DIGGING IN, MOVING ON:

THE EXPERIENCES OF BREAST CANCER DRAGON BOAT PADDLERS

by

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Abstract

It is commonly believed that breast cancer dragon boating benefits survivors in a range of psychosocial areas, but there have been few empirical studies to investigate such relationships. An interpretive description design and a critical health promotion approach were used to explore the psychosocial experiences of women who breast cancer dragon boat. In-depth interviews with six participants were analyzed. Themes that arose from the data are: (1) moving past isolation – networks of like-minded support, (2) taking control, (3) journey into adventure, (4) affirmative outlook, (5) confronting painful experience, (6) rebuilding identity, (7) and spiritual engagement. The findings illustrate that dragon boating provides breast cancer survivors with a significant venue for change and the opportunity to move beyond traumatic elements of cancer.
TABLE OF CONTENTS

Abstract .................................................................................................................. ii
Table of Contents .................................................................................................. iii
List of Tables ......................................................................................................... vii
Acknowledgements ............................................................................................... viii
Dedication ............................................................................................................... ix

Chapter 1
Introduction .............................................................................................................. 1
Out of Deep Waters: How I Came to Explore the Topic ........................................ 1
Paddles Up: The Emergence of Breast Cancer Dragon Boating ........................... 4
Rationale ............................................................................................................... 7
Statement of the Problem ..................................................................................... 9
Definition of Terms ............................................................................................ 10
   Section One: “Breast Cancer Survivorship” ...................................................... 10
   Section Two: Definition of Terms Used ........................................................... 11
Assumptions ........................................................................................................ 14
Summary ............................................................................................................. 15

Chapter 2
Literature Review .................................................................................................. 16
Redefining Cancer Survivorship ............................................................................ 16
Breast Cancer and Psychosocial Wellness ........................................................... 17
Social Context of Breast Cancer: Brief Introduction to Dominant Discourses .... 19
Participant Accounts in Breast Cancer Research ............................................... 21
Psychosocial Growth: The Posttraumatic Growth Model and Cancