including ones that are feminist. For example, Young states that “... for many, if not most, women, breasts are an important aspect of identity. While their feelings about their breasts often have been multiple and ambivalent, nevertheless they are a central element in their bodily self-image (Young, 1990: 203).

The notion that breast amputation problematizes and threatens women's femininity and womanhood seems to have first appeared in 1952 in an article by Renneker and Cutler (1952) that looked at the psychological problems of adjustment to cancer of the breast. Heavily influenced by Freudian theory, this paper was a joint initiative between a group of psychoanalysts and surgeons and was an exploratory study of possible psychosomatic aspects of breast cancer. Responding to a "state of inertia in the psychological handling of women with breast cancer", Renneker and Cutler were concerned with the psychological meaning of the breast and with gaining an understanding of the range of emotional shock associated with breast destruction (Renneker and Cutler:833). According to Renneker and Cutler:

"Remove a woman's breast and she has lost her badge of femininity. Psychologically it has the same qualitative meaning as loss of the penis in man...The breast therefore, is the emotional symbol of the woman's pride in her sexuality and in her motherliness. To threaten the breast is to shake the very core of her feminine orientation" (Renneker and Cutler, 1952: 834).

"The surgeon has to be acutely aware of these dual meanings [breasts as connotative of femaleness and motherhood] of the breast. He must understand that the primary emotional reaction connected with disease of the breast usually is not a fear of cancer or death, but is rather the shocking feeling that the basic feminine role is in danger....Her first problem is that of protecting her breast; only later does she begin protecting her life" (Renneker and Cutler, 1952: 834).

This initial article, referred to as a "classic work" within the psychosocial literature (Wilmot, 2001), set the tone for and has informed and influenced other 'seminal' as well as recent studies on the psychosocial effects of breast cancer (Polivy, 1977; Reaby, 1998; Reaby and Hort, 1995; Steinberg, et al., 1985; Yurek et al., 2000). As recently as 2001 the Renneker and Cutler paper was cited in a study by Wilmot (2001) on the effects of breast cancer on women's sexual self and womanhood.

"Thus the principal psychological reactions to mastectomy seem to centre on the threat to femininity it presents, possibility even more than fear of death from the disease itself. Denial appears to be a frequently used defence mechanism, protecting the patient against the full impact of losing a breast" (Polivy, 1977: 78).

"A woman's definition of self is based on a lifetime of feedback about having breasts, menstruation, and being able to engage comfortably in sexual activity. Breast cancer threatens this self perception" (Wilmot, 2001:283).

So powerful is this assumption of loss of and threat to women's femininity that there is very little research that refers to or addresses the complex, multiple and contradictory ways in which women experience and understand their sense of self as feminine or as female within the context of breast cancer and breast loss, and how women resist the reduction of this aspect of self to that of their breasts. To the best of my knowledge, the few exceptions that exist include Kahane's (1995) self help directive, Hall's (1997) analysis of four feminist writers' experiences of mastectomy, and Langellier and Sullivan's (1998) study on women's "breast talk" within the context of breast cancer. This assumption however, has not been thoughtfully or rigorously investigated, particularly within the traditional breast cancer care literature. Missing from many of these investigations are women's own understanding and experiences of breast cancer (Braddon, 1999; Loveys and Klaich, 1991; Thomas-MacLean, 2004, 2005). According to Bredin,:

"Despite the wealth of literature concerning the impact of breast loss on a woman's body image, sexual and psychological adjustment, there have been few studies within the medical and nursing literature directly quoting a woman's private perspective; how in her words she experiences her changed body" (Bredin, 1999: 1113).

The following is an attempt to understand how women who have lost (mastectomy) or had changes to (lumpectomies) their breast(s) as a result of breast cancer surgery make sense of this experience. How do women understand and experience the loss of their breast as a result of treatment for breast cancer? What factors mediate this experience, and how is a women's sense of self as feminine or female problematised, if at all?

Following a discussion of the methods employed, I begin with a section that addresses the responses of women for whom the loss of their breast was not an initial or primary concern and did not threaten their sense of self as feminine or female. This is followed by a section that contextualises women's experiences of breast cancer. The third section focusses on the group of women that did experience the loss of or changes to their breast as problematic for self definitions as feminine or female. The fourth section moves on to a discussion of how this second group was able to re-frame their breast cancer experience and reclaim their self identity as female or feminine. The fifth section addresses how this new resolve can be momentarily challenged. In the last section I conclude by summarizing the study's findings and discussing their significance in relation to our understanding of how women who are treated for breast cancer respond to the loss of or changes to their breast in ways that are multiple, complex and contradictory, and which go beyond what is represented in the breast cancer literature.

## Methods

Two data collection techniques were utilized in this study. The first consisted of in-depth interviews that became more open-ended as they proceeded. Participants were encouraged to tell their own stories and unscheduled prompts and follow up questions were utilised in order to elicit a breadth and depth in responses (Breakwell, 1995). This was to allow women to "reveal in their own words their view of their entire life, or part of it, or some aspect of themselves" (Bogdon and Taylor, 1975:6). Of the thirty one women interviewed, twenty-six tapes were transcribed (this owing to time and financial constraints) and were used in this study. Most of the interviews lasted between one and one-half hours, although there were a few that lasted longer, the longest taking five hours. Interviews were conducted and audio-taped after consent was obtained in a place of the interviewee's choice, which was usually in her home. Some interviews were conducted at the team clubhouse after practices and one interview was conducted at the university. The interviews were transcribed verbatim and were read and reread in order to identify recurrent themes and sub-themes both within and between participants accounts.

Like other qualitative approaches the focus here was on the interpretive, on "people's own written or spoken words and observable behaviour" (Bogden and Taylor, 1975:4). In keeping with the spirit of this research tradition, there was no intent to quantify the experiences of these women but rather to capture the subtleties and complexities of their lives as women living with breast cancer who dragon boat. The collection and analysis of the data was informed by the inductive grounded methodology of Glaser and Strauss (1967) and Strauss and Corbin (1990) which is a general methodology for developing theory that is grounded in data that is systematically gathered and comparatively analysed. Also known as the constant comparative method, theory is generated initially from the data, or if an existing grounded theory, is elaborated on and modified as new data is carefully compared against it (Strauss and Corbin, 1990). At the beginning of the interview process I was sensitive to the themes and analytical categories that were initiated by the respondents themselves and incorporated them, when appropriate, into the list of questions for subsequent interviews. I conducted an analysis of the first 15 transcribed interviews in order to get a sense of the data and to discern the predominant themes and categories. This informed the analysis of the 11 remaining interviews.

A second technique, participant observation, which is "characterised by a period of intense social interaction between the researcher and the subjects, in the milieu of the latter" (Bogdon and Taylor, 1975:5) was also employed and continued for five years. The decision to engage in participant observation was a secondary consideration and emerged as I became involved with the group as an "support member". As a result of my participation, I took on an "active membership role" and became "more involved in the setting's central activities, assuming responsibilities that advance the group, but without



fully committing [to] the members' values and goals" (Adler and Adler, 1994: 380). Regular contact and interaction with the group as a whole began in January 2003 when the team began their winter training for the racing season. These training sessions consisted of weekly weight work outs and paddling sessions at a local swimming pool. I also joined the team for the bi-weekly on-water paddling practices that began mid-May of that same year when they were able to safely take to the water. I participated in these activities with the team regularly and also joined the small but regular group of women for drinks at a local pub after pool and paddling practices. I also attended various team activities and travelled with the team to many of their regular season dragon boat competitions. I was invited to and attended the 10<sup>th</sup> year anniversary celebration of the first breast cancer dragon boat team in Vancouver BC in June of 2003 with the team. Participant observation ended after the 2007 season.

### **The group**

As a group, this team of dragon boat racers was fairly homogenous (similar in social class, ethnicity, sexual orientation, marital status, most had children) including the group of 26 women that I interviewed. During the five years that I was with the team, membership grew from approximately fifty members in 2002 (including approximately ten women who no longer paddled but remained as associates), to over seventy members by the end of the summer of 2007. Of those seventy members forty-nine were active paddlers. Associate members were usually women who once paddled but no longer could due to physical limitations or because they had moved onto other interests but wished to maintain some contact or association with the team. Often these women would attend or help out with fund-raisers and from time to time would come out to watch the team compete.

Of the 26 women whose interviews were used for this study, 22 were married; 4 were either single or never married. All of the women but one identified as heterosexual, and one woman stated that she was neither hetero or homosexual. At the time of the interviews, the women's ages ranged between 29 and 73 years. All of the women were of the Christian faith except one woman who said that she was agnostic. All of the interviewees but two identified as Canadian, and with further probing identified as either European or Anglo-Saxon. There were no women of colour involved with this group at the time of the interviews. Half of the women had attended or completed university, while 9 women had attended or completed college and 4 had completed high school. The annual combined family incomes ranged between CAN\$ 20,000 and CAN\$ 100,000+. One women refused to disclose financial information and another said that she had no idea what her family income was. This particular group of women were white, well educated, affluent and professional, a demographic that appears to be characteristic of most breast

cancer support and self help groups (Gray, et al., 1997:281) and women's athletic teams. (Deem, 1987; Sternfeld et al., 1999).

The medical treatments that the women had received varied depending on their diagnosis - the type of cancer they had (ductual, lobular, inflammatory, etc., ), the stage it had reached (size of the tumour, if there is lymph node involvement and if the cancer has spread beyond the lymph glands), and its grade (growth rate (slow or fast) of cancer cells)<sup>11</sup>. Seven women received radiation therapy, nine received chemotherapy and six women received both. Nine women were taking Tamoxifen, a drug used to treat and manage women's breast cancer if it is estrogen fed. Five of the women had reconstructive surgery. Several women had a range of other conditions they were dealing with besides cancer, including fibromyalgia, lupus, scoliosis, arthritis, bad backs; some had been treated for other cancers such as ovarian, uterine and thyroid cancer. Five of the women interviewed were unable to paddle regularly because of health conditions; the remaining 21 were symptom free through the time I was with them.

### **Women's responses to a diagnosis of breast cancer**

Recent qualitative research on the psychosocial experiences of breast cancer has begun to focus on other aspects of the breast cancer illness experience including previously neglected areas of concern. Some of the areas include: long-term changes to embodiment (Thomas-MacLean, 2005) and disability (Thomas-MacLean et al., 2008), suffering (Arman and Rehnsfeldt, 2003; Crouch and McKenzie, 2000), the nature of illness demands (Loveys and Klaich, 1991), memories of treatment (Thomas-MacLean, 2004), living with uncertainty (Nelson, 1996), breast cancer as a 'journey' (Lindop and Cannon, 2001) and women's experiences of living with breast cancer post-treatment (Colyer, 1996, Paillasse, 1997).

It is within some of this 'alternative' literature on the experience of breast cancer that we find discussions of this disease as disruptive, disabling, catastrophic, and as life altering, often resulting for many in an existential crisis of self (Colyer, 1996; Payne et al., 1996). The women represented in these studies also spoke of experiencing initial feelings of shock, fear (Colyer, 1996; Lindop and Cannon, 2001; Payne et al., 1996) and disbelief (Payne et al., 1996). The women in the group interviewed spoke of similar initial feelings and experiences when they were diagnosed with breast cancer. They did not make reference to concerns about the possibility of losing their breast.

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<sup>11</sup> <http://www.cancerbackup.org.uk/Cancertype/Breast/Causesdiagnosis/Staginggrading#5542>

I was just in shock. I was totally, totally shocked. And my husband just went white. My husband was very quiet and he just said so what happens now? (Babs)

I didn't go nuts or anything, it's kind of like you have like a numbing feeling and it didn't register in terms of what was going to happen with that information. Like its okay, I've got it. (Emma)

Ah ... (sigh) I think I was just so traumatized with the fact of having breast cancer that I hadn't really thought about losing my breast. (Didi)

Among these imminent concerns about dying were other considerations which had to do with the practical and involved the anticipated impacts that their treatment modalities might have on their daily lives. Loveys and Klaich (1991) found that along with fear and other worries that were the result of the "demands of illness" were also concerns about financial and occupational changes that would arise as a result of time off from work as women underwent and recovered from treatment. Queenie stated that the first thing to come to her mind when she received her diagnosis was how she was going to continue to pay for her car. For Dorothy a whole series of concerns came to mind including having to put both short and long term goals and plans on hold. For these two younger and single women, managing the resultant economic and social strains that often accompany a major illness experience were first and foremost in their minds upon diagnosis.

The first thing I thought of, like, you think of the insignificant things. First thing I thought of was great, how am I going to pay for my car? Honestly. And then when he said mastectomy the first thing that went through my mind was oh, there goes my social life. I'm 27 I wasn't married, I wasn't seeing anyone at the time. (Queenie)

When it came back positive I was floored. I really didn't think it was going to be. I'm sure there was a moment of fear. There wasn't a lot of mortal worries because my sister and my mom made out so well. It was more, shit, I can't go on my holidays, I have to stop looking for my condo, I have to put my life hold. I might have to go through what Janice went through with chemo. I have to do surgery which, I hate surgery. It was more the momentary things. (Dorothy)

Also of concern among several women was how their breast cancer illness experience was going to negatively affect their families and how they were going to go about telling them that they had breast cancer. For Penelope, telling her aging parents, particularly her father who was quite ill, was going to be difficult for her. Emma was not only worried about telling her husband that she had breast cancer but also her father who

had lost a sister to the disease. These women, like the women in Lloyd et al's (2000) study who chose prophylactic bilateral mastectomy, put their own concerns aside and instead focussed on the possible and anticipated consequences that their premature death and treatment side effects might have on their families. Both Penelope and Emma felt that they needed to protect their loved ones from any distress that was associated with their illness.

How am I going to tell my parents? That was the one thing that was on my mind. Not my kids, my parents.... because my dad has been ill for many years and my mom is the major caregiver and I have been half a caregiver because of proximity and I didn't know how they would handle it...I dreaded telling my parents.  
(Penelope)

And then its just a matter of trying to tell people, tell my husband, oh god that was hard. And then my parents. Oh telling my dad, cause my aunt, his sister died of breast cancer I think about 5 years before that. So I was really, I didn't want to have to tell him. (Emma)

For a number of women interviewed, the possibility of losing their breast was not their initial or foremost concern when they were diagnosed with breast cancer, (Taylor-Brown, et al., 2000). Rather, their responses reflected a variety of reactions and concerns that were grounded in and shaped by the realities of their daily lives. The women remembered experiencing feelings of shock, devastation and the incredulity of being diagnosed with a life threatening disease at the age of twenty-eight, thirty-six, forty-four and fifty-eight. They were concerned with how they were going to manage financial and day to day responsibilities, whether or not to defer goals and life plans, and if, when and how they were going to tell others, particularly intimates and other loved ones that they had a life threatening disease. Their initial concern or primary reaction to their diagnosis was not the fear of losing their breast, but had more to do with being diagnosed with a potentially fatal disease and the possibility of dying from it (Couch and McKenzie, 2000; Fallowfield and Hall, 1990; Langelier and Sullivan, 1998; Loveys and Klaich, 1991; Peters-Golden, 1982), including the social and practical consequences that treatment for the disease would have on their lives. This is not to say that the possibility of breast loss was not an issue nor a concern because it was for many women. However, it was a concern that emerged later in their "breast cancer journey" (Lindop and Cannon, 2001) and it was a concern that differed across women in terms of significance and degree.

### **Contextualising the experience of breast cancer**

Women's responses to the loss of all or part of their breast were multiple and varied, and revealed an experience that was complex, contradictory and contextually

situated (Millsted and Firth, 2003). How women responded to and made sense of their altered breast was mediated by a series of factors including but not limited to: how 'feminine identified' (importance of femininity - of 'doing' and of being regarded by others as 'feminine' - to their self concept and self representations) they were prior to their breast cancer; whether or not their breasts were integral to their self definitions as feminine or as a woman; the nature of the 'relationship' that they had with their breasts prior to their surgical treatment (i.e were they a source of physical pleasure or discomfort/pain, did they like how they looked and felt, were they a part of their sexuality and sexual play, how their sexual partners responded to their breasts, had they breastfed, were they a source of embarrassment, harassment or pride, etc); as well as their preexisting constructs of themselves as a "woman" and as feminine, and the importance that they placed on heteronormative physical attractiveness and appearance. According to Goldberg et al:

"Each woman interprets her own secondary sex characteristics in a unique fashion; physiological changes interact with cultural values and psychological factors. The importance a woman places on her breasts before surgery has a definite influence on her reactions later. The more the breasts are valued, the more a woman's body image will be shaken." (1984: 39)

Also influencing how women responded to the loss of their breasts were a series of socio-psychological factors such as their 'inner resources' and 'psychological make up', their coping abilities, age at diagnosis and position in the life course, their familial, social, and cultural environments including the emotional and financial supports that were available to them (Payne, et al., 1996).

Analysis of the data showed that there were two possible responses on the part of the women. One group consisted of those women who did not regard or experience the loss of their breast as a threat to their femininity or sense of self as a woman and those who did. However, this second group of women varied in how and to what degree their sense of self as feminine or as a woman was negatively impacted. The following section addresses the responses of the group of women for whom the loss of or changes to their breast did not affect their sense of self as feminine or female and the factors that shaped and mediated this experience.

### **Surviving breast cancer**

Within this particular group of women were several who regarded the loss of or changes to their breast as something that was 'inconsequential' and located the changes to and loss of their breast within a number of contexts, principally within the larger context of surviving a life threatening disease (Aaronson et al., 1988; Goldsmith and Alday, 1971;

Lloyd, et al., 2000; Margolis et al., 1990; Meyerowitz, 1981). When framed within this context, concerns about femininity and femaleness were less salient than existential concerns about recurrence and survival (Crouch and McKenzie, 2000; Loveys and Klaich, 1991; Paillasse, 1997; Spencer et al., 1999).

Breasts over life? There's no question. This group no. There are some women on the team that yes it is important, but the majority of them here I think all have the same philosophy. (Mighty Mouse)

No. I'd only ever known one person before this to have cancer and they died. So that's what the concern was. Yeah. (Mimi)

My focus was on surviving. I would and still would be willing to have anything cut out or off. I just wanted to live and with that came a determination to live life to the fullest as a human being, and to love, help others and just have a good time. (Sarah)

Particular aspects of women's lives also mediated this experience. Lola and Emma, both whom had younger children still living at home said that the loss of their breast was a "small price to pay" if it meant surviving and being around to raise and care for their children. Similar findings were found by Spencer et al (1999) who found that several women in their study were highly concerned with the possibility of not being able to live out important relationships, and of not being around to see their children grow up.

No. To me it was a small price to pay (loss of her breast) because my children were quite young, they were 11, 8 and 4 at the time and it was just before Christmas that I found out. So to me it was a small price to pay. (Lola)

You know, no, because I just kept looking at my daughter, and thinking oh god, like I just want to live. Um I guess I always thought you know if it really bothered me I could have the reconstruction. I'm not, I wasn't concerned about it. I just wanted to make sure that I live long enough to see my daughter secure in her own life. (Emma)

Women's relationship with their breasts also mediated this experience. There were several women in this group who regarded their breasts as an inconsequential body part. Within the context of breast cancer, breasts were objectified as diseased and gendered and sexual meanings became unimportant to their sense of self. Here excised or altered breasts were accorded little meaning or significance and the overriding concern for this group was the removal of what they perceived as a dangerous appendage that could potentially and prematurely end their lives.

Get rid of it, it's only a boob, who cares. That was me... That's right, who cares! Who cares! (Esmeralda)

I just wanted to be rid of it. I know that some of the girls fought to keep their breasts and all that and I was like, if its got cancer in it I don't want it. Just get it out, take it away. (Babs)

In a similar vein, some women like Reluctant Paddler and Bette regarded the loss of their breast(s) as inconsequential when compared to the possible loss of other, and more 'important' body parts such as an arm or a leg. In this context the breast was accorded a low status on the 'body part hierarchy', and was perceived as an unimportant and unnecessary appendage because it lacked purpose, was only an aesthetic, or simply was "there" and did not or no longer had a particular function. Losing a breast was perceived as having little consequence to their physicality and was also seen as not interfering with their lives or their corporeality in the same way in which another body part like an arm or a leg or even a finger would.

They're not terribly important because for me they're not functional. Like my arms and my legs I need. My breasts, they just kind of hang, part of myself but not part of my, how can I explain it? Like a machine that has a part that's just there for aesthetics, that's how I consider the breast. It doesn't actually do anything functional for me, I mean it does for some people, but not for me. (Reluctant Paddler)

Because it didn't interfere with my life. A leg would interfere with my life, a foot would interfere with my life, God even a finger interferes. You hurt your finger and you can't do up your stupid button. So not even that it was invisible, just that it wasn't going to interfere with my lifestyle. (Bette)

Surviving cancer was paramount and this took precedence over any concerns about keeping one's breast (Spencer et al., 1999) or what possible impact the loss of their breast might have on their sense of self as feminine or female. Those with younger children felt both a need and a responsibility to be alive to care for and raise their children, and were more concerned with what life would be like for them if they were not around to care for them. Within the context of surviving a life threatening illness, several women constructed and regarded their breasts as unimportant and inconsequential to their daily lives and referred to them as unnecessary pieces of skin or as low ranking body parts that they did not need to function or to survive, and which they could live without.

## **Unimportance of femininity**

Also within the group of women who said that their sense of self as feminine or female was not threatened or usurped by the loss of their breast were several women for whom femininity (i.e. looking, acting and being regarded by others as feminine) was of little interest or concern. Both Morgan and Reluctant Paddler stated that they did not identify with, feel, nor regard themselves as particularly feminine in the first place, so a threat to self definitions and self perceptions of femininity was a non-issue for them.

I never considered myself a feminine person. I had three brothers and I was a tomboy. What they could do I could do just as good you know? And only back then that I wore high heels and a dress, that's what I consider feminine. I never was. I even felt comfortable in men's clothes. (Morgan)

I don't, and I've never felt, and I don't mean this to sound the way it's going to sound, I've never felt particularly feminine. You know how some women like to be feminine, and I'm not not feminine, but I have never felt greatly feminine. I look at other people who are very feminine looking and I have never felt that I am. (Reluctant Paddler)

Some of the same women also said that the loss of their breast did not challenge their sense of self as a woman (femaleness) because they were still 'essentially' the same person regardless of changes to their physical self. For these women having breasts was not the primary nor sole criterion by which they defined or experienced themselves as women, and they rejected the reduction of their sense of self as female and feminine to the presence or absence of breasts.

I do not think that the changes in my breast has changed my sense of self as a woman because I feel that inside myself I am still the same person in my heart and no physical change in my breast has changed that feeling. (Macaulay)

I don't consider myself any less a woman because I now have one wonky breast. (Reluctant Paddler)

I feel I'm a woman, you know? Like, I don't feel just because I've lost a boob that I'm no longer a woman. (Babs)

Of interest was the response of one woman who said that having breast cancer can 'actually' reinforce one's sense of self as female or feminine rather than threatening it because breast cancer was predominantly a 'female' disease.



No because breast cancer is definitely a female dominated illness and so even having that you can't feel unfeminine or not like a woman because the majority is women who get it. (Lola)

Unacknowledged and ignored in the breast cancer literature are those women for whom the loss of or changes to their breast did not affect their sense of self as feminine or female, and whose existence in part challenges this assumption. Although women are well aware of the cultural norms of heteronormative femininity, this does not necessarily mean that there is an "unmitigated internalization" (Langellier and Sullivan, 1998: 85) of these discourses and practices, or that there is a desire to emulate and participate in them. In their study of women's breast cancer narratives, Langellier and Sullivan also found women who did not refer to concerns about femininity and body image as a result of breast loss and who were critical of these concerns in their breast talk. They state that although breast cancer problematises women's taken-for-granted experiences of being breasted, the meanings associated with gendered breasts cannot be reduced to a singular meaning or experience (Langellier and Sullivan, 1998).

### **Ambivalence about breasts**

According to Millsted and Firth, "Women's breasts are invested with social, cultural and political meanings which shape the ways in which we make sense of and experience our embodied selves." (2003: 455) The ways in which women respond to the loss of their breast as a result of breast cancer and the nature of the impact, if any, that it has on their sense of self as feminine or female will be shaped and mediated by these socio-cultural and political meanings, including counter discourses and meanings that challenge these narratives. However, mediating these multiple meanings are women's own perceptions of their breasts that are the result of the nature of the relationship and the kinds of experiences that they had with their breasts prior to their illness experience. Within this particular group of women were several who felt ambivalent about their breasts because of how their breasts looked and as a result, accorded their breasts little prestige or significance. Reluctant Paddler felt ambivalent about her breasts because they didn't resemble the cultural ideal of the perky breast while Babs's ambivalence was because she felt that her breasts were too small.

They didn't ever look the way I thought they should look. They didn't look like the models on tv, but that's okay. Myself, they felt about what I would expect, but looking, you know the perky little breasts that some people have, I'd never have perky little breasts. (Reluctant Paddler)

Oh, they were too small. I look at my sisters and they got my share. (Laughing)  
And my oldest sister, she's 18 months older than me. She's out here. My youngest

sister, she's 11 years younger than me and she's out here. What happened to me?  
(Babs)

Others were ambivalent or indifferent towards their breasts because they did not like the way that their breasts felt. For both Babs and Morgan, their breasts were at times painful and for Morgan burdensome because they were too large.

They got sore before my periods and then it was ahhh stay away from me don't even touch me. (Babs)

Yeah, well, yeah how they looked when I was younger. Now as I say, last 20 years, I wish I could have taken some off. No, now they're a burden. (Morgan)

Breasts were also unimportant or were lacking in meaning to women like Princess Margaret and Babs because they were not a source of physical and sexual pleasure, nor were they a part of their sexuality or sexual play.

Not to me, to my husband. (Princess Margaret)

They were never very sensitive. I know for some women to have their breasts, you know, attended to when they were having sex and that I never felt that way so they were never very sensitive so I never, it wasn't a big thing to me. (Babs)

Breasts were also unimportant because they did not have a particular role or function at this particular stage in their lives.

No, because I'm not sexually active at this point. No. (Mimi)

It did not change my sense of self as a woman at all. I was 43 and I was not going to have any more children to breastfeed, therefore the loss of my breast was almost superficial. I can still nurture. (Babs)

Thus for a number of women, breasts were neither a valued nor desired physical attribute and for a number of different reasons. Even though the female breast is imbued with social and cultural power because of its sexual connotations, (Langellier and Sullivan, 1998; Lee, 1997; Millsted and Firth, 2003; Young, 1990) many of the women did not regard or experience their breasts in this manner, nor did they use their breasts to relate to, influence or gain favour in their relationships with men.

No, I sort of, that's not my style. [*Were you aware of their power, were you aware that they could be used?*] No, well maybe when I saw it in other people but not for me. [*Not something you ever cultivated in yourself?*] No. (Reluctant Paddler)

And for Bette and Penelope, breasts were simply there and had no special meaning or significance, and for Penelope, even within the context of breastfeeding.

They were there. (Bette)

To me it was just a natural part of motherhood, something that, again, I didn't, it was just something that you did, that I did for a while and then that was all. It wasn't this big thing for me. It was just something natural, that's what they're there for. (Penelope)

Prior to their breast cancer illness experience, the women were already positioned towards their breasts in a number of complex, contradictory and contextually situated ways as a result of the "kinds" of breasts that they had (large vs. small, perky vs. saggy), as well as how they regarded (liked vs. disliked) and experienced their breasts physically and in their relationships with others (i.e. as a source of pleasure or pain, importance to their relationships with others, as source of power or as a burden, how others responded to their breastedness and whether or not they were validated or derided for the look and presentation of their breasts). This prior positioning will to varying degrees shape and inform how women make sense of and respond to the loss of their breast and whether or not and to what degree this impacts their sense of self as feminine or as a woman (Goldberg et al., 1984; Lloyd et al., 2000). For the women quoted above, breasts (and for some within the context of having breast cancer) were regarded with ambivalence and were not perceived as integral to either their sense of self as feminine or as a woman.

Of particular interest was the group of women (and a group that has been ignored and unrepresented in the literature) for whom femininity was not a part of or important to their self concept. The women said that they did not "feel" particularly feminine in the first place or were interested or invested in (doing) femininity, so for them, the loss of their breast as a threat or challenge to their sense of self as feminine was a non-issue. For the women in this group, the loss of their breast(s) did not threaten or usurp their sense of self as a woman because this core aspect of self identity was not predicated on or reducible the possession of breasts. These women challenged and refused this reduction and regarded their sense of self as women as more complex, and breasts were not the sole means by which they understood or experienced themselves as women. Relevant here were the ways in which women were already orientated toward or positioned by their breasts prior to their breast cancer experience. Several women revealed an attitude that was ambivalent because of the ways in which they did and did not experience their

breasts. For these women breasts were of little importance because they lacked function or meaning and were not a part of or were integral to their self concept or to embodied experiences that were defined and experienced as feminine or female. Hence, for this particular group of women, their sense of self as feminine or as female was not centred around or dependent upon their breasts and their responses revealed that the gendered self concept is fragmented and multiple, complex and contextually mediated and is not unproblematically or naturally connected to or necessarily located within women's embodiment and physiology.

Breasts do not a woman make. (Mimi)

Everything wasn't dependent on my breasts.... [they] didn't define who I was.  
(Martha)

### **Breast loss as a threat to femininity or femaleness**

The second group of women were those who reported experiencing a sense of loss or challenge to their sense of self as feminine or as a woman as a result of having lost all or part of their breast to breast cancer. However, for many of these same women this threat or challenge was limited and was influenced and shaped by a series of factors that were contextually specific. Although the notion of a challenge or threat to femininity or femaleness is a predominant assumption and assertion within the breast cancer literature, missing from these analyses is an understanding of the nuanced, multiple, contradictory and complex ways in which women make sense of this experience and just how women's sense of self as feminine or female is threatened or challenged by the loss of their breast. According to Millsted and Firth:

"Women's breasted experience is complex, contradictory and conflicting - we do not just have one response but many and these responses are local and specific to each context in which we find ourselves, and our intentions, purpose and sense of agency within these contexts." (2003: 463)

In the following section I focus on the ways in which women's sense of self as feminine or as female as problematised by the loss of or changes to their breast and what factors were instrumental in shaping and influencing this experience.

#### *Threats to self identity*

For the women in this second group there were several who were negatively affected by the loss of or changes to their breast because their breasts had become an

integral part of their sense of themselves as either female or feminine<sup>12</sup>. For these women their sense of self as female or feminine was experienced through their breasts. For Veronica, her breasts were fundamental to her sense of self as feminine because they had come to define her as large breasted even at an early age, and as a result, orientated her towards her breast in particular ways. As the recipient of both welcome and unwelcomed remarks (i.e. approving gazes and comments but also cat-calls and unsolicited sexual remarks) from men about the size of her breasts, Veronica's breasts made her feel different and special. For Didi, her breasts were in a number of ways integral to her sense of self as feminine because of how she physically experienced her breasts (as a major erogenous zone) and the role that they played in her relationships with others.

I would say they were probably pretty important because they came along really early and so they defined who I was, good and bad growing up... So early on it was just the fact that I had the bra on and nobody else did. (Veronica)

They were a part of my femininity, a part of my sexual being, a part of my nurturing as a mother. I had very sensitive nipples, a major erogenous zone for me. (Didi)

The loss of a breast also challenged Esther's and Lola's sense of self as feminine because of how their bodies now looked and/or felt. Altered or missing breasts, surgical scars and/or burn marks from radiation left several women feeling unattractive and deformed, while others said that they felt that something was missing and were aware of their body (and of being in their body) as feeling different and incomplete.

*[Did you feel like a lesser woman?]* Yep, oh yeah. I felt freaky, deformed. Deformed I guess. Freaky is a little too strong. *[And now?]* But it's taken, even to this last, 3 months ago, when I got the second reconstruction. (Esther)

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<sup>12</sup> Most of the women interviewed made a distinction between femininity (how you look and feel) and femaleness (what you are biologically) and what was negatively affected by the loss of or changes to their breast. A few women regarded femaleness and femininity as the same thing as they regarded femininity as a 'natural' effect of being biologically female. However, the women tended to regard the loss of/changes to their breast as a threat to their sense of self as female, rather than femininity because they could still look feminine. None of the women regarded the loss of or changes to their breast as negatively affecting both femininity and femaleness - it was either one or the other.

Yeah because you just don't feel whole, you feel like there's something missing, especially since it is like a sexual organ. [*So that was a distinctive loss for you was the sense of femininity?*] Yes it was. (Lola)

Often these reactions and feelings of being unfeminine or unwomanly came from elsewhere and were the result of other peoples' negative or critical responses to the loss of their breast. Lucille said that although she had accepted how she looked, it was the way in which her husband responded to her amputated breast and his continued pressure for her to have breast reconstruction that challenged her sense of self as feminine.

Not as much. [*And can you say what changed, why you feel less feminine?*] I don't know, I guess it's partly due to the way my husband feels and it's almost a defensive thing where I'm thinking, I don't care you know, kind of thing. I think that has a lot to do with it. Maybe with a different partner I still would, but it has changed my attitude, it has changed the way I feel. (Lucille)

The attitudes and advice of some breast cancer oncologists and other health care practitioners (as medical experts) also had the potential to contribute to women's feelings of being unfeminine or unwomanly. Bush (2000) argues that medical discourses play a fundamental and important role in constructing and defining femininity, and is now the dominant discourse in controlling women's bodies. Mighty Mouse spoke of how her doctors tried to dissuade her from undergoing a much wanted second mastectomy because of their belief that a mastectomy would have negative psychological effects. Meanwhile, Lola, Princess Di and Macaulay reported that they chose to have reconstructive surgery because their doctors offered it to them, but insisting that it would be the "best thing" for them.

Well I think from the way the doctors deal with it and you know they really try to put you off from having that mastectomy because they think you're not going to be able to handle it. And I think its more, and especially because most of the surgeons are male. I think it's their perspective of what we probably feel when it's actually their own feelings. If they could just get by that. (Mighty Mouse)

I'm not the type to challenge the diagnosis of the doctor. Like I won't, like research and I just accepted. I figured if they've been in school for so many years they know what they're doing. (Lola)

Yes because the doctor thought it would be the best thing for me. (Princess Di)

So you know if I didn't have the reconstruction I think I probably would have been perfectly fine but it was just offered and I accepted and I just went in that direction. (Macaulay)

Just as the actual responses of others challenged and problematised women's sense of self as feminine or as a woman, the imagined and anticipated reactions of others that women now had "in their heads" could also produce this effect. Several women felt that family, friends and society in general now viewed them differently because of the changes to their bodies. Similar results were found by Paillasse (1997) who reported that the women in her study stated that they felt that friends and family members no longer responded to them in the same ways as they did prior to their breast cancer diagnosis. Gabby, whose husband was a "breast man" was concerned that he would find her less sexually desirable because of her missing breast.

Men are divided up into leg men and breast men and that's a fact. And they'll either notice a girl's legs or they'll notice her breasts. Well, my husband was a breast man and so I was dealing with that over here. (Gabby)

Martha was concerned that those who knew that she had breast cancer would now regard her as less feminine even though she herself did not feel this way. However, Martha also felt the need to work that much harder in order to ensure that she continued to look sexy and attractive so that people would not regard her as diminished.

I just want to prove to other people that I still got it, that it hasn't masculated me in any way to have this disease. That I'm still feminine and wanting to make sure other people still know that because I still know it.... And I think probably if I had to push it I would say I really take care to look still sexy or very attractive in clothing just to show people that even though I had breast cancer, I'm still me, I'm still here and there's nothing really missing and it just goes part and parcel with okay I've always had it, I still got it. (Martha)

This concern with others' less than favourable perceptions shaped how the single women positioned themselves in terms of possible future relationships. They worried about what impact the loss of or changes to their breast would have on these potential relationships. Dorothy for example, felt that to disclose to others that she had breast cancer and was either scarred and single breasted, moved her from a position of being potentially discreditable to a position of being discredited (Crouch and McKenzie, 2000). The women were aware of the stigmatising effects that disclosing their breast cancer status to others could potentially have for them.

It has crossed my mind that I have not had a relationship since. That it has crossed my mind that the person will have to be warned (laughing) which I guess if you talk at all to someone it's bound to come up, but it's a major part of your life.  
(Dorothy)

However, many women like Lola and Suzanna responded in ways that gave the impression that they were of "two minds", that they had moments when they experienced the loss of their breast in troublesome ways but also had moments when they regarded this experience as not all that bad.

I thought, I couldn't look at it, but I wasn't as bad as I thought... I don't feel quite whole. I feel like something is missing. Yeah, but, and I also thought well, it's nothing visible, that from the outside, not like an arm or a leg or everybody looking at you could see that you had lost something. (Lola)

I know it's not there, I know I'm one sided but I'm able to laugh about it.  
(Suzanna)

The responses above indicate that for many women the loss of their breast threatened or problematised their sense of self as feminine or as a woman but in a series of different ways. Some women felt that the loss of or changes to their breast altered their sense of who they were because their breasts had or continued to play an important and instrumental role in their lives and were key in shaping their sense of self as this or that kind of person. Others experienced a sense of loss or threat to femininity or femaleness because of the way in which their bodies now looked and felt. Their altered and scarred bodies no longer conformed to, or looked even less like the dominant cultural ideals and representations of normative femininity. The reactions and responses of others both real and imagined be they sexual partners, medical experts or the 'generalised other' also played a role in shaping and influencing how, and to what degree the women internalised the loss of their breast as a threat to their sense of self as feminine or female. For many of the women in this group, having breasts and the meanings that were accorded to their breasted embodiment (i.e. how they physically experienced their breasts) were integral to their understanding and experience of themselves as feminine or female, while for others, their sense of self as female or feminine was dependent upon others's responses and evaluations of them and their bodies as female/feminine (Millsted and Firth, 2003).

However for many of the same women, these reactions and feelings of loss and threat were transitory and lessened or faded over time. This was the case for both Sophia and Meryl.



As time went on I got more relaxed about it and, I mean I don't feel myself, or I don't consider myself gorgeous with a partial breast but I can laugh a little bit more now about it than I did at first. It took me a while. (Sophia)

Oh, never think about it. No. [*Or even when you lie down you go oh that's different?*] Well, again seven years you get used to it. [*So it's not like every once and a while you have this strange perspective?*] Oh I'd say a year after treatment, I'd say yeah. Not a bother. (Meryl)

Most of the women in this second group eventually made a series of adjustments and came to define their experiences and themselves in ways that most of the time, made the loss of their breast secondary or less problematic. Over time, almost every one<sup>13</sup> of the women was able to re-frame this experience in ways that did not dwell on the negative effects of their breast cancer surgery.

### **Re-framing breast cancer and reclaiming femininity**

The further these women were away from their breast cancer surgery and treatment experiences, the easier it became for them to begin to re-frame this experience that went beyond the assumption of loss of or threat to femininity. Similar to the ways in which individuals respond to the disruption of a critical illness, these women were able to bring about a "negotiated settlement" (Charmaz, 1995; Gadow, 1982; Williams, 1996), between a disrupted gendered body and gendered self. This "realignment" between the self and the now problematised and marked body had to be actively struggled over and consciously worked at in order to turn this experience around. Gabby stated that she consciously made the decision to put her cancer experience behind her and to not let its negative effects interfere with her life. Emma worked hard at accepting her breast cancer body and altered self by not hiding her single breastedness from other women when showering and changing at her local swimming pool.

So now you've got a choice and I think that you have to consciously do this. You're either going to drag that little bag around with you for the rest of your life because you've just been handed your life and the fact is that, like its all a learning process. (Gabby)

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<sup>13</sup> There was one woman in the group interviewed who continued to struggle with how her breast looked 30 years after her initial treatment and two breast reconstructions. Highly conscious about all aspects of her physical appearance, the loss of her breast was but one among many concerns and insecurities that she had about her physical appearance and sense of attractiveness.

I remember when I was at the Y swimming all the time and just, like, took my bathing suit off and here I am you know one breast and having a shower and it took a lot. I had to do it, I had to do it cause that's the way that I was able to accept myself. And so I was comfortable with it. (Emma)

Although difficult from time to time, the women were able to manage and come to terms with the loss of their breast by developing alternative bodily practices or new or modified ways to think about and relate to their breasts and their bodies. Didi, whose breasts were an integral part of her sense of self as feminine (as sexual and sexually desirable), and played a physical part in her experiences of sexual pleasure, said that she was able to reclaim part of her femininity and sexuality by accepting her body and developing a new awareness of her breasts.

Initially I did. Yeah initially I did and with time and distance from the diagnosis from the treatment, just developing an acceptance and a new awareness of what my body is and what my breasts are. Yeah, that's changed. I can't say it's all in a negative way... initially because of the loss of sensation. Physiologically there was a numbness and a loss, a separation that took place and I think over time I've got that connection back [but] it's not the same connection. (Didi)

Some women like Dorothy and Charlie adjusted to and managed the changes to their breasts by referring to their altered breast as like a war wound or badge of honour that turned this mutilating and life threatening illness experience into one of accomplishment and pride. Here the altered breast and mutilated body became signifiers of passage and of a difficult and traumatic experience that was weathered and won.

I've gotten used to it and it's almost like a war wound to me now. At first I was a little self conscious and there was less difference. Maybe I put on weight or the left one's gaining or something. I'm noticing a big difference now but I've gotten used to the fact and it's the least of my issues with my appearance. (Dorothy)

I like my body. I like my body now. I like my body with my scar. When it was fresh and really ugly, and like I said its beautiful now, it's my badge, and like here it is and I'm not afraid to show it. I'm okay with it. (Charlie)

And in ways similar to the women in the first group, the women in this second group also came to (re)prioritize other aspects of their lives over that of their breasts and how they now looked.

Except for this, (pool of fluid under her arm) that's why I wear black a lot because you don't notice this. I can't wear white because you can see it. At the same time

you've got to remember you're alive. Okay, that's the bottom line here. I'm here.  
(Gabby)

With the exception of a few studies like the one by Krouse and Krouse (1982) who found that women treated with mastectomy experienced an initial but brief crisis of identity and eventually adapted to the loss of their breast, missing from much of the breast cancer literature is an understanding that many women do eventually adjust to a body marked by breast cancer and that many women regain or reaffirm a sense of self as feminine after a period of disruption and self doubt. Similarly, Charmaz (1995), in her study on adapting to chronic illness, found that although appearance concerns impact women more so than men, compared to men women tend to show a greater resilience in facing illness and a greater ability to adapt to an illness experience. For the women in this group whose sense of self as feminine or female was problematised, over time they were able to regain a sense of control over both their lives and their bodies. Although their bodies initially felt alien and unfamiliar especially right after treatment, over time these feelings of strangeness dissipated as the alien and unfamiliar became integrated into their new embodied normal and familiar (Charmaz, 1995).

*[Did you miss your breast, did you miss it not being there, were you aware of that?]* Yes and no. Sometimes but not a whole lot because I did have the thing [the prosthesis]. And when that was on it felt very normal, like you almost forgot that it wasn't real. *[Is that right?]* Yeah, but I didn't wear it at night, I didn't wear it to bed or anything and then in the morning, you know you'd go take your shower and then, "Oh yeah! (Laughing.) Oh yeah, yeah." *[And that felt okay?]* Oh yeah. In fact, the first time I got it I put it on and went "Feel my boobs!" (Macaulay)

### **Benefits accrued from dragon boat racing**

Like the women in the first group, this second group of women were also able to re-cast their breast cancer experience from that of loss and threat to one that was in several ways regarded as beneficial (Carpenter et al., 1999; Colyer, 1996; Loveys and Klaich, 1991; Utley, 1999). An important benefit that emerged out from their breast cancer illness experience was becoming a member of the dragon boat team. Participation in dragon boat racing had a tremendous impact on many of these women's lives and in several ways constituted a life altering experience for them as this sporting activity and group of women became an important and vital force in their lives.

In a way it's opened some doors like the dragon boat and meeting a lot of other fabulous women, really exceptional women and it's just amazing. Probably more positive than negative. (Meryl)

Oh god it saved my life. I think, in terms emotionally... You know, especially after I had the cancer and my body had, it was such an assault that it took a couple of years just to get back. (Emma)

Being a member of the team and socialising with women who shared a similar and difficult life experience but who held counter-hegemonic perspectives concerning the loss of their breast (e.g. the women in the non-threat group), played an important role in helping some of the women in this second group come to terms with their feelings of loss or threat. For Sophia, participating in dragon boating accorded her the opportunity to develop a different outlook on life that enabled her to feel happier and better about herself.

It's given me a whole different outlook on life. It's just lifted me, it's given me a lift on how I feel about myself. Just, it's made me feel happier. (Sophia)

These alternative view points were often expressed through the use of 'gallows' style humour and by making light of the fact that they were now 'slightly off' or single breasted. Gabby who was large breasted and who had a mastectomy now used her empty bra cup as a 'catch all' and where she kept her handkerchief, lipstick and assorted sundries.

Learn from it, make the best of it and laugh at it. Laugh at the fact that you can do that and of course with the dragon boat team. I have this rag because I'm sweating all the time while I'm there. I take the rag and I dry myself and then I went in here [she puts her hand over her top and into her bra] and I brought out a lipstick. I don't think they'll ever forget it. (Laughter). I said what did you want? Lets see what I've got down here, a bus ticket! (Laughter) Get on with it, get over it and make light of it. We've been given another opportunity here because some of our colleagues haven't. (Gabby)

Being a member of the dragon boat team also allowed women the opportunity to be with and see other women who were 'just like them' and who continued to look, act and 'be' feminine and women in spite of the fact that they were missing all or part of their breast. The 'physical' existence of the team helped to reaffirm and reinforce some women's sense of self as feminine or female and provided them with 'living proof' that 'being' feminine and female were not solely predicated on having breasts, (or that not having a breast(s) meant you were unfeminine), thereby challenging the assumption of threat, lack and loss.

[*What makes you feel feminine?*] Dragon boating. I really do because I'm around all these strong women who've all been through this and they're saying yeah you

know we might be missing this and this but we're still women. And I think a little stronger because we're not so obsessed with looks or breasts. I mean to one extent, or obsessed even if it's just obsessing that we're missing. I don't know, just being around them really. And yeah, you find that you look good. I come to practice, I almost feel like I'm more at home around all the other women who've been through it too. And you know what? Like when I'm there I forget the whole age difference, I really do. Every now and again one of them will say "Oh you're around all these women that are older than you" and I forget that when I'm around them. Feminine, like I see feminine women. Like they just, I don't think femininity can be, it is defined as like how prissy you are but it shouldn't be. (Queenie)

Not only did the dragon boat team allow some women to see themselves and other women as still feminine, it at the same time also allowed them to challenge narrow and prescriptive constructions of femininity. Being in the company of this group of women It also afforded them the opportunity to shift their focus away from the loss of their breast(s) and on to other and more positive aspects of their body and physicality. The experience of dragon boating for this particular group of women living with breast cancer was about living a full, active and productive life after breast cancer and not dwelling on the negative effects of one's illness experience. The focus instead was on what you could do and what you were capable of doing rather than what you could not. What emerged for many women from this experience was the development of a body that was athletic, healthy, fit, muscular, and powerful. Dragon boating enabled some women to once again, and other women for the first time, to experience their bodies differently and as a site of pleasure and pride in ways that were different from that of the heteronormative (i.e. the concern over conventional feminine attractiveness and thinness).

Well, even the dragon boat ladies, when we first started getting down to our tee-shirts, somebody said to me "How old are you?" And I said 56, and they said "God, I hope I have your body when I'm your age!" And I said thank you. This isn't all God given, some of this is worked for. (Martha)

The dragon boat and the clubhouse areas were spaces and places that allowed women the opportunity to accept and come to terms with the loss of their breast in an environment that was accepting and supportive. When on the boat or hanging around the clubhouse, these women were able to be themselves as single breasted, lopsided or even flat chested women. In these environments the women did not have to apologize for nor hide from others their physical difference for fear of upsetting or offending them. Gabby who struggled with wearing her gel prosthesis (it was rather large, heavy and cumbersome) and whose husband would chastise her when she would go without it, found that the dragon boat team, the clubhouse, the boat and the training pool were locales that

allowed her to express who she now was. Mimi who had a double mastectomy and who chose not to wear prostheses, felt a sense of empowerment because she too could be herself in this environment and not what others expected her to be - breasted, 'normal' and masking her difference.

So now the only place I go without it is the dragon boat because I tried to. First of all I had to express myself, myself was nothing there. (Gabby)

All of this might have been a totally or would have been a totally different experience without the dragon boat because it's given you a power base to work from. If you were going through all of this as an isolated individual it would have been totally different. But being a part of this group where the joke is you can't wear your prosthesis on the boat because it weighs too much it has to go overboard, it's a totally liberating thing. It allows you to be who you are, not who you're expected to be and that has been a huge bonus. (Mimi)

Although this second group of women experienced a sense of loss or challenge to their sense of self as feminine or female as a result of the loss of or changes to their breast, this sense of loss was a transitory and fragmented experience that eventually became less salient over time. The women in this group were able to re-frame and reclaim their sense of self as feminine and female by thinking differently about the loss of their breast and by establishing a new awareness of and 'relationship' with their breasts and their bodies. Integral to this experience was the role played by the dragon boat team that allowed women, through strenuous physical activity and team camaraderie, to experience and think differently about their breasts and their bodies. By communing with women who shared a similar life experience, these women were also exposed to alternative definitions of the situation concerning the meaning(s) of loss of their breast and were able to see for themselves the femininity and femaleness of other women who like them had also lost all or part of their breast to breast cancer.

### **Momentary challenges**

It is important to note that although many were able to frame and re-frame their breast cancer experience in a more positive light, accept and come to terms with the loss of their breast as well as regain or reconstruct a sense of self as feminine or female, there were moments, although fleeting and which could arise at any time, when this new resolve was challenged or threatened. Both Sophia and Emma mentioned that there were moments when they did not feel good about their marked or single breasted bodies.

Sometimes I feel okay about my body and other times I don't. (Sophia)

I have more moments now than I did then at that time. (Emma)

These moments of self-doubt however, did not always originate from within the women themselves. Rather, they were often the result of the critical comments or reactions of others who brought back into their consciousness a sense of difference or lack which undermined their confidence and challenged their new but fragile resolve. Veronica who had from a young age enjoyed the approving glances and comments of others concerning her physical attractiveness now felt as though their gazes were no longer favourable but critical and dismissive.

I think it does in that it affects your confidence, you know, like I was aware of being looked at and stared at and now it's being, how do I say this properly? It's being, I knew before when I got stared at it was an appraising kind of a glance, whereas now as I get looked at or checked out, it's right away, well what's wrong? (Veronica)

Women's own bodies acted as daily reminders that they were missing all or part of their breast which also brought back feelings of lack or loss. This aspect of corporeality was not simply about how the body looked; it was also about how the body now felt. Didi was aware that the surface of her body now lacked the smooth and continuous feel that it had pre-surgery, while Gabby's awareness of her missing breast was triggered by another body part that had also been compromised by her surgeries. Often it was the pain experienced from her "frozen" shoulder that would trigger Gabby's awareness of her missing breast.

Definitely, it's not that smooth continuous feel that I had pre-breast cancer. It feels hollow. (Didi)

Oh absolutely. But not everyday. Not every minute and not everyday. And not every week, but oh yeah. Because of the shoulder I'm very aware of it (her breast) not there. When I go to physiotherapy I'm very aware of not there. I wake up in the middle of the night and I'm very aware of it not there. I used to say the first 10 seconds it's a sting, you wake up (snaps her fingers) and you're right there again but I'm past the stinging, I'm just aware of it. (Gabby)

One's body, as a daily physical reminder, was not just about the loss of a body part deemed feminine and female; it was also a physical and daily reminder that they have breast cancer (Crouch and McKenzie, 2000). Thomas-MacLean (2005) states that changes to a woman's body acts as a constant reminder of her illness, limitation and disability and that her breast cancer remains as a present and immediate experience.

It's just something we know. Its in the back of your mind, it will always be in the back of your mind. When you get up in the morning and you know yeah you're disfigured, yeah, but you're alive. So that's all you care about but every morning when you take that shower, it's there to remind you. Every time you look in the mirror to get ready you know its different, you're alive but it's different. I guess maybe it's in the back of our psyche when we go to bed and will we wake up tomorrow? (Mighty Mouse)

However, just as the reactions of others as well as living with a scarred, altered and problematised body sometimes reinforced their sense of loss and could undermine their reconstructed senses of self as feminine or female, the reactions of others and the experiences of one's own body could also help in enabling them to move past and beyond these disruptive moments. Integral to this experience were the reactions and responses of significant others, particularly those of husbands or intimate and sexual partners. If husbands were accepting and continued to be supportive, then women were less concerned with or critical of how they looked and were able to readjust to and re-accept their altered or missing breast. Similarly, Lindop and Cannon found that where body image and femininity were concerned, married women and women with partners "expressed higher needs in relation to husband's/partner's acceptance of a changed appearance than their own adaptation to it." (2001:769)

It took a period of adjustment [*Was he generally supportive?*] Yeah he was. I think at first it was a shock for him too, but I think as time went on he was very supportive. He was more comfortable with me and that's just the way we are, take the good with the bad. And I think his support helped me to think differently about myself. I think if I had someone or I was with someone that didn't like me as, didn't like my body the way it was, then I think it would be harder for me to adjust if I was with a man that didn't like my body. (Sophia)

Also, the thoughtful and supportive remarks of 'knowing others' helped some women to get past these difficult moments and to once again accept the changes to their bodies by contextualising and framing this experience for them and reassuring them that they were still the same person regardless of having lost a breast. Gabby credits an oncology nurse with helping her to put into perspective what losing her breast 'actually' meant (losing something that was threatening her life), and that in the larger scheme of things, it was something that had to be done.

And she said you have not lost any of your authentic self. You have not lost your heart, or your soul or your mind. You haven't lost any of your sense of humour. You haven't lost an arm or a leg. You've lost something that was going to end your life. I knew she was right, so I held onto her hand and she took off the



dressing and I looked down. And it wasn't the prettiest sight in the world but it wasn't the worst sight in the world either. She opened a door and pushed me through it and she pushed me down an aisle that I was going to be on the rest of my life. (Gabby)

Over time, several women like Babs and Didi became used to their altered or single breasted body (and for a few others total breastlessness) and spoke of developing a new orientation toward it, as well as a new embodied normal that included their missing or altered breast(s). For these women, their altered and scarred bodies eventually became incorporated into their embodied sense of self. Tait (1996 in Horden, 2000) states that it is a myth to maintain that breast surgery, and in particular mastectomy, results in all women having a negative image of her body. Although this may be the case for some women, other women are able to adapt to a changed body image over time.

I suppose now I can't even, I can't imagine having two. I'm just not aware of it. You see I'm fairly small, so it's, it wasn't as if, now when I run, then you can feel them. I imagine its almost like an amputation that you can actually think you can feel because I can't remember being aware that only one is jiggling. (Babs)

Yeah, I've sort of come to terms with the structure of my breasts and the lack of sensation. There's a lack there but it's a part of me now. You know, it's not foreign anymore than it was initially. (Didi)

Once again, many of these women were able to regain this re-framing and resolve and became better at keeping it in place.

My breast was just a piece of flesh, that's what I told myself. Funny how something that always got in the way became very important when it was gone. I guess it took a few months to realize I was still who I was previous to breast cancer. (Macaulay)

When I was going through the treatment I'm sure that it affected me more. Now no. You don't have a good image of yourself and it's, you know, and you're not feeling good. To me its more an issue of being tired and not feeling good. (Lola)

First of all I'm not going to worry about my body as much anymore. I can't be bothered. I am what I am. (Dorothy)

Helping women to get over these disruptive moments of self doubt was the dragon boat team. Not only did the dragon boat team provide these women with an activity that gave them an alternative way of relating to their body that was positive and not breast-

centred, but in their interactions with other women, including those who felt differently about the loss of their breast, exposed them to the possibility of thinking differently about what happened to them in relation to the loss of their breast.

There's also a whole group of people who need to be pulled up by just what this dragon boat does, and to be there for each other. We're not talking breast cancer, lots of times its never mentioned in a night, in any night. But you also know that there's somebody there to give you a hug if the hug is needed or to say to you "hey". And so you have to deal with it here and up here, you're whole physical being has to be back into it. (Gabby)

I was more self conscious with the first lumpectomy than with either mastectomy.... But that was before (the dragon boat team). With the recurrence and with the team I realized exactly what was important. Being alive was important. Feeling strong and healthy that was important. (Mimi)

I'm not overly comfortable with my body now, but I'm not uncomfortable, I'm just at a good plane. Considering everything that I've been through, It's okay. Everybody is hung up on how they look and it's okay, you know. I'm forty-two, three kids, survived cancer. And cellulite, come on baby! (Laughter.) (Lola)

Although over time many of the women were able to adjust to and accept the loss of or changes to their breast and bodies, they did experience moments when this new resolve was challenged. Any number of things could problematise this new resolve and this ranged from women's internalisation of dominant cultural discourses about ideal femininity and beauty, to the negative reactions and critical comments of others, to women's embodied awareness of their bodies in terms of how they now looked and felt. However, some of those factors that problematised women's resolve also enabled them to get past these moments, particularly the supportive comments and behaviours of physical intimates. Over time the women in this group were able to develop a new awareness of and orientation towards their bodies so that their altered or single breasted bodies became a part of their new embodied normal and were able to some degree 'forget' about their bodies and begin to once again take them for granted<sup>14</sup>. Integral to this process was the

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<sup>14</sup> This new taken-for-grantedness of the breast cancer body is a limited one because of the constant possibility that their cancer could return, and worse as metastatic breast cancer. The further away that they are from their diagnosis and treatment experiences the less heightened their awareness of (and anxiety over) their bodies. However, aches and pains once ignored or considered inconsequential can no longer be regarded in this way, and instead have to be monitored and attended to

dragon boat team in which membership offered women alternative ways to think about the loss of their breast as well as alternative ways to experience and 'relate' to their bodies.

## **Discussion**

The belief that the loss of a woman's breast to breast cancer threatens women's sense of self as feminine or as female within much of the breast cancer (psychosocial) literature is premised on problematic theories about the nature of femaleness as well as on popular cultural assumptions and values concerning the female breast, the nature of femininity and what it means to be a woman that are often not grounded in women's lived experiences. Medical discourses about loss and lack continue to reinforce and reproduce popular cultural values that define, judge and reduce women to biological and physiological processes. These discursive practices aid in the perpetuation of cultural relationships that value women primarily for their physical appearance and attractiveness, and as sexual objects of male heterosexual desire (Bartky, 1998; Bordo, 1997; Price and Shildrick, 1999; Young, 1990). Although not the only discursive practice at play concerning women and breast cancer, it is a dominant one and continues to enjoy a privileged position in breast cancer treatment protocols and after treatment and care practices (Bush, 2000; Ussher, 1991).

"The enormous pressures to construct women's bodies as passive and fragmented objects - by both social and medical discourses - threaten to reduce women's bodies to breasts and to reduce breasts to objects for others to view and use."  
(Langellier and Sullivan, 1998: 91)

How women treated for breast cancer experience the loss of or changes to their breast and the impact that it had on their sense of self as feminine or female is fragmented, complex, multiple and contradictory. Contrary to popular and medical discourses of loss, lack and threat, not all women in this study experienced the loss of or changes to their breast as a challenge to their sense of self as feminine or female. Those that did, experienced it in a variety of contextually mediated and situated ways. However, a sense of self as feminine or as female remained and suggests that women's identities as feminine and female are at one and the same time fragile and resilient and can be challenged but not totally usurped.

Concerns with feminine appearance are a nonissue for some, a marginal issue for others, and a manageable issue for still others (Langellier and Sullivan, 1998: 85).

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in case it is a sign of recurrence.

What grounded this experience for most women was the experience of having a life threatening disease. Some located the loss of their breast immediately within this context so that a threat to femininity or femaleness did not become an issue nor a concern at all, while for some femininity was not an aspect of their self concept that they accorded any import or identified with. Although some struggled with the loss of or changes to their breast, this was a struggle that was uneven and intermittent, and the struggles that the women spoke of were not all the same and reflected the particular contingencies of women's lives, as well as personal orientations.

Relevant here were the importance that breasts had for women in regards to their self definitions as feminine and female, including how they physically 'lived' and experienced their breasts, what roles their breasts played in their relationships with others and how these others, particularly husbands and sexual partners, responded to the loss of or changes to their breasts. Over time the women were able to locate the changes to their breast within the larger context of surviving breast cancer, as well as come to understand and experience their breasts and their bodies in other ways, some of which became incorporated into their existing self definitions as feminine or female.

Integral to the ways in which the women were able to come to terms with the changes to their breast, and regaining or finding new ways to experience their breasts as part of their sense of self as feminine or female was the dragon boat team. The team, the club house and surrounding area offered the women a safe and accepting place away from the critical gaze of others where they could be women living with breast cancer who were missing all or part of their breast(s). These spaces allowed women the opportunity to be in the presence of other women who not only held antithetical views concerning the loss of their breast, but whose self presentations (i.e. choice of clothing, hair styles, makeup, physical attractiveness) reinforced popular conceptions of femininity and femaleness.

Since the focus within the breast cancer literature has been on the negative impact of breast loss (or changes) on women's sense of self as feminine or female, missing for the most part is an understanding of how other side effects can also challenge and problematise women's sense of self as feminine or female. A few studies have mentioned how hair loss (Freedman, 1994; Payne et al., 1996; Thomas-MacLean, 2004) and weight gain (Thomas-MacLean, 2005) has negatively impacted women's feminine identity, but details are lacking. Hair loss was particularly problematic for several women because of the stark effect that it had on their physical appearance; the shock of being bald, of being a bald woman and not looking 'like oneself', and of feeling physically unattractive. These experiences problematised women's own conceptions of themselves and how they thought others now perceived them. Freedman states that "In our culture hair is used as an indicator of personality, attractiveness, sexuality and femininity. The concept of self identity is transmitted to others with a great initial emphasis on the appearance of the

hair.... How she feels about her hair is often how she thinks others feel about who she is as a person.” (1994: 337)

Two things need to be addressed within the breast cancer literature that focusses on the impact that the loss of or changes to a breast has on women’s sense of self as feminine and female. The first is a more thorough understanding of how and in what ways women understand and experience the loss of their breast as a threat to their sense of self as feminine and female, and why some women experience it as a threat to one and not the other.

Secondly, there is a need for studies that focus on the psycho-social impacts of breast cancer to move beyond the assumption that the loss of or changes to their breast as a result of breast cancer is a threat to women’s sense of self as feminine and female, and instead focus on and listen to women’s own perspectives and concerns regarding their experiences of breast cancer, and to pay greater attention to these other neglected areas.

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### **Paper 3: “Now I say I’m better.” Better bodies and better selves. Breast cancer and the transformative effects of competitive dragon boat racing.**

Dragon boating has become a popular recreational and competitive sporting activity among women living with breast cancer across Canada, the US and internationally. At present, there are an estimated 93 breast cancer survivor dragon boat teams world wide, including Canada, the United States, Australia, China, England, Italy, Malaysia, New Zealand, Poland, Singapore and South Africa (Parry, 2008). The dragon boat racing phenomenon among women with breast cancer began in Vancouver, British Columbia in 1996 and was linked to a research initiative undertaken by a sports medicine doctor to challenge what he felt were unsubstantiated medical claims about women’s physical limits after treatment for breast cancer. Until that time, both expert and popular wisdom dictated that women should refrain from strenuous upper body activity in order to prevent the development of lymphedema, a painful and persistent swelling of the arm, hand and torso regions. Lymphedema can be the result of lymph node dissection - the exploration and removal of lymph nodes from the armpit area to see if they contain cancer cells, from breast surgery (lumpectomy or mastectomy) or radiation of the axilla (armpit) (Harris and Niesen-Vertommen, 2000; Harris et al., 2001; Riegle, 2006). The goal in creating this particular dragon boat racing team was to “challenge this taboo” (McKenzie, 1998: 376) and to “help people living with breast cancer understand that they can lead full active lives despite the physical limitations imposed by this disease” (McKenzie: 378).

In this paper I focus on the experiences of women on one of these breast cancer dragon boat racing teams. The team is located in a southern Ontario city and draws women from a number of local and surrounding regions. Inspired by the growing popularity of the sport among those with breast cancer, an initial group of 22 women became the first members of the team in the spring of 1997. Over the past ten years, approximately one hundred plus women have joined and left the team, including ten women who have died as a result of breast cancer. The team currently consists of over 50 active paddlers, including one who is a man.<sup>15</sup>

In its initial years the team functioned primarily as a source of recreation and emotional, physical, social and in certain circumstances financial support for its members. Over the last several years, however, there has been a shift in the team’s focus. While the

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<sup>15</sup> Since breast cancer is a predominately gendered disease (more than 99% of breast cancers occur in women\*), in this paper I am interested in understanding the experiences of the women only, and will not be including the experiences of the men in my analysis. \*[www.phac-aspc.gc.ca/ccdpc-cpcmc/bc-cds/index\\_e.html](http://www.phac-aspc.gc.ca/ccdpc-cpcmc/bc-cds/index_e.html)

purpose of the team is to continue to support each other, particularly when a team member is re-diagnosed or is facing a crisis, the competitive aspect of the sport has emerged as an important and organising feature. Many team members will describe their team as “a support group on land but a competitive dragon boat team on the water”. The decision to become competitive occurred during the team’s fourth year of existence and came from the women themselves. No longer wanting to be regarded as “just another women’s breast cancer survivor team” the group decided that they wanted to “kick it up a notch” and become better skilled and physically competent at this activity.

To do this the team began working out twice a week, engaging in weight training and conditioning sessions in the off-season to improve their strength and stamina and in the summer by increasing the physical intensity and duration of their paddling work outs. The current workout regime is as follows: Training for the summer season begins in early January at a local pool once a week with aerobic and anaerobic workouts on Saturday morning with a certified trainer. Once May arrives, the team takes to the water for bi-weekly paddling practices and are expected to continue aerobic and anaerobic workouts on their own throughout the week. Several women on the team have even hired personal trainers to help them become fitter and stronger by working on and enhancing those muscle groups that are integral to dragon boat paddling. Paddling season ends in early September but the team remains “on the water” until the end of that month. During the 3 months that they are not paddling, team members are encouraged and expected to remain physically active. Team members are also expected to make a commitment to the team by regularly attending the winter training sessions, and must attend at least 75% of paddling practices in order to be eligible to compete during the next racing season. Since the team has now become competitive in the races it enters, new members are not allowed to compete in most competitions<sup>16</sup> their first year. This recent decision is premised on the assumption that new members are not likely to have the level of fitness required to compete, especially if they are currently undergoing or have recently finished treatments for their disease.

As a result of this “competitive turn”, the sport of dragon boating has had a series of impacts on the women’s bodies, as well as on their understanding and experience of their bodies. In this paper I look at how women on this dragon boat racing team experience bodies compromised and problematised by the illness experience of breast cancer and how and why the desire to be competitive has become important for so many of them.

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<sup>16</sup> There are two events that are set aside specifically for them to compete in so that they do have an opportunity to race and to experience what it is all about.

Over the past two decades social scientists in a number of disciplines (sociology, cultural studies, feminism) have paid a great deal of attention to the body and have been preoccupied with a number of concerns ranging from how to conceptualise the body (as both a biological and social entity), its role and function in social action, and the ways in which it is represented and experienced (Bartky, 1998; Bordo, 1997; Bourdieu, 1984; Butler, 1990; Connell, 1987; Elias, 1978; Falk, 1994; Foucault, 1977; Frank, 1990; Goffman, 1963; Grosz, 1994; Leder, 1990; Martin, 1987; Merleau-Ponty, 1962; Shildrick, 1999; Shilling, 1993; Synnott, 1993; Turner, 1992; Witz, 2000; Williams, 1996, 1998).

The literature that focuses on experiences of the body in the context of illness has tended to emphasize themes such as the body as diseased, in a state of decline, or as a source of disappointment or betrayal (Bury, 1982, Charmaz, 1995; Frank, 1990, 1991; Gadow, 1982; Kestenbaum, 1982; Kleinman, 1988; Leder, 1990; Turner, 1992; Wendell, 1996; Williams, G. 1984; Williams, 1996; 1998; Williams and Bendelow, 2000; Zola, 1991). It is my contention that the appeal of dragon-boat racing for those women with breast cancer who participate in the sport lies at least in part in the alternative ways it allows them to experience their body. Membership on the team has provided the women - and for many, the first time in their lives - the opportunity to participate in a physically strenuous and now competitive sporting activity. It is not that the sport distracts them from or takes the focus off their bodies, but instead does exactly the opposite. The competitive activity of dragon boating orients them towards their bodies, but in ways that are positive, life affirming and empowering. In the context of dragon boating, the body becomes not simply a locus of disease and distress and something they mistrust or from which they feel alienated. Instead their bodies become something over which they experience a sense of control in the face of an illness that can leave them feeling powerless and out of control (Blinde and McClung, 1997; Guthrie, 1999). Rather than feeling inadequate, imperfect, and in the case of those who have undergone surgery, maimed and mutilated, they experience their bodies as strong, fit, healthy and capable. Thus I argue that the competitive activity of dragon boating has a positive and transformative impact on women's corporeality and enables many women to experience their compromised and problematised bodies as a source of physical vitality and pleasure.

In developing this argument, my paper begins with a brief review of the literature on experiences of the body in illness. This is followed by a discussion of the methods I used to conduct my study. The remainder of the paper is divided into four sections. The first section addresses the saliency of context within which the activity of dragon boating takes place - among a group of women diagnosed with and treated for a life threatening disease. The second section addresses the corporeal limits and socio-cultural barriers that women were able to face and overcome as a result of their participation in the activity of dragon boat racing. Sections three and four discuss the corporeal and then identity gains that the women experienced as a result of their participation in dragon boat racing. I



conclude by summarizing the study's findings and discussing their significance in relation to our understanding of the body in illness and how through experiences like dragon boat racing the body can be experienced as much more than disruption and betrayal, alien and loss, but as powerful, healthy, physically vibrant and pleasurable.

## **Methods**

Two data collection techniques were utilized in this study. The first consisted of in-depth interviews that became more open-ended as they proceeded. Participants were encouraged tell their own stories and unscheduled prompts and follow up questions were utilised in order to elicit a breadth and depth in responses (Breakwell, 1995). This was to allow women to "reveal in their own words their view of their entire life, or part of it, or some aspect of themselves" (Bogdon and Taylor, 1975:6). Of the thirty one women interviewed, twenty-six tapes were transcribed (this owing to time and financial constraints) and were used in this study. Most of the interviews lasted between one and one-half hours, although there were a few that lasted longer, the longest taking five hours. Interviews were conducted and audio-taped after consent was obtained in a place of the interviewee's choice, which was usually in her home. Some interviews were conducted at the team clubhouse after practices and one interview was conducted at the university. The interviews were transcribed verbatim and were read and reread in order to identify recurrent themes and sub-themes both within and between participants accounts.

Like other qualitative approaches the focus here was on the interpretive, on "people's own written or spoken words and observable behaviour" (Bogden and Taylor, 4). In keeping with the spirit of this research tradition, there was no intent to quantify the experiences of these women but rather to capture the subtleties and complexities of their lives as women living with breast cancer who dragon boat. The collection and analysis of the data was informed by the inductive grounded methodology of Glaser and Strauss (1967) and Strauss and Corbin (1990) which is a general methodology for developing theory that is grounded in data that is systematically gathered and comparatively analysed. Also known as the constant comparative method, theory is generated initially from the data, or if an existing grounded theory, is elaborated on and modified as new data is carefully compared against it (Strauss and Corbin, 1990). At the beginning of the interview process I was sensitive to the themes and analytical categories that were initiated by the respondents themselves and incorporated them, when appropriate, into the list of questions for subsequent interviews. I conducted an analysis of the first 15 transcribed interviews in order to get a sense of the data and to discern the predominant themes and categories. This informed the analysis of the 11 remaining interviews.

A second technique, participant observation, which is "characterised by a period of intense social interaction between the researcher and the subjects, in the milieu of the

latter” (Bogdon and Taylor, 1975:5) was also employed and continued for five years. The decision to engage in participant observation was a secondary consideration and emerged as I became involved with the group as an “support member”. As a result of my participation, I took on an “active membership role” and became “more involved in the setting’s central activities, assuming responsibilities that advance the group, but without fully committing [to] the members’ values and goals” (Adler and Adler, 1994: 380). Regular contact and interaction with the group as a whole began in January 2003 when the team began their winter training for the racing season. These training sessions consisted of weekly weight work outs and paddling sessions at a local swimming pool. I also joined the team for the bi-weekly on-water paddling practices that began mid-May of that same year when they were able to safely take to the water. I participated in these activities with the team regularly and also joined the small but regular group of women for drinks at a local pub after pool and paddling practices. I also attended various team activities and travelled with the team to many of their regular season dragon boat competitions. I was invited to and attended the 10<sup>th</sup> year anniversary celebration of the first breast cancer dragon boat team in Vancouver BC in June of 2003 with the team. Participant observation ended after the 2007 season.

### **The group**

As a group, this team of dragon boat racers was fairly homogenous (similar in social class, ethnicity, sexual orientation, marital status, most had children) including the group of 26 women that I interviewed. During the five years that I was with the team, membership grew from approximately fifty members in 2002 (including approximately ten women who no longer paddled but remained as associates), to over seventy members by the end of the summer of 2007. Of those seventy members forty-nine were active paddlers. Associate members were usually women who once paddled but no longer could due to physical limitations or because they had moved onto other interests but wished to maintain some contact or association with the team. Often these women would attend or help out with fund-raisers and from time to time would come out to watch the team compete.

Of the 26 women whose interviews were used for this study, 22 were married; 4 were either single or never married. All of the women but one identified as heterosexual, and one woman stated that she was neither hetero or homosexual. At the time of the interviews, the women’s ages ranged between 29 and 73 years. All of the women were of the Christian faith except one woman who said that she was agnostic. All of the interviewees but two identified as Canadian, and with further probing identified as either European or Anglo-Saxon. There were no women of colour involved with this group at the time of the interviews. Half of the women had attended or completed university, while 9 women had attended or completed college and 4 had completed high school. The annual

combined family incomes ranged between CAN\$ 20,000 and CAN\$ 100,000+. One women refused to disclose financial information and another said that she had no idea what her family income was. This particular group of women were white, well educated, affluent and professional, a demographic that appears to be characteristic of most breast cancer support and self help groups (Gray, et al., 1997:281) and women's athletic teams. (Deem, 1987; Sternfeld et al., 1999).

The medical treatments that the women had received varied depending on their diagnosis - the type of cancer they had (ductual, lobular, inflammatory, etc., ), the stage it had reached (size of the tumour, if there is lymph node involvement and if the cancer has spread beyond the lymph glands), and its grade (growth rate (slow or fast) of cancer cells)<sup>17</sup>. Seven women received radiation therapy, nine received chemotherapy and six women received both. Nine women were taking Tamoxifen, a drug used to treat and manage women's breast cancer if it is estrogen fed. Five of the women had reconstructive surgery. Several women had a range of other conditions they were dealing with besides cancer, including fibromyalgia, lupus, scoliosis, arthritis, bad backs; some had been treated for other cancers such as ovarian, uterine and thyroid cancer. Five of the women interviewed were unable to paddle regularly because of health conditions; the remaining 21 were symptom free through the time I was with them.

### **The Diseased Body**

The body has for the last twenty years been a major object of concern within sociology, with calls that have gone from an initial plea to bring the body back in to sociological theory (Frank, 1990; Shilling, 1993; Turner, 1992; Williams, 2006) to the need to develop a more integrated analytical and non-reductionist framework for understanding the relationship between the body, self, and society (Shilling, 1993; Williams, 2006). However, it is only relatively recently that the body has become an explicit topic of focus and debate within the sociology of health and illness (Williams, 2006). According to Kelly and Field, "in most types of sociological narrative about chronic illness, the body remains theoretically elusive. Its existence is seldom explicitly denied, but its presence has a kind of ethereal quality forever gliding out of analytic view" (1996: 242).

This "implicit presence" of the body within the sociology of health and illness is in part the result of the ways in which the illness experience has been conceptualised and addressed within symbolic interactionism. Within this paradigm the focus has been on

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<sup>17</sup> <http://www.cancerbackup.org.uk/Cancertype/Breast/Causesdiagnosis/Staginggrading#5542>

meanings, particularly, how the individual makes sense of and experiences chronic and disabling illnesses, and the ways in which they negotiate a realignment between a body, self and identity disrupted by an illness condition (Williams, 1999). Within this 'negotiation model' of illness (Gerhardt, 1989), key concepts include the biographically disruptive character of chronic illnesses (Bury, 1982), the narrative reconstruction of this disruption (Williams, G., 1984), and resultant losses to self and identity (Charmaz, 1983).

As a model of illness that focusses on the disruptive nature of chronic conditions and the losses of capabilities and identities, the body is deeply implicated in these experiences because of the body's relationship to the self. Here the body and the self are regarded as inseparable but different, and that the self in all its representations is embodied. With the onset of a chronic and or debilitating condition, the relationship between body and self is disrupted and problematised, and those afflicted become aware of their previously taken-for-granted bodies and eventually realize that they have suffered lasting bodily losses (Bury, 1982; Charmaz, 1995). These embodied experiences of disruption and loss result in an estrangement between the self and the body, and the body "becomes a central aspect of experience, albeit in an alien and dysfunctional sense" (Williams, 1996:26).

In this conceptualisation of the ill body the body is characterised as a negative and limiting force in people's lives, giving rise to existential states of alienation and otherness, as well as a range of negative feelings that include sentiments of betrayal, mistrust, uncertainty, vulnerability, anger, resentment and shame. Here the ill individual is regarded as someone "who is trapped within his/her body and who is required to adjust or adapt to the limitations this engenders" (Williams, 1999: 802).

To illustrate, the ill body:

"It erupts. It is out of control. One damned thing follows another.... Chronic illness is a betrayal of the fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost. Life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion, shock, anger, jealousy, despair." (Kleinman, 1988: 44-45 in Williams, 1998: 62)

When wholly unanticipated, even middle-aged people may view their bodily changes with a sense of betrayal. They may describe their past bodies as "invincible," "indestructible," and "immortal" and express regret and anger about their losses. In turn, their anger and regret intensify when ill people feel that their illnesses control them. They have lost control of their body as an object they assumed they could master. Moreover, they view themselves as over-taken by an alien force." (Charmaz, 1995: 662)

Until recently, the body within the breast cancer literature can also be characterised as an 'absent presence'; the predominant focus has been on the negative effects of breast amputation and its impact on psychiatric morbidity (Fallowfield et al., 1986; Kemeny et al., 1988; Pozo et al., 1992; Steinberg et al., 1985; Wellisch et al., 1989;), sexuality (Bukovic et al., 2004; Fallowfield et al., 1986; Koh, 1999; Renneker and Cutler, 1952; Steinberg et al., 1985; Wilmot, 2001), body image (Polivy, 1977; Renneker and Cutler, 1952; Renshaw, 1994; Schover, 1994; Steinberg et al., 1985), and feminine identity (Bruner and Boyd, 1999; Clifford, 1984; Koh, 1999; Kunkel et al., 2002; Margolis et al., 1989; Pikler and Winterowd, 2003; Reaby, 1998; Reaby and Hort, 1995; Renneker and Cutler, 1952; Steinberg et al., 1985; van der Riet, 1998; Wilmot, 2001).

It is in the literature on body image that one would expect to find a range of studies on how the body in breast cancer is experienced. However, originally and even to date, this area of concern remains focussed on the damaging effects of surgery and with comparing the positive psychosocial outcomes of breast conservation and reconstruction with the negative effects of mastectomy (Cohen, et al., 1998). This limited focus on amputation (and the possible restoration of the breast) "ignores the larger issue of living with a body that has been treated for a life-threatening disease" and fails to account for the wider range of ways in which women view and experience their bodies within the experience of breast cancer (Cohen, et al., 1998: 835-6).

Very few studies to date exist on women's embodied experiences of breast cancer beyond that of a concern with body image and breast loss. The few that do (Braddon, 1999; Cohen, et al., 1998; Crouch and McKenzie, 2000; Thomas-MacLean, 2005) focus on certain aspects of embodiment - loss of body symmetry, unpleasant sensations, lymphedema - which also tend to be predominantly about disruption, loss and disfigurement.

"Thus despite indications of bodily acceptance, changes to one's body are a constant reminder of illness, limitation and disability, so that breast cancer is always an immediate and present experience, even beyond treatment" (Thomas-MacLean, 2005: 207).

"It is the problem of her maimed and asymmetrical body among other bodies not so affected. The other is the problem of fear; fear of the interior environment of her body which is not visible, and not fully known or understood (Crouch and McKenzie: 201).

"... the loss of a breast meant that their body was now alien to them and they now had to learn to live in a body which did not feel like their own. Their whole sense

of being was disrupted and there was no longer a trust of their body” (van der Riet, 1998: 10).

My argument here is not that the literature is wrong or that it mis-characterizes or overemphasizes the devastating impact that illness in general or breast cancer in particular can have on women’s sense of self or on their own bodies. Many of the themes emphasized in the literature would resonate with almost any woman with breast cancer, including those interviewed for this study. There were certainly moments prior to their participation in dragon boat racing where they experienced their bodies a source of alienation, betrayal and loss. Even after their commitment to dragon boat racing there are women who continue to struggle with their relationships with their bodies. The positive body images that dragon boat racing allows remain fragile and can easily be challenged. It takes little more than the subtlest suspicion that their cancer has returned, the briefest glimpse of their missing breast, the death of a team-mate or an unintentional reflection that in spite of all their hard work and success, they have “not beat it yet,” for a more problematised experience of the body to emerge. Certainly, the profound sense of alienation that these women experienced from their bodies post diagnosis and post treatment is integral to understanding their powerful responses to the activity of competitive dragon boating.

It is my contention that insufficient attention has been paid to the complex, contradictory and multiple ways in which the compromised and ill body of chronic conditions such as breast cancer,<sup>18</sup> is also lived as a “healthy body” and is experienced

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<sup>18</sup> There is some debate as to whether breast cancer should be regarded as a chronic illness or condition. McKenzie and Crouch argue against conceptualising breast cancer as a chronic condition because of women’s limited association with the health care system which is characteristic of chronic sufferers’ experiences (2004:140). Similarly, Tritter and Calnan (2002) argue that considering breast cancer as a chronic condition “might do a disservice to those affected by the illness and fails to consider the non-chronic aspects of cancer” (2002:164). However, what these authors fail to recognise or consider, are the chronic and long term side effects that are often the result of the treatments for this disease. Many women in this study, as well as in studies by others (Shapiro and Recht, 2001; Thomas-MacLean, 2005), referred to the bothersome and often limiting long term side effects associated with their surgeries and auxiliary treatments. The more problematic chronic side effects included but were not limited to: painful lymphedema, arthritis, limited range of motion, chemically induced menopause and hot-flashes, sleeplessness, fatigue, weight gain, loss of sensation and numbness and embodied feelings of loss and unevenness. Breast cancer as a type

beyond that of disruption and loss, alienation and betrayal. As Kelly and Field state, "Illness, like life itself, is a multi-phenomenal experience and therefore a multi-layered object of analysis. From the perspective of the person who has the illness and in whose body the physical or psychological pathology exists, or is defined as existing, the illness will be felt in a variety of ways." (Kelly and Field, 1996: 241)

As the remainder of the paper will show, to assume that a diagnosis of breast cancer, or the damage that the treatment for this illness can do to a body inevitably and irreversibly problematizes women's experiences of their body, is to miss a critical part of some women's experiences, and the complexity of ways in which the ill body is lived.

### **The Experience of Dragon Boat Racing**

While the remainder of the paper focuses on the dragon boating experiences of women in this study, it is important to keep in mind the context for these experiences. These were not women simply engaging in physically intense and challenging activity (ie. triathlons, rock climbing, marathon running), or even women participating in physically intense and challenging activity after medical treatment for a disease. These were women who became involved in dragon boat racing in the context of being diagnosed with, treated for and living with breast cancer. As a result, the women brought to their dragon boating experiences traumatic and painful embodied memories associated with their diagnosis and treatment experiences (Thomas-MacLean, 2004). Scarry (1997) has written insightfully about the effects on the body of a physically traumatic experience such as breast cancer:

When the body has been through a trauma, our memory of it has a physical presence for weeks, months or even years after. Of course sometimes this is because of its lasting physical effects (for example new limits to the body and its capacities). But there is something more than this: the somatic presence of the memory that reaches beyond the physical symptom. Like the kinaesthetic sense of which we are barely conscious and yet without which we struggle to function in the world, these 'bodily memories' are an invisible, yet tangible, presence." (Scarry, 1985:110 in Stacey, 1997:98)

For many of the women in this study there were days where they felt that they could not imagine the possibility of life after breast cancer, let alone think about participating in a physically challenging and intense new sport. The women remember the

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of illness experience is one that shares characteristics of both acute and chronic illness conditions.

shock of their diagnosis. They remember how they looked and felt during and after their surgeries, chemotherapy and/or radiation treatment sessions - the constant fatigue, pain, nausea and vomiting, looking pale, being bald, scarred, breastless, demoralised and afraid. Their breast cancer experiences forcefully and dramatically shaped their experiences of dragon boating. Even before they get into a boat for the first time, dragon boating is pregnant with symbolic significance for them. Their experiences with breast cancer explain why their first encounter with this activity can be so emotional for them. As Charlie explains:

The first day I got off the boat and I looked at Sarah and I started to cry. That I'm here, I can do this, isn't it beautiful out on the water? Oh my god, my body can do this. I'm with these other women that have shared the same things and we all know where we're coming from. Very empowering. Strength, mentally. Power and sense of awe that I could be so sick, on a death bed literally, on a death bed last August. To get out of a boat a year after having chemotherapy... I get emotional still. (Charlie)

Their embodied experiences and memories of breast cancer are always potentially “at hand” and in the back of the women’s minds as they become further involved in the experience of dragon boating<sup>19</sup>. In fact, they often use these memories to motivate themselves. They were often incited by the team coach prior to “big” races to remember who they were and what they had been through when they were paddling and to let these memories of treatment and diagnosis spur them on. They contrast these memories with where they are now - alive, physically active and strong, paddling in a dragon boat and capable of pushing themselves physically and mentally through and past physical thresholds once unimagined or never thought possible. Gabby recalls Mighty Mouse giving the team a pep talk before a race. She told the women to remember what they had been through, to remember every needle, and to remember what chemotherapy felt like. She told them to picture themselves now, competing against elite women’s dragon boat teams, teams made up of women *without* breast cancer, as well as co-ed teams of younger and athletic women and men (an important distinction for many of the women who are in mid-life). The implication of the talk was that what others might consider to be a disadvantage of the “breast cancer” team was, in fact, its strength. To them, they had overcome breast cancer and everything involved in its treatment to reach this point and had proven themselves victors.

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<sup>19</sup> This experience is further reinforced, publically, during the “pink carnation ceremonies” (a ceremony which usually involves the reading of poem to honour women who have died from or who are living with breast cancer) that are often held at competitions where there is a breast cancer division.



## **Overcoming corporeal limits and social barriers**

Serious involvement in dragon boating racing for those women who pursued it, meant overcoming a number of barriers. Some of these barriers were physical, the result of the disease and its treatments, while other barriers were social and cultural, the result of women's particular location within gendered social relations and practices.

Women diagnosed with breast cancer endure multiple assaults to the body from the disease and from treatments for the disease (Riegler, 2006) which can problematise physiological and biological processes both during and long after these treatments have ended (Love, 2000; Thomas-MacLean, 2004). Women's experiences with breast cancer often challenge their confidence in and understanding of their bodies, and raise questions for them as to what they can and cannot do. Bodies that had been take-for-granted or that had been experienced as unproblematic were no longer understood or experienced in this way. The body in breast cancer becomes an uncertain, volatile and mutilated body, one that has new sensations, pains and limitations. It is also a body that can now no longer be trusted due to the very real possibility that their cancer can recur. Dragon boating has the potential to turn this around. Gabby explains how dragon boating helped her to challenge, as well as overcome, both the physiological and psychological limits she experienced as a result of her illness and treatment:

Seven years ago I thought my time here was over, and as to my energy, well, there was none. I could not believe it. I could not walk up a flight of stairs on most days. This from someone who had considered herself an outdoors kind of gal. Summers had been spent outside, preferably in the water and it was over. Winter sports I loved best and it was over, my life was over. Now wait a minute, not so fast, don't give up on me just yet. Another chance to do something outside, on the water with a team of individuals who talk the same language. (Gabby)

Dragon boating also allowed many women to challenge self imposed limitations that they held about their physical abilities. Some of these self-imposed limitations had been shaped by medical, popular and gendered discourses that construct strenuous sport as requiring a level of exertion that is beyond the biological capabilities of most women (Dowling, 2000; Hall, 2002; Lenskyj, 1986; Mewett, 2003). According to Young (1980), women more so than men learn to underestimate their bodily capacities and often decide before hand that a task, particularly if it is physical, is beyond their abilities. As a result, they tend not give it their best effort and if they make the attempt, they are generally surprised at what they can accomplish. This was evident in the experiences of several women who reported how they were shocked but also delighted to discover that they possessed the ability, strength and stamina that was required to successfully participate in an activity as physically demanding as dragon boating.

Oh I love it. It takes serious energy and serious strength and I can do this. I shocked myself. But hey, I can actually do this. (Didi)

I consider myself not very athletic, but geez, I can keep up with them. I say hey, I'm in there, I can do this. (Morgan)

For many women their ambivalence to sport begins early in their lives, and organized sporting activities do not become a major part of or interest in the culture of girls and women in the same ways that they do for boys and men (Fasting, 1987; Sleep and Wormald, 2001). Due in part to gendered social practices, generations of women have been taught that certain physical activities such as sports were inappropriate for them (Harrington et al., 1992). Young girls also tend not to regard organised sport and physical activity as a way to achieve self-confidence, relaxation and enjoyment or as a way to achieve a powerful body. As young women they tend to drop out of competitive and team sports participation as soon as they can (Deem and Gilroy, 1998), and as a result, many girls and young women do not develop bodily competencies and skills in the way or to the same extent as do boys and young men.

These general observations about women's experiences of physical activity and sport were reflected in the comments of the participants in this study. Dragon boating enabled Lady Di who as a young girl was often overlooked by others for team sports, to develop new physical competencies and skills and to also experience the thrill and enhanced self confidence of excelling at a physical activity. The activity of dragon boating allowed Didi, who as a young woman in high school so disliked physical education that she stopped taking it, the opportunity to discover corporeal pleasure in and through physical activity and sport.

I was active but I was one of the ones, if you were on the baseball team, I was last to be picked. And now if you've talked to Mimi, she introduces me to new people as one of the star paddlers and I think: "Are you making fun of me or do you mean this?" Because for me, I would think they were making fun of me because I've never been in this position. (Lady Di)

As a kid I hated exercise and in high school I could hardly wait to get out of gym, I think in grade 10 you could drop it as an elective. And I could hardly wait to get out of it. I took swimming lessons as a kid and basically after I got out of high school that was it. I just didn't exercise. (Didi)

Particularly salient were the experiences of one of the women on the team who chose not to be interviewed for the study. In an informal conversation later in the study the woman explained that it was her participation in dragon boat racing that gave her the self

confidence to not only train for and compete in several Ironman triathlon competitions by the age of 64, but to also teach herself to swim at the age of 60 after years of being terrified of the water.

Other social constraints worked to place restrictions on women's physicality. Emma's limited involvement in sporting activities was related not only to her gender but also to her culture. Emma grew up in a traditional Italian household and was denied the opportunity to participate in sporting and recreational activities because these kinds of activities were not seen as appropriate or necessary for girls.

Remember, I was in an Italian home. [Sports] was not something that was important. My physical activity involved working around the house. You know I wanted to join the basketball team, no that wasn't going to happen because that wasn't important, and because we lived out in the country that meant that my dad would have to come and pick me up and that was out of the question because there was no time because everybody was working within the house. (Emma)

Although many of the women had engaged in a variety of physical activities throughout most of their lives (and many intermittently), the majority of them lacked both organised team and competitive sports experience outside of and beyond that of high school. Nor had the majority previously trained to participate in a sport prior to their dragon boat experience. Along with the social and personal constraints that limit and impede women's access to and participation in organised and competitive sport (ie. time constraints, lack of a sense of entitlement to leisure pursuits, work and childcare responsibilities, the nature of gendered power relations within the home, social class location, ethnicity, level of education, etc.) (Deem and Gilroy, 1998; 1992; Harrington et al., Sternfeld et al., 1999) are powerful discourses about the inappropriateness of strenuous physical activity for women (Harrington, et al., 1992).

No, no it was not something we were really allowed to do. (Sophia)

Mediated through numerous medical, scientific and popular discourses is a concern and preoccupation with the assumed detrimental effects of strenuous physical activity on women's bodies, reproductive function and health (Burroughs and Nauright, 2000; Dowling, 2000; Hall, 2002; Lenskyj, 1986; Mewett, 2003), and the belief that athletics is beyond the natural physical abilities of the female body. More recently, medical and popular concerns about women's participation in physically strenuous sports centre around a cultural anxiety with the masculinization of women's bodies (Deem and Gilroy, 1998; Fasting, 1987, Lenskyj, 1986), the loss of femininity and the threat to normative heterosexuality (Deem and Gilroy, 1998). These discursive practices among others (i.e. popular and hegemonic representations of "heterosexiness" and physical

beauty) inform, shape and constrain women's desire to participate in competitive sports that require displays of physical strength and are physically demanding. For many of the women interviewed, dragon boating was their first foray into the arena of organised and competitive sport. It was also their first experience with a physical activity that required them to become strong, competitively fit and to develop their bodies in ways not previously experienced (i.e. developing upper body strength and musculature).

### **Corporeal Gains**

Those women who chose to remain with the team and who regularly attended and participated in team practices and training sessions began to experience the corporeal benefits or gains of dragon boat racing. The gains are significant:

#### **Experiencing the restored body:**

Dragon boating for women living with breast cancer was started initially as a therapeutic activity intended to prevent the onset of lymphedema and as a way to promote the idea of "getting women back to normal activity following breast cancer treatment without fear." (Kent, 1996: 969) Although there is a vast body of literature on the rehabilitative effects of physical exercise and athletic activities for many chronic conditions (Atlantis et al., 2004; McNeely et al., 2006; Schulz et al., 2004; Taylor et al., 2004), the benefits of exercise has until recently been ignored within cancer care literature (Kolden et al., 2002; Pinto et al. 2002).

The women on the dragon boat team spoke of similar restorative and rehabilitative benefits. Several claimed that their participation in dragon boating allowed them to regain some or all sensation and mobility and flexibility in parts of their bodies that had been compromised by their surgeries. For example, Didi, a woman in her fifties, explained the damage that was done to the nerves in one of her arms in an effort to ensure that all cancerous cells were removed during her surgery. Since she started dragon boat racing, she has regained sensation in the arm and improved functioning:

Well they sacrificed nerves in my left arm in order to get a suspicious looking lymph node...Now a lot of that has come back actually since I've started dragon boating. I've had less numbness in my arm, so yeah. I really have to credit dragon boating and that strenuous upper body movement for giving me a lot back. (Didi)

Another teammate, Gabby, discussed how her shoulder had become "frozen" as a result of her mastectomy and how she had to deal with constant feelings of tightness and limited range of motion and how it affected day to day functioning. While dragon boating

had not significantly improved the problem, Gabby felt that at least, it was helping her to maintain the functioning that remained in her shoulder:

I don't know, if I had not been dragon boating, I am much more aware of the tightness when I'm not paddling. I have to think that the dragon boating has kept it, controlled it in the sense that it hasn't got worse. It helps maintain it. I think if I had not been doing this I would have serious problems with this shoulder and have to go physio all the time. (Gabby)

Some women credited the activity of dragon boating for allowing them to feel as though they had returned to a prior state of corporeal embodiment, and that they were able to once again experience their bodies as relatively unproblematic or what had once been their embodied 'normal'. Charlie stated that because of dragon boating her body now felt like it did prior to her treatment experiences, and Gabby reported that paddling enabled her to regain a state of embodiment and achieve a level of body competence that she thought she had lost and could not ever again experience.

But my body, is, right now my body feels like it was prior to this whole thing happening. And the (dragon boat team) girls, I think they help with that because they get you out and they get you moving. (Charlie)

Dragon boating has provided me with the medium wherein I could reach beyond what I thought I would ever again accomplish. Physically, remember, I could not get up the stairs alone and did not know what the human body was capable of. (Gabby)

Among the women in the study were those who were dealing not only with the physical effects of breast cancer, but also with other, unrelated, conditions such as fibromyalgia, osteo and rheumatoid arthritis, degenerative disks, and 'bad' knees and backs. The burden for them was particularly difficult because they were also dealing with the pain, physical symptoms and inconveniences of these diseases as well with the side effects of their breast cancer experiences. For these women, dragon boating had the additional benefit of relieving the symptoms of their other conditions. In the following example, Emma, discusses finding relief for her fibromyalgia:

Oh god it (dragon boat racing) saved my life...Not so much from the cancer aspect but from my fibro (fibromyalgia) because I never thought I could do it. You know, especially after I had the cancer and everything my body went through, it was such an assault that it took a couple of years just to get back. (Emma)

Thus for a number of women, the activity of dragon boating was regarded as restoring aspects of embodiment that had been disrupted and problematised by their breast cancer treatments, and allowed some to regain a previous state of 'corporeal normality'. Dragon boating also allowed a number of women to experience their bodies in ways that felt familiar and 'unproblematic', even though they continue to live with and in a 'volatile' and uncertain body that has been seriously compromised and problematised by treatments for a life threatening disease.

I had to relearn how to do some stuff just the limited range of motion ... Because reaching for stuff is hard. Going down into the dishwasher was hard, vacuuming was the worst and I still don't like vacuuming and that's just because I'm still missing that 20 degrees so that's difficult. But outside of that, no I got it all back.  
(Mighty Mouse)

### **Experiencing the fit body:**

Given that women's participation in leisure and physical activities (i.e. aerobics, walking, jogging) remains constrained and limited by work and family commitments and relationships, it is more difficult for women to not only participate in but to regularly commit to activities like organized team sports. Deem states that "If there is little time and space in some women's lives for leisure, there is also unlikely to be much time for sport." (1987: 423) The aforementioned constraints, including women's lack of a sense of entitlement to physical activities including sports and the feelings of guilt (Henderson, 1991) that women often experience when they do take time out for themselves (and away from their families), limit women's participation in activities like competitive sports that require both time and dedication. However, for the group of women interviewed, the majority did not, or no longer felt guilty about taking time out for themselves, and this appeared to be the result of several factors. At the time of the interviews, the majority of women had children who were in their teens or older and who were capable of caring more for themselves. Also, the majority of women interviewed were middle aged (40+) or older and had, or were beginning to develop a sense of entitlement to time out for themselves. However, it was a diagnosis of and treatment for breast cancer that was the most salient here. As a result of breast cancer, many women felt that they should, as well as needed to take time out for themselves in order to care for themselves<sup>20</sup>.

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<sup>20</sup> Similar results were found by Shannon and Shaw in their study of breast cancer as a catalyst for changes to women's leisure. They found that as a result of a diagnosis of breast cancer leisure activities became a priority in women's lives and was something that the women felt entitled to because of the health benefits associated with leisure (2005: 211).

Give up my time with my family? Yes, Tuesday nights and Saturday mornings and race weekends you can find me on the water. It is just something I do for me.  
(Charlie)

My garden is now a little wilder, my house not as clean, my entertaining not as lavish. My family friends and church work still get attention. Is this a sacrifice?? I think not! (Sweet Pea)

A diagnosis of and treatment for breast cancer disrupts assumptions about daily life and future expectations and often initiates changes to a woman's sense of self bringing about a re-examination of who she is. This for many women can lead to a reordering of lifestyle and life goals which may also include a higher prioritization of oneself (Arman and Rehnsfeldt, 2003: 518). Having breast cancer allowed many of these women to make a "legitimate" and incontestable claim to put themselves first and to demand time out and away for themselves, something they may have felt that they could not have done prior to their illness experience.

As a result of breast cancer and their participation in and commitment to dragon boat racing, as well as being a member of this particular (competitive) team, the majority of women reported that they were now in the best physical shape that they had ever been in, or felt better than they had ever felt in their lives. Although active throughout most of their lives (racquetball, aerobics, walking skiing, rollerblading, swimming), this group of women had not experienced competitive team sports or had participated in leisure activities that required the intense physicality that competitive dragon boat racing demanded. Particularly salient is that this occurred for many at mid-life and after having been treated for a life threatening disease that compromised their bodies and problematised embodiment and comportment.

Now I say I'm better, of course of the dragon boating. I'm in better physical shape and have more flexibility than I had for absolutely years and years and years.  
(Bette)

I probably do more, I'm probably more fit because, I never did anything for the first 30 years of being married. I got married in my early 20's, ah, got into dragon boating, what's it been, four years now? Yeah, and I've never done more exercise. I wasn't into anything and I never joined no clubs I never went to the Y. No, this has got me doing more strenuous things, and I figure I'm better, good at my age.  
(Morgan)

In a study in of how two different groups of women experience their bodies through two different types of physical activity (wilderness canoeing and aerobics),

McDermott (2000) found that women come to experience their bodies and physicalities in significant ways through appearance and become body conscious through appearance related concerns. For the women in McDermott's study, weight management and body shape issues continued to be related to the women's interest and participation physical activity. Although in general concerns about body shape and weight continue to remain salient for the dragon boaters, (particularly because of weight gain that is often the result of their cancer treatments), their decision to participate in dragon boating did not stem from existing body image concerns. For these women dragon boaters living with breast cancer, their interest in dragon boating emerged as the result of a diagnosis of breast cancer and among other things, the desire to be active and to challenge oneself after being treated for a life threatening disease. Participating in dragon boat racing as a means of losing and or managing their weight as a result of treatment side effects or appearance concerns did not emerge as a reason to paddle. Although physical appearance (looking attractive, desirable) remains important to these women, what differed was that they were less concerned with mimicking or achieving dominant cultural ideals of physical attractiveness such as being and looking thin. Rather, the women interviewed were proud of how their bodies looked because their bodies not only appeared strong and fit, but also felt strong and fit. Being fit and toned was evidence of how hard they had worked at paddling and reflected how serious they had become about this physically demanding athletic activity. Within the context of dragon boating, their ideals of physical attractiveness had changed to also include the physically fit, muscular and athletic body, which had come to be regarded as both attractive and desirable.

### **Experiencing the powerful body:**

Women tend not to approach physical tasks requiring strength, force and muscular coordination in the same manner as men. This is not the result of differences in brute muscular strength, but rather to the ways in which men and women each learns to use his or her body in approaching these types of tasks (Young, 1980). Young states that: "Women often do not perceive themselves as capable of lifting and carrying heavy things, pushing and shoving with significant force, pulling squeezing, grasping, or twisting with force" (Ibid: 142). Even among women who are regularly involved in strenuous physical activities, being strong, as well as exhibiting public displays of physical power, competence and strength remains problematic. In her study of "women in fitness" who seek muscular strength, Dworkin found that women's bodily agency was constrained not by the biology of their bodies but by ideologies of femininity that structure the upper limit on their bodily strength and musculature, thereby creating a "glass ceiling" on their muscular strength (Dworkin, 2001). Becoming and being strong and powerful remains problematic for women because it challenges dominant cultural beliefs about femininity, masculinity and heterosexuality. Women in sport learn, especially those who engage in traditional male sports and activities, that they can be strong but that they must also



maintain a balance between their feminine and less feminine characteristics and portray a heterosexually attractive appearance (Krane, 2001: 116).

Although these cultural concerns and anxieties over women's physicals displays of strength and power remain as a potent constraining force in women's lives, for many of the women in the group interviewed becoming, feeling and looking strong and powerful was experienced as a source of pleasure and pride. As a result of dragon boat racing and due to the regular aerobic and anaerobic workouts involved in their training regimens, many women reported that they were aware of the physical changes that were taking place to their bodies. Many also reported that they now felt physically strong and powerful in their bodies, and the strongest and most powerful that they had ever felt or been in their lives. Although many women stated that they felt capable, competent and coordinated in their bodies (those who did not spoke of weight concerns and of being clumsy), for several women feeling as strong as they now did was a new experience and pleasurable for them.

Usually when I'm working out I do feel stronger, and I know I have packed on muscle since I started dragon boating. Like, I'm just aware of it, feel that (flexes her forearm). [*Yeah, Popeye.*] So I mean yeah, it has a lot to do with the dragon boating. I have shoulders for the first time in my life. (Dorothy)

So you know I'm surprised at the amount of strength that I actually do have. And then the paddling, this canoe trip, this 5 hr canoe trip. My husband kept saying slow down you're not dragon boating. (Emma)

### **Experiencing the muscular body:**

Along with feeling fit and powerful was an awareness of how their bodies had changed and were transformed into muscular bodies as a result of their paddling and training experiences. Despite the fact that the women continued to struggle with body image issues, particularly over concerns with body size due to weight gain (which was for some as, or more problematic (in the long term) than the loss of their breast), the women were also pleased with and were proud of their bodies as they became more muscular, toned and defined. This group of women liked the fact that their arms had become muscular, their backs wider and that they had developed a physique that was similar to those of serious athletes.

I like the way it looks (her body) when I'm in good physical shape, especially with the dragon boating now and doing the heavier upper body stuff. I've got a "V" to my back and when you work with athletes and you see that V. (Mighty Mouse)

And somebody said, it was actually Dorothy last week, she said, man look at my arms I'm getting Popeye arms, and we are. And this is my left arm and it's not my strong arm, but it's getting bigger than my right arm. And our shoulders are really developing. (Reluctant Paddler)

The satisfaction, pleasure and sense of reward that comes from having transformed their (breast cancer) bodies supersedes any concerns that the women might have about developing musculature. The literature shows that concerns about musculature are not uncommon among women involved in sports, including those at an elite level (Krane et al., 2004). Although some degree of visible muscle (i.e. toned and defined) is now regarded as acceptable and even as desirable for women (Markula, 1995), some athletic women are careful to avoid developing masculine looking muscular bodies (Krane et al., 2004). Large, bulky and 'veiny' muscles on women continue to be regarded as transgressive, unattractive and unfeminine and can also call into question women's (assumed) heterosexuality (Brace-Govan, 2004; Deem and Gilroy, 1998; Duff and Hong, 1989; Krane, 2001; Krane et al., 2004; Lenskjy, 1986). However, for the majority of the women dragon boaters, this was simply not the case. On the contrary, they took pride in their new muscular physiques and were appreciative when others commented on their muscled and toned bodies. Often these compliments come from fellow boaters but they also from family and friends as well:

I got muscular quite fast in that arm, but like the girls on the team, especially the new ones, have been coming to me this year and saying boy do you ever look good, what do you do? Well if you worked as hard at this as I do, you'd know. (Lady Di)

Like now I have pipes. That's what the guys call them, Bette, you've got pipes. And my clothes are a little, some of shirts are a little bit tighter around my arms because of that but that's because of the dragon boating which is I suppose because of the cancer but it's not the cancer. [*And how do you like having pipes?*] It's kind of neat, my girlfriends think its fun because I never did anything. It's fun, yeah. (Bette)

This lack of concern with becoming bulky and "veiny" could be the result of several factors. Experiencing their bodies as strong and muscular was a new embodied experience for the majority of the women interviewed who lacked prior experience training for or competing in an activity like dragon boating and at the competitive level<sup>21</sup>.

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<sup>21</sup> It should be noted that these women's muscles did not become muscular in the same manner or to the same degree as women body builders and weight lifters,

These women were also coming into this new muscularity and physicality as women whose bodies have been assaulted by treatments for breast cancer, so the development of toned and defined muscles became a source of bodily pride. This allowed them to shift their focus away from the negative aspects of their breast cancer bodies to that of a body that was strong, healthy, fit and vital. Furthermore, these are also women whose bodies are aging and which contravene the hegemonic ideal of the young and attractive body. Women face a “double standard of aging” (Sontag, 1972 in Hurd, 2000) and are judged more harshly than men when they begin to show visible signs of advancing age (Hurd, 2000). Being strong and muscular also enabled many women, as it did Esther, who was body conscious throughout most of her life and who was anxious about her aging body, to feel at the age of sixty-nine, vital and youthful in her body.

...that whole aging process it's one way of, well you can't beat it, but you feel that you have to keep your energy level, so you're kind of fighting against the depression of the aging... I feel quite young and I still have energy and enthusiasm I think that's important. I've got to keep things in my life that I really like doing. (Esther)

Only one woman in the group made any reference to becoming too muscular. Sophia, who felt that she had a predisposition to ‘bulk up,’ talked about not wanting to become too large lest she appear “masculine.”

I really do not want to be bulky and I tend to go that route. Yeah my body is more muscular so I thought no, I don't want to do too much. I do like the weights but I take the good with the bad. ... When I'm in a bathing suit you can see that I'm more muscular but I don't want to be masculine looking. (Sophia)

Even Sophia, however, appreciated the physical strength that came with stronger muscles:

“I like the physical strength of it”, she said, “The physical thing, I do like that.”

Hegemonic femininity however, remains a potent and organising force in many women's lives and even though they may challenge its dictates as they develop strong and muscular bodies, they continue to experience moments where they feel compelled to work at maintaining (or at least continue to harbour the desire for) a small and thin body that aligns with the socially accepted body ideal. However, as women continue to engage in physically strenuous activities and develop and transform their bodies into bodies that are

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but they were aware of their changing and enhanced musculature.

muscular, fit and strong, they also challenge and resist this singular or hegemonic feminine ideal as the only way of corporeal being for women (Krane, 2001).

### **Experiencing the healthy body:**

Through their participation in the activity of dragon boating, many women, including those who continued to suffer from chronic treatment side effects or from other chronic illness conditions (fibromyalgia, chronic fatigue, bad backs and knees, Lupus, etc.,) stated that they once again felt 'good' and felt 'healthy' in their bodies. Several of the women also said that they now felt the 'healthiest' that they have ever felt in their lives, or had felt since their breast cancer illness treatment experiences.

I basically feel as healthy or healthier than I have, and that's something [due to] the dragon boating. And because I did this, I started the dragon boating and found it so difficult. I had to get fit for the dragon boating so I work out in the gym and do all that kind of stuff. (Reluctant Paddler)

And actually becoming healthier for it. I'm physically still in pain but I think I'm healthier, yes and stronger. I think I'm stronger than I was before. (Emma)

Conceptions of good health and well-being are relative, variable and subjectively defined concepts (Nettleton, 1995), and individuals who have been diagnosed with a life threatening or chronic illness often continue to regard themselves as 'healthy' even though they may be afflicted with a serious illness or chronic condition (Corbin, 2003; Williams, 1983 in Nettleton:44). According to Corbin:

"just having a diagnosis of chronic illness doesn't lead to a construction of being ill. Constructing an illness identity takes more than that. Constructing an illness identity comes from a fear that one is losing control over one's body and/or that one can "no longer do" what one could do before, and also from the fact that one can no longer understand the body's language or trust it to act as it should. It doesn't matter if one has cancer, AIDS, multiple sclerosis, or Parkinson's disease; as long as one "feels good" and "can do" what one wants, then one might not necessarily see oneself as ill." (2003: 266)

Even though they had been diagnosed with a life threatening disease and continued to live with a compromised and problematised body, the women interviewed reported feelings of physiological good health and psychological well being. They attributed this favourable state to their participation in dragon boating. Similar findings have also been found by others (Gillett et al., 2002; Unruh and Elvin, 2004) in that 'being physical' acts as a sign of good health not only in terms of physical appearances (the

representational) but also in the feeling that one is actively contributing to one's good (instrumental) health by becoming and remaining physically active.

Hence, these women *felt* healthy and well because they were physically active and were engaging in a strenuous and competitive activity that was physically taxing and challenging. They felt healthy and well because they were now in excellent physical shape, and felt 'good' in their bodies even though they continued to struggle with physical discomfort, pain and limitation. They also felt healthy and well because dragon boating allowed them to feel as though they were doing something about their breast cancer. Through their participation in dragon boating, they were taking control, they were acting responsibly and they were engaging in "preventative" health behaviours by exercising hard and exercising regularly.

And you see when I was going through chemo I thought okay, it's putting me into menopause. I was concerned about my bones and okay, I have to exercise. I hate aerobics, what will I do? I was thinking of all this. Okay, and chemo and menopause, my bones are really going to have a problem and then there's this article in the paper about the dragon boat team that just started and I said to myself this is it. (Esmeralda)

Well I guess another aspect too we can't take HRT and this is a way of combatting it with the exercise and everything and the bone loss and all that. (Mighty Mouse)

Paradoxically, this group of women are the fittest and the healthiest that they have ever felt in their lives while at the same time are also 'critically ill' and are living with a life threatening disease.

### **Experiencing the body as a site and source of pleasure:**

I love it! I love it! I love it! I could be out there the whole hour paddling. I wish they'd let me but I know there's so many others that have to take turns to paddle. (Sophia)

Although living in a state of sustained liminality<sup>22</sup> (Little, et al., 1998) with a body compromised and problematised by treatments for a life threatening illness, many of the women were able to once again (and some for the first time) experience their bodies as a

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<sup>22</sup> Not only is this a prolonged dialectic between the body and self, but is also characteristic of the liminality of their bodies as both critically ill and healthy, impaired but able.

site and source of pleasure and physical vibrancy. Physically intense activities such as dragon boating can be difficult, physically taxing and downright unpleasant. However, the majority of the women interviewed regarded this activity as pleasurable, and in a manner similar to Monaghan's body builders, embraced and re-interpreted non-injurious, self-inflicted and self-controlled 'pain' as enjoyable (Monaghan, 2001: 345)

*[So when you're doing the dragon boat is that a pleasurable thing for you to be doing?]* Yeah, it is. *[Working out and sweating, heart racing and temples throbbing?]* And getting off this boat and my knees collapse. (Laughter) I always feel much better when I get off the dragon boat, I always do. There have been some times when you think, oh, I really don't want to go to this practice but I go and I always feel much better. (Didi)

Within the context of dragon boating, a number of women found pleasure in the dialectic between the pleasure-"pain" nexus (actually more like discomfort rather than pain given that pain is an indication that something is 'wrong' and usually will abruptly end the activity), where discomfort experienced from bodily resistance and exertion coalesces into embodied feelings of pleasure, euphoria and feelings of corporeal transcendence.

I get a high. I can't say I get a high from anything else other than after. Sometimes I'm wishing I was in because of the cold, but I seem to be driven, I can hang in there and keep going. It's the only thing that's ever given me that high that I think runners feel. (Esther)

For these women dragon boating was understood and experienced as pleasurable because of the sheer intense physicality of this activity and the "well spring of positive emotionality" (Monaghan: 345) that strenuous physical activity can foster. These women were pushing and straining their compromised and problematised breast cancer bodies past and through to new corporeal limits. Intense physicality often gave rise to intense emotionality as several women spoke of embodied feelings of pleasure and release that they felt during and after a race or an intense workout.

The first time I got off the boat I cried. I get emotional still. (Charlie)

Dragon boating has become part of my life. I love it. The people I met since I joined the team are wonderful. The exercise. I can't describe the feeling that I have once I am done racing and practising. It gives me such a lift. The competition, and I want to race more. I wouldn't mind trying racing further some day. Maybe when I retire. (Sophia)

Dragon boating was also interpreted as pleasurable because it was an activity that was for many life affirming by virtue of them being able to participate in this physically strenuous and taxing activity post treatment. This group of women's understanding and experience of the physically intense sport of dragon boating is mediated through an existentially traumatic and physically disruptive illness experience, so the activity of dragon boating as physically pleasurable is made meaningful within this illness context. The sheer physicality of dragon boating reinforced for many women that they were alive, vital and still able and capable of doing what they wanted and needed to do, and that they could continue to live a full and active life even in the event of a life threatening disease.

Oh, it just, it's life affirming you know, I can't imagine not doing it, like every time I go out I just, again reinforcing the fact that I am a survivor and I can do this and I can do whatever I need to do, and want to do. (Emma)

Love it !!! To do something that makes you free so alive, to be on the water, to see the sun-sets, to say my prayers of thanksgiving. To be a part of something that was so terrible. Just having the "Cancer" and then to be in remission and doing something that brings attention to the fact that I am ALIVE !!!(Charlie)

Dragon boating was also regarded as pleasurable because it gave rise to a sense of accomplishment and to feelings of self-satisfaction as a result of what these women had achieved personally as women living with a life threatening disease, and as a breast cancer dragon boat team who had become a formidable foe both within the breast cancer and "healthy" dragon boating communities.

Yeah so it's a real accomplishment, it's the biggest accomplishment actually that I have ever made in all of, other than having my daughter, you know I have to say. Going to university all that stuff, yeah they're all important but this to me is my greatest achievement. (Emma)

And then the accomplishments. Look at us, look at what we've been through, look at what has taken place and the recognition as well, especially by other teams. (Esmeralda)

## **Identity Gains**

Accompanying these positive changes to embodiment and to women's understanding and experience of their bodies, were identity gains that emerged out of these changes and transformations to corporeality.

Particularly salient was the identity gain<sup>23</sup> of athlete among this group of predominantly middle aged women who lacked prior competitive team sport experience. As a result of a diagnosis of breast cancer, but through the experience of competitive dragon boat racing and the resulting enhancements to corporeality, that the identity of athlete was made possible. The identity of athlete was a powerful new identity for many women within this group, however, the taking on of this identity was not seamless, but rather was one that many struggled over and resisted at first. For several women athletes were ‘naturals’ who were young, fit and physically talented and many women not only did not see themselves in this manner, but had not experienced their bodies in the same ways that they imagined that athletes would. However, within a season or two after the team’s decision to become competitive these same women were now self identifying as serious athletes.

No, not at all, no. I’m not a natural born athlete (laughing). (Macaulay)

I’ve never been an athlete but I am now. (Lady Di)

I don’t consider myself an athlete except now. (Esmeralda)

Up until this year, like joining the team, yeah I certainly did feel like I was a part of that [an athlete]. (Didi)

Other factors were also at play and which make possible the emergence of the identity of athlete. These include the increasingly competitive focus of the team (through the introduction of weight training regimes, paddling technique workshops and camps), the enhanced appearance and musculature of the women’s bodies, their increased level of physical fitness and corporeal competence, their success in winning the majority of the breast cancer cup challenges and being told by the team’s coach that they were athletes: “You are athletes now”. This identity was also reinforced from outside of the group through invitations to participate in competitions against elite women’s dragon boat teams but not within the identity as a breast cancer survivor team.

Although they are now being taken seriously as a women’s competitive dragon boat team rather than that of a ‘just breast cancer survivor team’, this was not the case at

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<sup>23</sup> Another identity that emerged was that of breast cancer survivor, although this was not an identity that was embraced by all. Several women rejected and refrained from calling themselves survivors because they did not regard themselves as cured because of the very real possibility that their cancer could return.



all dragon boating venues. Some organisers fail to take these groups of women seriously and continue to stigmatise, pity and patronize them. At one competition that I attended the team was taken out of the overall competition instead of advancing forward in the standings after winning their races against co-ed teams and were relegated to breast cancer challenge only and were not allowed to compete further. No explanation was given for this decision.

I started out saying we come first every time we're out there, we come first in our lane. Well it's gone beyond that because they are working so hard at it. They strive to do their best and they don't want to be "Oh the breast cancer team". (Mighty Mouse)

However, it is important to note that their identity as a breast cancer "survivor" team remains and it is an identity that many women refer to and remain proud of because they are an illness based team and have overcome certain hardships (both personally and as a team) to be where they are today. Hence their identity as an illness based team only becomes problematic within certain contexts, such as when they competing in certain venues against non-illness based and co-ed teams.

Other identity gains were also noted among the women in the group interviewed. For the youngest member on the team and who by the age of thirty had had a double mastectomy, participation in dragon boating allowed her to regain as well as maintain her sense of self as feminine and in a way that challenged and subverted (to some degree) popular representations of heteronormative femininity. Queenie found that being in the company of this group of mostly "older" women allowed her to regain her sense of self as feminine which had been problematised by the loss of both of her breasts, and by putting her into menopause at the age of thirty. What Queenie saw around her was not simply a group of older women who were also missing all or part of their breast(s), but rather women who were also strong and confident and for whom the loss of their breast did not masculinize or detract from their physical and public displays of femininity or self integrity. For Queenie, femininity was not simply about traditional representations of physical beauty and feminine comportment but had more to do with character and personal integrity.

Dragon boating [makes me feel feminine.] It really does because I'm all around these strong women who've all been through this and they're saying, yeah, you know, we might be missing this and this but we're still women. And I think I'm a little stronger because we're not so obsessed with what we're missing. I don't know, just being around them really. (Queenie)

There are now several studies that have noted how negative life events including a diagnosis of a life threatening disease like breast cancer, can lead to positive changes that improve a person's vision of themselves and of the future (Arman and Rehnsfeldt, 2003; Caldwell, 2005; Paillasse, 1997; Tedeschi et al., 1998; Utley, 1999). Utley (1999), who referred to cancer as "transforming" describes how women's view of cancer changed from being potentially lethal to offering them benefits and positive experiences, while Tedeschi et al (1998), referred to this same experience as "post traumatic growth". For Tedeschi et al., the post-traumatic growth commonly includes changes of self (e.g. regard oneself as survivor rather than as a victim) as well as changed interpersonal relationships (e.g. more emotionally expressive and compassionate), and individuals are also likely to express a greater appreciation of the simpler things in life and a desire to make the best of what may be left of their lives (1998: 221).

For both Esmeralda and Babs, their diagnosis of breast cancer came to be re-framed as a positive one because it lead them to dragon boat racing and this particular group of women.

I think of breast cancer as a positive thing because I would maybe not of made the change to the cancer clinic, I definitely would not have met the dragon boat team. When I was diagnosed I felt there's a reason for this, I don't know what the reason is but something good is going to come out of this and it has. (Esmeralda)

I wonder what my life would have been like at 50 had I not had it (breast cancer). Number one I wouldn't have been involved with the dragon boat team. That's a lot of friends that's a lot of time so it has had a very big impact positively. (Babs)

Although leisure activities have important inoculative, coping and restorative effects for individuals who have experienced a disruptive and negative life event such as breast cancer, less is known about the transformative and liberatory effects of leisure activities. According to Kleider et al:

"The lack of attention is due in part to an emphasis on restoration of that which has been lost, rather than on coming to terms with the reality of the loss and the question of how life can be profitably reorganized and redirected as a result of the disruption. The restoration of continuity is usually a priority for the individual affected and for those friends, family, and professionals in a position to help; attention is rarely given to how an activity fits with an *altered* conception of self." (2002: 230)

The competitive activity of dragon boat racing among women living with breast cancer is illustrative of the transformative and liberatory effects that leisure activities can

have to both identity and corporeality. Not only did this activity enable this group of women to regain aspects of self (femininity) and embodiment (regain sensation, mobility) disrupted and compromised by their illness experience, but it also enabled them to take on the new identity of athlete, and to transform their bodies so that they felt stronger, fitter and healthier than what they felt prior to their illness experience. These transformative changes to both self and corporeality that emerged as a result of dragon boat racing enabled the women to feel strong, confident, healthy and 'better' in their bodies and about their bodies, as well as feel better about themselves. The activity of dragon boating also allowed this group to women to think differently about their bodies and to challenge and resist discourses of loss and threat to femininity.

## Discussion

They're enormously strong women. I can't believe it. There isn't an "I can't" amongst them. But there's also a whole group of people who need to be pulled up by just what this dragon boat does, and to be there for each other. We're not talking breast cancer, lots of times its never mentioned in a night, in any night. (Gabby)

This paper has shown how the activity of dragon boating has allowed a particular group of women to not only reclaim a body that had been compromised and problematised by a diagnosis of breast cancer, but to transform that body into one that they viewed as stronger, fitter, healthier and in many ways "better." They were able to experience and enjoy their bodies in new and different ways, as well as in ways not experienced since before their diagnosis or in many cases ever. They resisted doubts on the part of health care providers, families and even their own doubts about the advisability of what they were doing and their abilities, to develop new skills and physical competencies. They learned how to think about their post-treatment bodies in ways that challenged medical and popular assumptions about disruption and alienation, lack and loss. They experienced their bodies instead as a site and source of pleasure and physical vibrancy. The extent to which this made a difference in the women's experience of breast cancer is reflected powerfully in the following quotes:

[Dragon boating] has given me such a different side of breast cancer and getting beyond it and not the medical crap that goes along with it and all this. (Mighty Mouse)

And you know it's funny we talk about this sometimes with other women there. It is the best thing that came from having breast cancer was being in a group like that, it was. Such negative stuff and that turned out positive in many ways. Physically and mentally, physically and mentally. (Sophia)

Dragon boating offered these women alternative discourses about what it means to live with a body marked by breast cancer. Through their participation in dragon boating, and by being in the company of other women who held alternative points of view concerning what it means to lose a breast to breast cancer, the women were able to think differently about their bodies. Being a member of this team offered the women a “power base” from which to draw, a place where it was the norm to be missing all or part of one’s breast. Changes to their bodies which would be regarded by many as transgressive and as stigmatising were in this context made ‘normal’, and this was often done through dark and off colour jokes and remarks about one’s missing breast(s) or wayward prostheses.

I actually wore it (her prosthesis) in a bathing suit once without a pocket in the bathing suit and it ended up down here. It was on the move! (Laughter) It was always on the move. I was sitting where you are sitting one night, my mother-in-law’s here, we’re watching television and it was just too much for me and I took it off and did this. [Put it behind the couch pillow.] And I continued to watch the show. And now two weeks later I’m looking for it. I have no idea where it is in this house! I am everywhere in this house and I said to Chip well where do you think it is? (Laughter.) You know what it looks like, come everybody look for Bertha! (Gabby)

As a result of their participation on the dragon boat team, many of the women came to think differently about their marked and scarred bodies, and being a member of this team allowed them to re-frame their perceptions of their bodies so that scars and missing breasts came to be seen as relatively unimportant, and sometimes as a badge of honour, an embodied sign of a battle fought and overcome.

I have muscle, more stamina and endurance. The scars on my body have less importance than they used to. (Didi)

I like my body. I like my body now. I like my body with my scar. When it was fresh and really ugly, no, but like I said its beautiful now, its my badge. And like here it is and I’m not afraid to show it. (Charlie)

The activity of dragon boating was also credited as having a transformative effect women’s corporeality and women’s experiences of their bodies, including the body-self relationship. This group of women come to the activity of dragon boating with a body-self relationship that had been disrupted, traumatised, compromised and problematised by a diagnosis of and treatment for the life threatening disease of breast cancer. Through their participation in this activity, and with a group of others who shared a similar disruptive experience, this group of women were in many ways able to go beyond the “negotiated settlement” (Charmaz, 1995; Gadow, 1982; Williams, 1996) that often occurs between

the self and the body when disrupted and challenged by critical illness. Even though the body in illness can be experienced as a limit or constraint, it can also be experienced as opportunity, (albeit an often dangerous one (Frank, 1991), and one in which the body can also be experienced as pleasurable, vital and healthy. Through their participation in competitive dragon boat racing these women were accorded the opportunity to not only regain aspects of embodiment problematised by their breast cancer illness experience, but were also able to transform their bodies and their selves in ways not previously experienced, and to “recreate and (re)produce” their bodies as “*better bodies*” and their selves as “*better selves*”. By “*better bodies*” I mean bodies that are now subjectively (and by some measures, objectively) understood and experienced as vibrant, stronger, fitter, healthier, and in a sense ‘better’ than what they were prior to this illness experience and ‘better’ because of it, but through the experience of dragon boating. At the same time however, these are bodies that continue to be understood and experienced as untrustworthy and dangerous and remain as an ongoing source of existential anxiety, uncertainty and fear.

Thus, this transformative effect was fragile and remains subject to disruption. Although the activity of dragon boating enabled many to ‘reconnect with’ and restore aspects of the body-self relationship that had been disrupted and problematised by their illness experience, this “reunification” was limited. The women were well aware of the possibility that their cancer could return as a local cancer, or worse, as metastatic cancer, a cancer that had spread to vital organs and sites throughout their body which would now end their lives. Co-present with their sense of respect for, confidence and pleasure in their bodies, was a sense of ontological insecurity and a mistrust of their bodies. However, the ways in which these women came to understand and regard their bodies post diagnosis and post treatment is important to understanding the saliency and significance of the activity of dragon boating among this group of women and the profound effect it had on their understanding and experience of their bodies.

**References - Paper 3: Better bodies and better selves. Breast cancer and the transformative effects of competitive dragon boat racing.**

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## Conclusion

What began as an initiative to challenge unsubstantiated medical claims about women's physical limits after treatment for breast cancer, has evolved into an alternative type of after care support for women living with breast cancer in the form of a recreational and competitive team sport. Reflecting the ways in which this intensely physical and strenuous activity resonates among the women who choose to participate, there are now over 50+ breast cancer 'survivor' dragon boat teams in Canada. For many women living with breast cancer this activity has become an important defining and organising force in their daily lives.

In this dissertation I looked at the experiences of the women who make up one of these competitive dragon boat racing groups. I was interested in the wide ranging and multiple impacts that this activity has on their lives including their bodies, sense of embodiment and self identity. Initially the intent of the project was to glean a deeper understanding of how a 'gendered' illness experience like breast cancer affected women's sense of self as female or feminine, and how women make sense of and adjust to a 'gendered body' that had been altered and problematised by treatments for this disease. However, once introduced to this group of women dragon boaters, I came to appreciate the unique opportunity they presented for me to study their involvement in dragon boat racing itself. Shortly thereafter I made the decision to include the women's dragon boat experiences as part of the focus of my dissertation. This, in turn, led me to the realisation of the significance that this activity had on how women framed and regarded their breast cancer illness experiences and conversely how this particular illness experience shaped and informed their experiences of competitive dragon boat racing.

Each of the three papers that make up the dissertation looks at an aspect of the intersection between the experiences of living with breast cancer and the competitive sport of dragon boat racing. The first paper is an exploratory piece that examines the multiple meanings dragon boat racing has for those who participate. The paper locates these meanings within the context of living with a life threatening and potentially mutilating disease, as well as within the context of the women's daily lives.

Participation in dragon boating provided the women with a series of benefits to corporeality and to self. They were able to experience their breast cancer bodies as stronger, fitter and healthier, and some to took on the identity of an athlete. They were able to recast their breast cancer illness experience as a mostly positive one and experienced its benefits in a series of transformative ways. As a result of their participation in competitive dragon boat racing, many of the women were able to make a "legitimate" claim for time out for themselves. The dragon boat racing enabled many to challenge the "feminine ethic of care" that so powerfully circumscribes women's



behaviour, as well as their sense of entitlement to time for themselves to enjoy activities that they find meaningful and pleasurable.

Participation in competitive dragon boat racing also provided the women with a sense of community<sup>24</sup> and belonging as women living with life threatening, mutilating and still stigmatising disease. The dragon boat racing gave rise to a sense of achievement, accomplishment, pride and purpose. It enabled many to commune with and to establish deep and meaningful bonds of friendship with other women in an environment that was safe, compassionate, tolerant and understanding. Competitive dragon boating also allowed the women to develop new physical skills and competencies. In doing so it allowed them to challenge and resist cultural discourses about lack and loss, and to develop alternative ways of experiencing their bodies post-breast cancer.

The second paper takes a deeper and critical look at the ways in which the loss of or changes to women's breasts due to treatment for breast cancer have been characterised within the medical and breast cancer literature as a threat to women's sense of self as feminine or female. In contrast, the findings of this study illustrate that not all women experience the loss of or changes to their breast as a challenge or threat to their gender identities. Those who did, experienced the loss in a variety of contextually mediated and situated ways. For many women a sense of self as feminine or as female remained although it was subject to periodic disruptions (as is femininity generally even when not problematised by a disruptive illness experience). Important to the ways in which women responded to changes to their breasts was the relevance that breasts held for women with regard to definitions of self as feminine or female, including how they regarded and experienced their breasts, the roles that breasts played in their relationships with others and how sexual intimates responded to the loss of or changes to their breasts. Their dragon boat racing experiences had an effect here as well. Team membership and participation in dragon boat racing offered women a safe and accepting place away from the critical gaze and remarks of others. It offered them a locale where they could be themselves as women living with transgressive bodies and a transgressive disease. Participating in dragon boat racing brought the women into the company of other women with similar experiences who held alternative views concerning the loss of or changes to their breast and their bodies. It also brought women into the company of other women whose self presentations reinforced popular conceptions and constructions of femininity and femaleness and reassured women that they were still feminine and female.

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<sup>24</sup> This particular dragon boat team in many ways constitutes a 'community of practice' in which these women living with breast cancer come to learn from each other, engage in joint activities, share information, build relationships, share a repertoire of resources, stories, experiences etc. [www.ewenger.com/theory](http://www.ewenger.com/theory)

The third paper addresses a major theme that emerged from the data. It explores in greater detail the positive and transformative effects that competitive dragon boating had on the compromised and problematised bodies and sense of self of women treated for and living with breast cancer. The dragon boat racing enabled the women to reclaim and restore a body problematised by treatments for a life threatening disease, but it also transformed their bodies into bodies that were viewed and experienced as stronger, fitter, healthier and in many ways 'better' than they were prior to their illness diagnosis and treatment. This transformative effect also had implications for the body-self relationship that had been disrupted and problematised by treatment for a life threatening disease and went beyond the 'negotiated settlement' that often results when corporeality has been challenged by illness. Even though the body in illness is experienced as a constraint or limit, through competitive dragon boating the women came to experience their liminal bodies as ability and opportunity albeit in the context of critical and potentially terminal disease.

Involvement in competitive dragon boating allowed many women to develop new physical skills and competencies and to experience their bodies as a site and source of pleasure and physical vibrancy. This enabled the women to think differently about their post-treatment bodies in ways that challenged medical and popular assumptions about disruption, alienation, lack and loss. These alternative constructions allowed them to recast their marked, scarred and single breasted (or breastless) bodies as a site and symbol of honour and pride. Rather than losses to identity which often accompany critical and chronic illness, several women spoke of identity gains. They saw themselves becoming a stronger and defined themselves as athletes.

However, it was clear that this transformative effect of dragon boat racing had its limits and that experiences of reunification remained fragile as the disease subjected women to the possibility of further disruptions and even death. Although able to reconnect with and restore a disrupted body and body-self relationship, the women were only too aware of the possibility of their cancer returning. While many women were able to regain a certain amount of confidence and trust in their bodies in terms of what they could do and what they could expect from their bodies (in terms of physical competencies), a subtle but persistent sense of ontological insecurity, mistrust and fear of their bodies was evident.

### **Common Threads**

Linking each of these three papers is the empowering and transformative effects and benefits of regular participation in the competitive team sport of dragon boat racing for women living with the life threatening disease of breast cancer. As a result of their regular participation in the competitive team sport of dragon boat racing, the women in

the group interviewed experienced a series of positive effects to self, corporeality and to their lives in general.

Their participation in dragon boat racing enabled many women to re-frame their illness experience in positive ways and to recast this experience as 'not regrettable'. Their participation profoundly changed some women's outlook on life while for others it altered the focus and direction of their lives. It was an activity that several found challenging and difficult but also rewarding and life affirming. It instilled in a number of women a sense of pride and accomplishment as individual women who had overcome a traumatic life event, and as a skilled and winning women's competitive dragon boat team.

Particularly salient were the ways in which participation in this physically intense activity empowered this group of women through changes to their corporeality and to identity, which emerged out of the disruption of the body-self relationship brought on by a diagnosis of and treatment for a life threatening disease. Within the context of this group of women dragon boaters, their empowerment through the activity of dragon boating was twofold: it empowered them as women living in a gender stratified world where many women remain disempowered and disadvantaged by being denied the opportunities to develop skills and qualities that could assist in the challenging and overcoming of their disadvantage position in society (Blinde et al., 1994). It also empowered women through a compromised and problematised corporeality where the body-self relationship had been disrupted by a diagnosis of and treatment for a life threatening disease. Participation in the competitive sport of dragon boat racing enabled many women to restore aspects of embodiment problematised by their illness treatment protocols, but also enabled them to transform their bodies and their selves into "better bodies" and "better selves".

In thinking about the common threads linking each of these papers, what soon became clear was the role and significance that sport, particularly team and competitive sport played in the experiences of this group of women. Regular participation in sport continues to possess the potential to empower women through their corporeality and to dramatically shape and transform their lives. In the following I discuss how regular participation in the team sport of dragon boat racing empowered women living with breast cancer and whose bodies have been compromised and problematised by this disease at three levels: the individual, the group and the social. Particularly salient were the transformative and empowering changes that women experienced at the societal level, a domain that is regarded in the literature on women and sport as less obvious and amenable to change.

## **Sport and empowerment at the individual level**

It is now well documented how sport and physical exercise are integral to the physical and personal empowerment of women (Blinde et al., 1994; Chrisler and Lamont, 2002; Deem and Gilroy, 1998; Hargreaves, 1993; Krane, 2004; McDermott, 2000; Theberge, 1987; Young, 1997). There are however some (Krane, 2001; Mutrie and Choi, 2000) who argue that certain types of health related exercise such as aerobics (and now pole dancing<sup>25</sup>) are beauty and appearance related and tend to enslave women (i.e. women exercise in order to achieve or conform to heteronormative ideals of attractiveness, slimness and femininity) rather than empower them. Nonetheless participation in sport and physical exercise including activities that may be problematic for feminist goals not only allow women to exercise their agency (Collins, 2002), but also empower women due to the physical and psychological benefits that long-term and regular participation in brings.

Women's empowerment through sport at the personal level takes the form of a series of benefits to both self and corporeality (Theberge, 1987). Through regular exercise and sport, women are able to physically develop their bodies in ways that result in increased physical strength, energy and stamina, which enhances women's overall fitness and health. Accompanying the development of a stronger and fitter body is the development of new physical skills and corporeal competencies that enable women to develop and reinforce positive attitudes concerning their bodies, including a sense of physical power that emerges from their experiences of bodily competence (Deem and Gilroy, 1998; Theberge, 1987). Enhancements to physicality can also give rise to feelings of emotional and psychological well-being, including a greater sense of independence as women realise that they are capable of doing more for themselves (Chrisler and Lamont, 2002; Krane et al., 2004). Engagement in sport and exercise can also bring about an increase in self confidence and assertiveness (Deem and Gilroy, 1998; Maguire and Mansfield, 1998; Markula, 1995) which can give rise to feelings of control, the adoption of a proactive approach to life (Blinde et al., 1994) and enhanced capabilities that enable women to seek out and create their own realities (Mustin et al., 2002).

Within the context of a critical illness, sport also can empower women at the personal level by taking the form of a series of positive changes to both self and corporeality and is the result of the restorative and transformative effects brought on by intense physicality. As a result of the teams' competitive turn and the increase in the frequency and intensity of team practices and workouts, many women were able to regain aspects of embodiment that had been problematised by their illness treatments, as well as rebuild their self confidence and regain a sense of control (Midtgaard et al., 2006) that had

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See pole dancing as a form of exercise. [http://en.wikipedia.org/wiki/Pole\\_dance](http://en.wikipedia.org/wiki/Pole_dance)

been profoundly disrupted by their illness experiences. Participation in this activity also empowered women by enabling them to regain a sense of trust - a trust in what their bodies could now do and were capable of post-cancer - even though their bodies had let them down and betrayed them and remain as a site and source of ontological uncertainty and anxiety.

My feelings about my body are mixed. For no fathomable reason, my body let me down. I had taken good care of it and whish, right out from under me it went. I was not sure I could ever trust it again and I had to build up a relationship with it slowly over time somehow. Dragon boating has provided me with the medium wherein I could reach beyond what I thought I would ever again accomplish physically. Remember, I could not get up the stairs alone and did not know what the human body was capable of. I sure have found the answer to that question. And on the lighter side, this is a body that loved to laugh and boy is it getting a workout here in this boat. (Gabby)

### **Sport and empowerment at the group level**

Participation in team sports can also lead to the empowerment of women at the group level. Team and group sport provides women with the opportunity to enjoy the experience of group effort in a competitive context that emphasizes cooperation and support in a community of women (Theberge, 1987). Team sport also has the potential to foster bonds of friendship between women based on shared backgrounds such as an interest in physical activity (Blinde et al., 1994; Young, 1997). Membership provides women with a readily available and convenient support group where they can confide in other teammates and share their problems and concerns (Blinde et al., 1994) in an environment of tolerance, compassion and understanding. According to Blinde et al., "sport provides a goal-oriented context in which close ties and a connectedness can be developed among women. Such relationships can encourage the adoption of a group identity and the striving for common goals. These interaction patterns and shared experiences can then promote the group empowerment of women. Being empowered at the group level, women are in a better position to facilitate their advancement at the social level" (Blinde et al., 1994: 54-5).

From the responses of the women in the group interviewed, it was clear that the competitive team sport of dragon boat racing accorded them the same kinds of benefits and support as those listed above. Although membership in team and group sports has the potential to provide women with a support group like atmosphere, there are some important differences in the nature of support between "well-women" and illness-based teams like this particular breast cancer dragon boat team.

First and foremost, participation in dragon boat racing for this group of women was the result of a diagnosis of and treatment for life threatening disease. This illness experience including memories of those treatment experiences remain an important organising and mediating factor in this groups's team sport experience, and as a result, the women are positioned differently towards this particular team sport experience than are "well-women" (i.e. as a group of women who have all shared a similar traumatic life event, and whose bodies and selves have been disrupted, compromised and problematised by treatments for breast cancer). A second important feature of this experience is that these women are participating in this activity within the identity of breast cancer survivor and at both the individual and collective levels,<sup>26</sup> rather than as "well-women" who might be participating because of an interest in dragon boat racing and within the identity of athlete. Thirdly, although the focus is on physical activity, the support group function of this group, even if it only emerges at critical moments, is a key organising component of this group's intent and dynamic unlike non-illness women's teams where support is unintentional, local and is not an organising or a defining feature of the group.

We call ourselves a floating support group. (Lola)

First and foremost we are a support group. We just come to it at a different angle then sitting in a group [*And just talking.*] Yeah, well just sitting and I went to some of the support groups for Lupus and it really turned me off. You know as far as they were concerned you should be lying in your house just waiting to die type of deal and "Oh I can't do this" and "I can't that do that. And I said no, if this is what a support group is about, this is not for me. And it was that that made me stay away from regular breast cancer support groups too because I didn't want to sit and just hear the sad stories. (Mighty Mouse)

Even though the team now identifies as a competitive women's dragon boat, the life threatening disease of breast cancer remains as an important defining and structuring force which informs the tenor and dynamic of the group, including the types of relationships and the nature of bonds of friendship that can emerge among the members of this group.

Sure it comes in once and a while (fear of recurrence). It certainly comes right there when somebody's had a recurrence on our team. You know they've got sick and then death, and those are monumental times in which you would have in those, in that environment. (Emma)

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<sup>26</sup> Even though there are women who reject the identity of breast cancer survivor, many of these women identify as women living with breast cancer.

The friendship bonds gets better and deeper with every year and with every changing health situation that involves giving of oneself emotionally to one another. (Esther)

Like “well-women” who are involved in team sports, participation in the sport of dragon boat racing for women living with breast cancer enabled several to take on the empowering identity of athlete which emerged as a result of the team’s competitive turn and the corporeal changes that the women experienced as a result of their enhanced work outs and paddling regimens. The taking on of the identity of athlete was for many an important and empowering experience and gave rise to feelings of accomplishment and pride. However, this identity of athlete was at times overshadowed by the very public identity of being a woman’s breast cancer survivor dragon boat team, and this was in certain contexts experienced as a constraint and was potentially discrediting. This sometimes occurred when the team competed in races against non-breast cancer teams where they were regarded by others (officials and other competitors) as “just a woman’s breast cancer team” and were not taken seriously as a competitor and were dismissed as an inconsequential foe. Thus there were contexts where being a breast cancer survivor dragon boat team was experienced as limiting and stigmatising, and there were occasions when the group desired to transcend this identity and instead be regarded by others as a competent and competitive women’s dragon boat team. Although membership and participation in a women’s breast cancer survivor dragon boat team can be experienced as positive and empowering it can also within certain contexts be experienced as problematic and a limit as a result of the group’s status as an illness based team.

### **Sport and empowerment at the societal level**

The potential for women to be empowered by sport and physical exercise at the societal level is according to Theberge (1987), less direct and obvious and tends to occur through related changes at the personal and group levels. She argues that as women begin to experience their own energy and power they are able to build relationships and organisations that develop their capabilities, and the opportunity for economic change and advancement becomes possible in all social arenas. There are however, others who argue that empowerment at the social level is limited particularly when it comes to an awareness of gender issues and their consequences. These authors state that women generally lack a critical understanding of the ideologies that perpetuate their disadvantage position (Blinde et al., 1994) and that leisure and sport do not necessarily have a significant influence on the materiality of women’s lives (Deem and Gilroy, 1998). Deem and Gilroy argue:

“Though it may have an impact upon their bodies and identities, it is unlikely to make their work less monotonous, give them more money, provide better housing or transform oppressive relationships.” (Deem and Gilroy, 1998: 92)

Contrary to the statements of those who see sport and leisure as a limited domain for the empowerment and advancement of women's position at the societal level, there were a number of women in the group interviewed whose experiences with competitive dragon boat racing challenge this contention. As a result of their participation in this sport, several women were able to make several significant changes to their lives and many that were either directly influenced as the result of their participation in the competitive sport of dragon boating. Through her involvement in this competitive team sport and by being in the company of knowing, compassionate and supportive others, one woman whose husband was critical of her post-mastectomy body and who pressured her into having reconstructive surgery, found the self confidence to not only challenge and stand up to her husband, but to also alter the power dynamic of her marital relationship. As a result of her actions she had challenged and in part altered larger gendered social norms and inequitable practices that had structured and informed her relationship with her husband.

Even that thing, the problem with my husband. I decided that it's not my problem, it's his problem. I am the best person I can be, that doesn't mean that I'm perfect though by any means but I try....So I like myself, and if he cant handle who I am now, then that's his problem. He can do whatever he wants with that.....You know what it is? The women finally click on, at least it was with me. I finally realized wait a minute, you know what, he needs me and why am I taking this from him? And I have a couple of times said, I wouldn't but I confront him, I say you know what, I'm not doing this anymore, I don't want to do this. And in fact, something happened and I left him, for like one night. And in my mind I was leaving, I wasn't coming back, we were done. And he called me the next morning and he begged and begged and cried. And I thought, okay now, I've got a little leverage here. Obviously he wants me around (laughter) and he knows if he doesn't watch it he will lose me because I'm not afraid to leave. And that changed things a little. (Lucille)

Participation in dragon boating also enabled two women to dramatically change the material conditions of their lives when they created their own businesses which had emerged out of their breast cancer and dragon boating experiences. As a result of her breast cancer and her association with the dragon boat team one women found the courage to start her own nursing consulting business where she advises and treats women suffering from lymphedema. A second woman created a business that was based on the two products (sports bras specifically for physically active women with mastectomies, and a



lightweight and inexpensive prosthesis for the bras) that she created as a direct result of her participation in dragon boating.<sup>27</sup>

My change in career.....and asking myself what am I really waiting for, life is so short. Why aren't I doing what I really think I'd like to do....I have done more stuff than I've ever. Number 1, started my own business, talk about gutsie for me! For me, I mean this is a major, major step away from security you know? (Didi)

However, as much as we loved the sport, we realized that we couldn't find a suitable bra top for those of us who had had a mastectomy, so I set about to design one. I had 12 made and asked my team mates to try them out and give me feedback. Their feedback indicated that I had the "perfect" sports-bra. I started a business called "Janac Sportswear" and launched the original sports-bra "Emma" and after much success added two new styles; "Penelope" and "Maria" named after two of my teammates.<sup>28</sup> (Babs)

Along with according women the opportunity to develop and strengthen their self confidence through enhanced corporeality and to make important changes in their lives in the form of taking personal and professional risks, participation in this activity and being in the company of similar others allowed some women to think critically about their illness experience. A few of the women interviewed questioned medical and popular discourses that blame women for their cancer by linking the causes of breast cancer with so-called "at risk" behaviours. These women questioned or were critical of the discourses of "risk", "responsibility" and "prevention", and instead of looking inward and blaming themselves for "getting" breast cancer, they turned their gaze outward and considered the possibility of economic and environmental factors as the reasons for their disease.

And it was very humbling to go I've got what? Uh no. I'm not in the at risk category. I'm not, like I do the, I did the low fat diet for god knows how many years. Physically active, you know average weight, athletic. [*You did everything right.*] I did, I did! And I was thinking okay, I did all the right stuff and you know this has happened and it was interesting. When I joined the dragon boat team, I did all this sort of comparison. Okay, like, I was trying to find a common denominator. If it isn't all this stuff, that they say if you go on a low fat diet,

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<sup>27</sup> Babs was recently on the CBC's Dragon's Den a show where new entrepreneurs present their ideas to successful Canadian business moguls in the hope that these individuals will invest in their businesses. Babs came away with \$50,000 in investment money.

<sup>28</sup> <http://www.janacsportswear.ca/>

there's always, sort of, you are at risk for breast cancer if dah-da-dah-da-dah-da and I had none of those. So then I go to the dragon boat team and once I did that I felt there is no common denominator here. Like there's all of these age groups, all of these different shapes and sizes all of these different temperaments. (Martha)

I do think that it's the area....I think it's the pollution in the air and it's what we drink, the pesticides the water, I really do believe that. I really love [her city], I love the water, everything about it but I do sometimes wonder if we hadn't come here, I don't think I probably would have got it. And that's what I've said to my sisters too. Even though its in the family, I think its environmental. It's all these hormonal cancers, they're terrible around this area. (Babs)

Their participation in the competitive sport of dragon boating also politicised some women with regards to their breast cancer and brought several into the public realm of breast cancer awareness and advocacy. Several women now speak regularly at breast cancer conferences, to various women's and men's groups, to medical and nursing students and are also involved in community outreach with a number of different breast cancer support organisations. Some of these same women speak critically about their breast cancer experiences as well as how both breast cancer and dragon boat racing positively impacted and transformed their lives.

Because I found it a different kind of support. I figured there have to be other, at that time women who didn't want to sit around and needed something, you still need to get some answers and the doctor's aren't going to give them to you. (Mighty Mouse)

But being a part of a group of survivors. Get out there and tell people. This is very important to me. I think people have to be brought aware, made aware, brought to the realization that this can happen to you. (Charlie)

As a result of their participation in the competitive sport of dragon boat racing and by being in the company of other women living with breast cancer who held alternative views about what meant to lose a breast to breast cancer, several women resisted and challenged dominant and hegemonic discourses of loss, lack and threat to femininity and challenged those discursive practices that tend to reduce women to their biological, physiological and reproductive processes.

They were there (her breasts). They were there to be used (laughter) when you feel like it. It didn't define who I was. (Martha)

Breasts do not a woman make. (Mimi)

I don't consider myself any less a woman because I now have one wonky breast.  
(Reluctant Paddler)

By participating in this physically intense leisure activity, these women are also challenging and transforming dominant discursive practices and relationships that seek to restrict women's participation in strenuous physical activities (i.e. as inappropriate or potentially damaging to women's physiology), including the challenging of popular assumptions regarding the limited abilities of those living with a critical illness. Mustin et al., (2002) state that when women are diagnosed with breast cancer they face a series of socio-cultural ideologies that typify them as victims including ideologies and negative stereotypes about their lack of femininity and sexual desirability. Thus engaging in sport can empower because it challenges societal assumptions and norms concerning what is acceptable, permissible (Gillett et al., 2002) and conceivable for women living with a health condition that remains as a stigmatised one.

Don't always listen to your doctor (laughter). If I had listened to him I wouldn't be dragon boating. "Oh you don't want to do that. I've had nothing but bad experiences with it. Oh god, oh you don't want to do that, I've had people die doing that". The trick is that they were probably going to die before they got in the boat (laughter). (Didi)

Despite the assertion that empowerment through sport is unlikely or limited at the societal level, from the experiences of the women in the group interviewed, it was clear that there were women whose lives were positively impacted and transformed in powerful ways. Through their participation in the competitive team sport of dragon boat racing as women living with breast cancer, these women were able to think differently and critically about their illness experiences and to challenge in varying ways gendered and medical discourses and practices that seek to restrict their agency as women, and as women living with a critical illness. Thus regular participation in team and competitive sport has the potential to empower, transform and enhance the lives of women living with breast cancer in two important ways: as women whose lives remained constrained and limited by the demands of paid and unpaid work and family commitments and responsibilities and as women whose bodies and selves have been compromised and problematised by a life threatening and potentially mutilating and disabling disease.

## **Contributions to the Literature**

This dissertation makes contributions to several substantive areas of sociology including the sociology of health and illness, the body and the sociology of gender.

## **Sociology of health and illness - The healthy body in illness**

Until relatively recently much of the literature within the sociology of health and illness has focussed on the experiences of chronic illness and disability. Experiences of health have for the most part been neglected (Lawton, 2000; Monaghan, 2001; Williams and Bendelow, 2000), although there are some notable exceptions by Crawford (1984) Saltonstall (1993) and more recently Monaghan (2001). Although studies about people's understanding of and lived experiences with illness remains important, there is a need to bring into medical sociology a more comprehensive understanding of healthy bodies including other forms of embodied experience (for example, Shildrick's (1999) monstrous body and Marshall's (1996) pregnant body) that remain neglected. According to Monaghan:

“Empirically and theoretically, what is therefore needed is an approach that brings socially inscribed and lived bodies - in all their various states, guises and (dis)abled manifestations - back into medical sociology.” (Monaghan: 332)

This study contributes both empirically and theoretically to the literature on the body in health and illness by illustrating the complex, multiple and contradictory nature of the body in chronic illness and how the chronically ill and problematised body is understood and experienced as more than betrayal, alienation and loss. The “ill body” - depending of course on the type of illness and the individual's location within the illness trajectory - remains or can become a body that is also experienced as a healthy, capable, and productive. The ill body may also be experienced as a site and source of vitality, resiliency and pleasure in spite of disease limits and constraints. Of particular saliency in this study was the ‘discovery’ that the body compromised and problematised by a life threatening disease (and treatments for that disease), emerges as a “*healthy*” body but also as a “*better body*”. It can be experienced as better than it was prior to the illness experience and better as a result of illness. This can also occur at the same time as the body is experienced and understood as a diseased and potentially ill-fated body. The body in illness and disability is a ‘liminal’ body. It is a body that is at one and the same time positioned between and toward ability *and* disability, vitality *and* ailment, life *and* death.

### **Limits of acute and chronic heuristic distinctions**

Findings from this ethnography offer critical insights into the ways in which health and illness are conceptualised within sociology and the implications that these conceptualisations have for our understanding of peoples' illness experiences. The predominant focus within medical sociology has been on the illness experience rather than on experiences of health (including other experiences of embodiment). The prevailing focus within the illness experience literature has been on chronic disorders

rather than on other types of disruption such as acute illness and injury (Lawton, 2003; Rosenfeld, 2006; Williams, 1999). As a result of these heuristic divisions, the similarities between chronic and acute illnesses and injury tend to be ignored, particularly the similar disruptive effects that acute illness and injury have on the body, the self and social relationships (Rosenfeld, 2006). Typifying illness experiences as either chronic or acute fails to understand that chronic illness and disability are complex, fluid conditions (i.e. people have “good” days and “bad” days including episodes where their illness or disability is more or less pronounced) that are contextually mediated and situated. Hence there are contexts where individuals are able to experience their bodies as “less disabled” or problematic (depending again on the illness experience and trajectory). Breast cancer is an illness experience that has characteristics that are both acute and chronic, although there is some debate as to whether breast cancer should be regarded as a chronic illness<sup>29</sup>. Typified as an acute condition because of how the disease is treated (a period of intense treatment followed by periodic checkups that lessen in frequency over time), the illness *experience* of breast cancer can also be experienced in ways similar to that of chronic illness conditions. Treatment protocols can cause long term morbidity and disability (i.e. pain, lymphedema, range of motion limitations; Thomas-MacLean et al., 2008) including disruptions to self, the social setting and people’s relationships with others.

Thus the ways in which illnesses are conceptualised have powerful implications and effects for people’s physical health and well-being. As a dominant definer of social reality, the medical profession has the power to determine and legitimate what is and what is not recognised as worthy of consideration, intervention and treatment. Hence there is a need to think critically about the assumptions that shape and inform illness categories. Or at least there is the need to question the usefulness of employing medical distinctions that are used to facilitate epidemiological studies and medical treatment regimens which often ignore the social and privilege the medical over that of the sociological (Rosenfeld, 2006).

### **Psycho-social literature on gender and breast cancer**

Apart from its conceptual and theoretical contributions, this study makes an empirical contribution to the psycho-social literature on breast cancer. It does so by addressing the multiple ways in which the body in this illness experience is lived and understood beyond that of negative impacts to psychiatric morbidity, sexuality, femininity and body image due to breast loss. These are themes that continue to dominate much of

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<sup>29</sup> Breast cancer is increasingly being regarded and referred to by others within the breast cancer medical community as a chronic condition because of an increase in women’s five year survival rates. See McKenzie and Crouch (2004) and Tritter and Calnan (2002) for arguments against typifying breast cancer as a chronic condition.

the research in this area. Deeply embedded within popular and medical discourses regarding breast cancer is the belief that the loss of a breast to breast cancer challenges and undermines women's sense of self as feminine or as a woman. There is also the assumption that this challenge to femininity and femaleness results in a series of related psychological problems, particularly ones pertaining to body image and sexuality. These assumptions however, have not been thoughtfully or rigorously investigated, particularly within the traditional breast cancer care literature. Missing from much of this literature are women's own voices and experiences of breast cancer.

This research brings to the forefront women's own understandings of this illness experience including the contextually mediated ways in which the loss of a breast to breast cancer is regarded and experienced. This includes a deeper and fuller understanding of women's breasted experiences and how these experiences position women in particular ways thereby influencing their responses to the loss of their breast within the context of breast cancer.

This research initiative also contributes to the growing number of empirical studies (Braun and Wilkinson, 2005; Langellier and Sullivan, 1998; Elson, 2002, 2003; Hallowell and Lawton, 2002; Kitlinger and Willmott, 2002) that address how gendered illness experiences or conditions (breast cancer, hysterectomy, polycystic ovarian syndrome, cessation of menses) impact and problematise women's gender identity, including the multiple, complex and often contradictory ways in which women respond to these types of disruptions, and to what degree if any, gender identity is threatened or problematised. Similar to the studies cited above, this research project also found that there was a group of women who challenged and resisted the concept of femininity and who stated that their sense of self as female or feminine had not been challenged or usurped. However, unlike these other studies, this study found a group of women for whom self identifying as feminine and the doing of femininity was of little importance to them so that the problematisation of this aspect of the self concept was a non-issue and was of little to no consequence to this aspect of self.

This research also illustrates the resiliency of gender for some women in spite of the loss or problematisation of a body part that is highly connotative of femaleness and femininity. At the same time, this research is also illustrative of how gender is across and within certain contexts, less salient among other women. Thus the disruption or problematisation of a gendered body part or process was regarded as inconsequential by these women because of the limited significance that genders holds for their self conceptions. This research also shows how gender, within particular contexts, is less embodied for some women than it is for others, and that the relationship between the gendered body and gender identity is not a simple, unmediated or essential one. Although identities are often embodied, embodied identity is an ongoing and contextually mediated

experience whereby some identities may be more embodied and thus more salient to the self than are others.

### **Future directions**

In this dissertation I looked at the experiences of women living with breast cancer who participate in the competitive sport of dragon boat racing. The study has emphasized the empowering and mediating effect that dragon boat racing has on women's embodiment and sense of self. There are still many more questions to ask and many possibilities for future research.

There is a need to explore in greater detail the self-help and support group function of this activity in terms of how support and care emerge, the types of support and care that are involved, who becomes involved in organising and carrying out emotional and physical care, how care and support are organised, how caring for a dying team member impacts the team and team members, and how support and care is regarded by family members. There is also a need to look at and compare the experiences of several breast cancer survivor teams in order to discern the similarities and differences between the groups in terms of how care and support is organised and carried out across a range of experiences. Also of interest would be the perspectives of family members of the women involved in this activity. How do the husbands, partners and children of the women who dragon boat understand this activity, including the care and support that is offered to their loved one? Do they see it as an intrusion in their lives or do they see it as a positive force in the lives of their mothers, wives, sisters, daughters and aunts, etc?

Attention also needs to be paid to the similarities and differences that emerge between teams that are recreational and those that have become competitive, including an understanding of how teams struggle with and manage the tensions that can arise when a team decides to make the transition to competitive racing.

It would be interesting as well, from the point of view of the questions that this dissertation raises about the complex ways women react to changed or lost breasts, to explore the significance that experiences with other kinds of illness have on women's experiences of their body. For example, Elson (2003) shows in her research on gynecological surgery how women construct a hormonal hierarchy based on the degree to which their ovaries were excised. Their sense of themselves as female was compromised more in women who had both of their ovaries removed than it was in women who had their uterus removed because of the association of ovaries with biological femaleness. Are certain gendered body parts more symbolic of femaleness and femininity than others, and how do women understand these distinctions? There are also interesting comparisons

to be made and explored in terms of different diseases and illness conditions across and between different genders.



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## **APPENDIX A**

### **Breast Cancer Questionnaire**

**Revised August, 2002**

#### **Interview Schedule**

I am interested in talking with you about your experiences with breast cancer including how and in what ways the effects of this illness and its treatments affected your self identity, your femininity, your body and what the loss of your breast(s) has meant to you.

What we will be talking about today are those kinds of thoughts and feelings that we tend to keep to ourselves, that are in our heads and come to mind every once and a while.

I'm afraid that I will be asking you questions that are both sensitive and difficult, and you might find some of them to be embarrassing. You do not have to answer any question that you do not feel comfortable answering and we can end this interview at any moment that you wish.

**Before we begin I would like you ask you a few demographic type questions:**

1. How old are you now?
2. How old were you when you were diagnosed with breast cancer?
3. What is your sexual orientation?
4. What is your marital status?
5. Do you have any children? How many?
6. What ethnicity do you consider yourself to be?
7. What is your religion?
8. What is the highest level of education that you have completed?
9. Are you presently employed?
10. What kind of work do you do?
11. What income bracket best represents your household? Hand card.
  - A. 20,000 - 40,000
  - B. 40,000 - 60,000
  - C. 60,000 - 80,000
  - D. 80,000 - 100,000
  - E. 100,000+

**A. Breast Cancer Experience (illness experience)**

When did you first notice that something was wrong with your breast(s)/how did you come to be diagnosed with breast cancer?

Can you remember what went through your mind when you were first diagnosed?

What kind of cancer were you diagnosed with?

What kind(s) of treatment did you receive?

Was the possibility of losing your breast(s) a major concern for you?  
Why/Why not?

Was the lumpectomy/mastectomy(ies) necessary or did you choose this for preventative reasons?

Have you had breast reconstruction?

What were your reasons for having/not having the reconstruction?

If had: What type of reconstruction did you have? **Get details**  
Are you happy with the reconstruction?  
How does the new breast(s) look and feel?

If did not: Do you use prostheses?  
Why/why not?

If yes: Are you happy with how it/they look and feel?  
Do you wear it often?  
When do you wear it/don't you wear it?

If not: Are you comfortable going without a prostheses? Why?

**B. Body**

Besides the loss or partial loss of your breast(s), have there been other changes to your body?

What are they?

How do you feel about these changes to your body?

Are you comfortable in your post-mastectomy/lymphectomy body?

Does your body feel different than before you became ill? i.e. phantom feelings, nerve damage, body not me anymore

Do you suffer from any body related side effects from the surgery or from the cancer treatments i.e. lymphedema, chronic pain?

Did/do you have any mobility problems or restrictions as a result of the lymphectomy/mastectomy or breast reconstruction?

Has the cancer treatments or surgeries affected how you go about your day to day?  
Do you need help doing things that you were once able to do by yourself?

Are you able to exercise?

What kinds of activities do you do?

Have you always exercised?

What kinds of changes or adjustments have you had to make since your surgeries?

Are you more conscious or aware of your body now than before your surgery?

How did you feel about your body prior to the illness?

Were you aware of your body when you were a younger woman?

Can you remember what you were aware of?

Are you confident in your body? Why/why not?

Do you enjoy your body, do you find pleasure in it?

Would you say that you are in touch with your body, that you listen to it and know when something is wrong?

Have you always been like this or is this a result of the cancer experience?

What does it feel like not to have your breast(s) or missing pieces of your breast(s)?

Prior to the breast cancer, did you feel feminine in your body? How so?

Do you feel feminine in your body now?

Do you feel like your body has betrayed you?

Are/were you angry with your body?

Are you now afraid of your body?

### **C. Breasted Experience**

What impact if any, has the changes or loss of your breast(s) had on your life in general?

On your self identity in particular?

On your femininity/your sense of being a woman?

On your sex life?

How important was/were your breast(s) to you?

Did you enjoy them or were they a bother?

Were they a source of power for you?

Were they important to your sexuality?

Did you like how they looked and felt?

How important do you think breasts are to most women?

To men?

Can you remember when you started to develop your breasts - what was that like for you?

Were you harassed as a result of the size of your breasts?

Has the loss of your breast(s) affected how you dress, how you walk, your posture?

How have others responded to your mastectomy - do you think that they treat you differently?

Do you notice people looking at your chest?

Do you miss your breast(s)? How so?

Do you feel any different not having breasts?

Do you feel that you over-compensate in any way for the loss of your breast(s)? How so?

How would you say our society characterizes the female breast?

### **D. Gender Identity**

Would you consider yourself to be a reflective person? Ponder or wonder about things?

What does femininity mean to you?

What kinds of behaviour?

How would you characterize a feminine woman?

What kind of feminine woman are you?

On a femininity scale of 1 to 10 where would you place yourself? Why?

Has this changed as a result of the breast cancer?

How important to you is being feminine, or regarded by others as feminine?

What sorts of things make you feel feminine?

What sorts of things do you do to look or be feminine? - i.e beauty regime/types of clothing

Do you think being or feeling feminine is a natural part of being a woman or is it something women learn and are expected to do?

What does masculinity mean to you?

Are there aspects about yourself that you would characterize as masculine?

What are they?

Have you ever felt unfeminine? Do you have an example?

Have you ever felt that you were different from or unlike other women?

In what ways?

Has the loss of your breast(s) affected your sense of yourself as feminine or as a woman?

Why do you think so/not?

What about the loss of your hair? Did that affect your sense of being feminine?

Do you think that there is a difference between being a woman and being feminine?

Is looking your best and having others find you attractive important to you?

Has this been affected by the breast cancer?

Is it important to you that you look like a woman, that you look feminine?

Are there other aspects of yourself that are more important than femininity?

Were/are you involved with the Look Good Feel Better program?

Why/Why not?

What did this program do for you?

How did you come to be involved with the dragon boat group?

What does this experience mean to you and what has it done for you?



## **APPENDIX B**

### **LETTER OF INFORMATION**

#### **Mastectomy and its Effects on Gender Identity and the Body**

I agree to participate in the research study being done by Rhona Shaw of McMaster University. I have been informed that this is a study designed to obtain information about how women who have had a mastectomy cope with and adjust to an altered body and a changed sense of self due to breast cancer and its treatments. The rationale for the study is to better understand how the loss of one's breast(s) affects one's sense of being feminine or being a woman, including how one feels and experiences a breastless body. While there is a lot of talk about breast cancer in terms of self examinations, early detection and at risk populations and behaviour, it is very important that we look at and attempt to understand how women experience, make sense of and cope with breast cancer and its treatment, and how this illness experience affects the day to day lives of women. This is an area of study that is under-researched and needs to be addressed.

I understand that:

- \* Participation in the study will involve one interview of approximately one to two hours in length and the keeping of a journal over a two week period about my thoughts, feelings and reflections of breast cancer, mastectomy and how it has affected my body and my self identity.
- \* The interview will be audio-taped only with my permission.
- \* I have the choice of having the journal returned to me once the investigator is finished with it or I may allow the investigator to keep it for other research purposes.
- \* All my responses will be held in the strictest confidence and all individuals, agencies and institutions mentioned will remain anonymous.
- \* I do not have to respond to every question or provide information I do not want to provide.
- \* I can stop the interview at any time and/or refrain from making journal entries.
- \* I have the right to withdraw from the study at any point during or after the interview and the right to have my data withdrawn without reprisal. I can withdraw simply by letting the investigator know.
- \* Information gathered in this study will be used solely for professional and education purposes.
- \* My identity and any information that would allow me to be identified will not appear in any publication, report or presentation.

- \* Codes identifying participants will be kept in a secure place in my home for the duration of the study so as to safeguard the anonymity of myself and anyone other than myself referred to in the interview.
- \* Once the study is completed the code lists and tapes of my interview will be destroyed.
- \* Once the study is completed I will be provided with a summary of its main findings.
- \* This project has been reviewed and received ethics clearance through the McMaster Research Ethics Board (MREB). If I have concerns or questions about my involvement in the study, I may contact: MREB Secretariat, Office of Research Services, McMaster University, (905) 525-9140 ext. 23142, <srebsec@mcmaster.ca>.

Rhona Shaw, M.A.  
Ph.D. candidate  
McMaster University  
(905) 545-1770  
shawrm@mcmaster.ca

## **APPENDIX C**

### **CONSENT FORM**

**Research Project Title:**        **Breast Cancer and its Effects on Gender Identity and Embodiment**

**Principal Investigator:**        Rhona Shaw M.A.  
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McMaster University  
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**Dissertation Supervisor**        Dr. Dorothy Pawluch  
Associate Professor  
Department of Sociology  
McMaster University  
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**This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more details about something mentioned here, or information not included here, please ask. Please take the time to read this form.**

#### **1.        Purpose of Study**

Breast cancer continues to be the commonest cancer among women and profoundly impacts and alters the lives of women in a series of ways. The goal of my research is to look at how the experience of breast cancer affects women's self identity, their femininity and their bodies. This study is part of my Ph.D. dissertation but it is also my intention to publish a number of academic articles about women's experiences of breast cancer. The primary objective of my study is to bring into relief the ways in which women who have been treated for breast cancer, begin to cope with and adapt to an

altered body and a changed sense of self that are the result of breast cancer and its treatments.

In order to do so, I would like to interview women who have had breast cancer because I am interested in how changes to or the loss of one's breast(s) affects one's sense of being feminine or being a woman, including how one feels and experiences an altered and/or breastless body. While there is a lot of talk about breast cancer in terms of self examinations, early detection and at risk populations and behaviour, it is very important that as a society we focus on understanding how individual women experience, make sense of and cope with breast cancer and its treatments, and how this impacts and shapes the day to day lives of women. This is an area of study that is under-researched and needs to be addressed, and I am hoping that you will be interested in taking part in my study. I would like to hear about your stories and experiences.

#### **– Participation and Procedures**

Participation in this study is entirely voluntary. If you agree to participate, the initial interview will take approximately one to two hours to complete. As an interviewer, I would be asking you a series of questions about how breast cancer and the loss of your breast(s) changed your life, particularly how it affected your feminine sense of self and how it altered your body and your relationship to it. For example, I will be asking you questions like “When did you first notice that something was wrong with your breast(s)?”; “What kinds of treatments did you receive?”; “Do you miss your breast(s)?”; “Has the loss of your breast(s) affected your femininity, your sense of being a woman?”, “Does your body feel different to you than before you became ill?”.

I would also like to be able to contact you at a later date should any new questions arise or if clarification is required. These follow up contacts may take anywhere from five to thirty minutes, depending on the question and may be done over the phone. You are not obligated to answer any of the questions I may ask during the interview and follow up phone call and you are entitled to stop the interview and end the phone conversation at any time.

#### **– Participation and Withdrawal**

If you agree to be in this study, you may also withdraw from the study at any time without penalty. If you choose to withdraw, you may exercise the option of removing your data from the study, and information you have provided will be destroyed at your request. The investigator may withdraw you from the research if circumstances warrant doing so.

– **Potential Risks and Discomforts**

The McMaster University Research Ethics Board (MREB) requires research participants to be informed of any possible risks involved. I think that you are the one best able to evaluate such risks and on that basis decide what information you choose to provide.

If, as a result of our discussion, you think it would be useful to talk to a counsellor, I will be pleased to provide to you an agency to contact.

– **Potential Benefits to Participants and or Society**

This study will provide a rich and textured first hand account of women's own interpretations of their experiences of breast cancer and its effects on their self identity and their body. It will locate women's experiences at the centre of the analysis and allow them to speak for themselves and in their own voices. My research is an attempt to bring to light women's feelings about what has happened to their bodies and their sense of self as women and as feminine. As a result, it is my hope that this research will contribute to a fuller and more complex understanding of the breast cancer illness experience.

My research is also an attempt to address a gap in the academic literature on gender and embodiment. My study may be viewed as an attempt to study how gender is socially constructed and how gender becomes embodied both on and through the body by socially mediated practices. My research findings may also be of interest to individuals who are touched by breast cancer or those who are involved in the treatment and management of this disease.

– **Payment for Participation**

Participants who agree to participate in this study **will not be paid** for their participation. Your participation is strictly voluntary.

– **Anonymity**

Interviewees are notified in this Consent Form that I will guarantee anonymity and confidentiality. All identifying information will be removed and if need be pseudonyms will be used. For those participants who wish to remain anonymous, anonymity will be guaranteed.

– **Confidentiality**

With respect to confidentiality, all interview data will be securely stored and only accessible to myself and my supervisor Dr. Dorothy Pawluch. Copies or transcripts of the interview sessions will be kept in a secured filing cabinet that has a lock and is in my home. The information gathered in the interviews will be retained by myself. I do not intend to destroy the interviews as I would like to use them again at a later date in order to do a historical comparison of women's breast cancer experiences. Should this not come to fruition, I will then destroy the tapes and dispose of the transcribed interviews. Again because the information gathered in the interviews will be analysed as part of my dissertation, the findings may eventually appear in published in the form of academic journal articles or as a book or chapters in a book.

**9. Rights of Research Participants and Ethics Clearance**

**You may withdraw your consent at any time and discontinue without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This project has been reviewed and received ethics clearance through the McMaster Research Ethics Board (MREB). If you have any further questions concerning the ethics review of this project or questions about your involvement in this study, please contact:**

McMaster Research Ethics Board Secretariat  
C/O Office Research Services  
CNH 111  
McMaster University  
Hamilton, Ontario  
L8S 4M4  
Telephone: (905) 525-9140 ext. 223142  
Email: srebbsec@mcmaster.ca

**I understand the information provided for the study “Breast Cancer and its Effects on Gender Identity and Embodiment” as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form to retain for my records and reference.**

---

**Participant's Signature**

---

**Date**

**In my judgement, the participant is voluntarily and knowingly giving informed consent and possesses the legal capacity to give informed consent to participate in this research study.**

---

**Signature of Investigator**

---

**Date**

## APPENDIX D

The following emerged as a cathartic exercise the day after having competed in two dragon boat race competitions with the breast cancer survivor dragon boat team that I was studying for my dissertation. I read this piece to the women at a general meeting in the fall of 2003. It was very well received and I think it was critical in establishing my special relationship with and privileged place among this group of women. I continue to get requests for copies of this article and last summer was asked to read it to a group of family members (mostly husbands) at a home town dragon boat festival.

### Going Native in a Dragon Boat

I begin with a quote from an article I found in a Sociology journal on conducting research in preparation for my doctoral thesis on breast cancer, embodiment and femininity. The article titled “Interviewing: The Art of Science.” stated that: “Because the goal of unstructured interviewing is *understanding*, it becomes paramount for the researcher to establish rapport. He or she must be able to put him or herself in the role of the respondents and attempt to see the situation from their perspective, rather than impose the world of academia and preconceptions upon them. Close rapport with respondents opens doors to more informed research, but it may also create problems, as the researcher may become a spokesperson for the group studied, losing his or her distance and objectivity, or may go “native” and become a member of the group and forgo the academic role”.

The latter described what happened to me on Sunday May the 25<sup>th</sup> 2003 to be exact. I went native (or as far native as I possibly could not having had breast cancer) the moment I got into a dragon boat with nineteen other members of the Knot A Breast dragon team.

On that day Val was feeling ill and needed to go home and I was asked if I would like to paddle in her stead. I *leapt* at the chance. I really, really, really wanted to experience for myself just what this dragon boat thing was all about. It looked like it would be a great workout, and as a former athlete, dragon boating was something that I thought that I might be able to do, and do well. And I thought, how hard could it be? Once you’ve got the proper paddling form figured out the rest I assumed would fall into place. Boy was I wrong!

When our race was called I got into line with the rest of the dragon boat team and headed down to that place where the boats were located. As I was walking down the hill to the launch area I was thinking to myself ‘this is it’. Today I’m going to find out first hand what this attraction with dragon boating is all about and why it has become an



important part of this group's self identity. This is after all what we Sociologists are supposed to do. It is our job to try to get into the heads and hearts of those that we are studying as closely and as accurately as possible and to convey to others the meanings and nuances of human lived experience. It was my quest to try and understand why a group of women and men living with breast cancer, and a number of them who did not regard themselves as athletes, would take up dragon boating of all things. (Like having breast cancer wasn't enough of a test for them.)

Thus it was on that Sunday in May that I came to truly understand what it meant to be a dragon boat survivor. So I stand before you today to share with you my harrowing initiation into dragon boat culture.

I managed to make my way into the dragon boat (and not all that gracefully I might add) without falling out of it, or onto the others already seated, and I found my seat near the end in the 8<sup>th</sup> position on the left. Initially I was to sit in the engine room on the right hand side but I asked Kathy Levy if I could switch with Robin because she can paddle both ways and I wasn't sure if I could paddle on the right. Not only was this my first dragon boat race, but it was also my first time in a dragon boat and I wanted to be sure that I was comfortable in by ability to paddle. This decision to change positions would end up being the smartest thing that I had ever done in my life. I truly believe it was a form of divine intervention.

Now I'm relatively comfortable seated in the boat and Margaret Ann gets in beside me, and tells me to shove over, she has to sit in there too. She sits down next to me and I ask her what in the hell am I supposed to do with my feet, where do they go? Margaret Ann shows me how she positions hers, one out in front, the other up against the gunnel and I do the same. It's a little cramped and a little too familiar in here but not a problem, I'll adjust. By this time everyone is seated and ready to go so we push off from shore and Alex our coach yells "Paddles up" and on "Ready" we begin paddling in order to make our way to the starting line. With conviction I thrust my paddle deep into the water and it registers instantly! That water is freezing and I'm going to have to put my hand in there again! Okay I tell myself, this is not a problem, eventually I won't notice how cold the water is because my hand will become frozen and numb and I won't feel a thing.

So we are paddling in unison the 200 or so metres to the start line. Down and up, bend and rotate, down and up bend and rotate. This is the mantra that I play in my head over and over again in order to keep me focussed. *I will soon come to despise these six words.* Down and up, bend and rotate, down and up bend and rotate. Is it me or is it a long way to the starting line, it's much further than it looked from where we set out. I can already feel my breathing getting a little quicker, my right arm getting a little tighter and

we haven't even started the race yet! Don't worry I say to myself, you always feel like this when you begin any type of physical exercise. It takes a minute or two for your body to warm up and adjust. You'll get into it, you'll find your groove, after all, you work out and you used to be an athlete, you used to play varsity basketball, you know you can do this. Down and up, bend and rotate, down and up bend and rotate.

Finally we arrive at the starting line and get the boat pointed in the right direction and with some trepidation I turn to Margaret Ann and ask her "What in the hell do we do here, how does this start thing work?" She can tell that I'm nervous and I must have been because I don't remember asking her this. After all, this is my first race, this is my first time in a dragon boat, I'm getting a little freaked out. Margaret Ann explains things to me and I try to imagine in my head what a start that might look like. Okay, no problem I tell myself I can do this, I used to be an athlete, I used to play varsity basketball, I can rise to the occasion.

Alex then calls for our attention and presumably begins to tell us how we are going to do this race. I don't hear a single thing she is saying because I can't hear her over the sound of my pounding heart, which is about to come out of my chest. I see her lips moving, and in slow motion, but nothing is coming out of her mouth and I don't know how to lip read. Okay, don't worry I say to myself, just watch your friend Aggie who is a few paddlers up and over (and where I am supposed to be looking by the way according to proper dragon boat paddling form) and do what she is doing. Aggie is a strong and skilled paddler, she's one of the original members of this team, this is her 6<sup>th</sup> year. That's right, sixth year, S-I-X, Six! What is she, nuts! I will soon be of the opinion that anyone who gets into one of these contraptions a second time is certifiably insane.

I become aware of the start-guy telling us to back up our boat a couple of strokes, then he tells another boat to pull forward two strokes. I assume that this is to make sure that everyone is in alignment so that no boat gets an unfair advantage. This two-step goes on for a few moments until the start-guy is satisfied. He's ready and begins to give us the count down, it's Ready, ready 3 - 2 - 1 and he blows the whistle! We're off. The boat lurches forward, and I start paddling. Down and up, bend and rotate, down and up bend and rotate. Not only do I start paddling, but I start paddling with such a ferocity that anyone watching would get the impression that I thought that I alone was going to paddle the boat the 500 metres to victory. Down and up, bend and rotate, down and up, bend and rotate.

Hey, you know what, things are going rather well. This kinda feels good. I feel very powerful and if I do say so myself, I think my form is rather exceptional! This is much easier than paddling at the side of a pool. I'm really enjoying this! Down and up, bend and rotate, down and up bend and rotate. I am now in what is called The Zone. The

endorphins have kicked in and my mind and my body are at one with the universe. Dragon boating is such a rush! Down and up, bend and rotate, down and up bend and rotate, down and up and.... It isn't very long before this sense of euphoria, this being in the zone begins to wane. I notice that I am beginning to fatigue. My breathing is becoming harder and more rapid, my lungs are beginning to burn and my left arm is doing whatever it wants. Down and up bend and rotate, down and up, bend and rotate. I am no longer in the zone. I am now acutely aware of my body and it is on fire! Every muscle fibre, cell and membrane is beginning to complain, rebel even. I suddenly realize that I have approached this race as if it were a sprint! A sprint! Can you imagine? It's 500 metres long for crying out loud. What in the hell was I thinking? I must be mad. I have totally under estimated what this dragon boat racing thing is all about. (I will later be consoled that this was, after all, my first race and my first time ever in a dragon boat.)

I begin to wonder how much more of this do we need to do here and just where in the hell are we anyway? That finish line has got to be here somewhere. I stop looking at the back of Aggie's head and glance over at the shoreline to get a sense of where we are, but that doesn't help me at all. Shouldn't there be flags or something clearly demarcating where the finish line is? What kind of show are they running here anyway? In the near horizon I see groups of people standing by the boathouse and wonder if that is where the finish line is. Thank god I say to myself. That's not so bad, I think I can keep it up until then, but just.

T-h-e-n I become conscious of the buoy line, of the alternating red and white balls that float on the surface of the water and that mark the boat lanes and the race route. Hey wait a minute, ... what-the-hell-is-going-on-here? These balls extend further beyond the boathouse, much further, and I can barely see the last one. It is at that very moment I realize that I'm in trouble, serious trouble. As far as I can tell there's at least another 250 metres to go! Well, my mind freaks out and my body is right there with her. I can no longer breathe and I can taste the vomit (yes vomit) that is making its way up and into my throat. I-stop-paddling. I have to, it's not a choice. My lungs are killing me, I can't believe how much they are hurting. I don't remember ever experiencing anything like this before and I used to be an athlete, I used to play varsity basketball, I know pain. I swear to God I'm going to honk, yes honk up both of my lungs right here in the boat. Not only does it hurt like hell, but I feel terrible about stopping, not only because I have failed myself as a former athlete who thought she could overcome any pain barrier, but because I have failed my boat mates who, despite *their* pain and suffering, are continuing to paddle, and with everything they have I might add.

It is then that Donna breaks my "reverie" and roars at me to "keep paddling". I do what I am told. I plunge that paddle into the water and try to get back into the down and up, bend and rotate, down and up bend and rotate. This I'm afraid lasts for what seems

like an eternity but in reality is only a few seconds and I once again have to stop paddling. However, I keep with the motion of the down and up, down and up, *doing what I think one is supposed to do when one can no longer paddle*. I am now focussing on propelling that boat forward with my body, willing it through the water with my mind. I hear a voice behind me, Donna again I think, loud and clear *and in a tone not even my mother has used with me*, to keep paddling. Others concur.

It becomes blindingly obvious to me at that moment that I have committed the cardinal sin of dragon boating, I stopped paddling. I had no idea that, even if you were about to meet your maker (and I was about to), and you were in a dragon boat, you were still expected to keep paddling. Tough group.

Well, that paddle flew back into that water (how it got there I still don't know) and I paddled with every inch and ounce of my being. Down and up, bend and rotate, down and up bend and rotate. To hell with looking up and over at the back Aggie's head, instead I'm hunched over to my left, head down at my knees my arms flailing about above me, trying to keep that *f@#king* paddle moving in and out of the water. I don't give a shit how I look, (*whispering*) I just gotta live through this. So it's back to the down and up bend and rotate, down and up bend and rotate. It is at this time that I go in. I go into that place in my head where it is just me and myself, and me and myself are having a conversation about what I am made of and why on earth would I ever agree to participate in a dragon boat race of all things. What the hell was I thinking?

It is then that I hear them. I hear my boat mates grunting and groaning and sputtering, and snorting, encouraging each other to dig hard, to find that extra god knows what that lives somewhere deep within them that will allow them to finish this race. I leave the conversation that I'm having between me and myself, which by the way has become angry and hurtful, and I wonder if we happen to be anywhere near the finish line. I think we are, as we have just passed the boathouse and the various groups of sick bastards that have congregated along the shoreline to watch us suffer. *What joy, what bliss!* This will soon be over. Okay, okay, okay I say to myself. Focus Rhona focus. Down and up, bend and rotate, down and up bend and rotate. This mantra has now been replaced by another, which goes something like "Don't puke, don't puke, don't puke". Remember, you used to be an athlete, you played varsity basketball, you better finish this. I too start grunting and groaning, however what comes out of my mouth are not words of encouragement and support but rather four lettered ones. I-don't-care. If its going to take a barrage of expletives to get me across that finish line then so be it. I hope that if I offend anyone they will forgive me or at least take my present condition and circumstance into consideration.

I don't remember much after that. I think I went to that place where people go when they're experiencing something catastrophically traumatic. Like a plane crash. I know we crossed the finish line at some point because everyone stopped paddling. I know I continued to use profane language as I looked for my right lung that was now floating somewhere in the boat. I became aware of Margaret Ann beside me who I think couldn't believe her ears. I was showing her a whole other side of myself that I assume she didn't know existed. Never mind I tell myself, it'll be alright. Margaret Ann understands. She once put her back out one Saturday morning while doing a weight workout in preparation for the paddling season. I hear she's got quite the mouth on her, cusses like a truck driver! One other thing that I do remember was my sense of indignation when I realized that we were going to have to paddle our way back and with dignity (I had none by this point) to the place where we got into the boat. I just assumed that we were going to be towed!

So that was my first dragon boat race experience, my first time in a dragon boat and one that I will never forget. Yes I did get back into that boat a second time that day and the experience wasn't as bad as the first, although this time I knew what to expect, and it still scared the hell out of me. I guess what I said earlier about being certifiably insane for getting into a dragon boat for a *second time* now applies to me. However, I do take some comfort in the thought that I was clearly at a disadvantage here. I have to keep in mind that these women and men of Knot A Breast had the upper hand on me. You see they've all had breast cancer and I haven't. I haven't had to look the very real possibility of my mortality dead in the eye. I haven't had to endure the shock of a diagnosis of breast cancer, the fright of surgery, the loss of my breast, the insanity of chemotherapy, the burning of radiation, the indignities of tamoxifen or the dark and lurking fear of recurrence. These women and men have gone places in their heads that I pray to God that I never have to go. They have been tested in ways that I haven't. As a result, they now have something very special living inside of them. You know, the moment that I met this group in the summer of 2002 I knew instantly that there was something very particular about these people and that something truly amazing was going on here. What that special something was eluded me, until now. I initially assumed that this specialness, this energy that I could see and feel emanating out from all around them was the result of having faced breast cancer.

However, having gone as far native as I possibly could (or would want to for that matter) with this wonderful group of people, and by getting into that damn boat with them, I am now of the opinion that this specialness, this certain *je ne sais quoi*, is not just because they are breast cancer survivors who dragon boat, but because they are also dragon boat survivors who live with breast cancer and who choose to get into a dragon boat year after year and give it everything they've got.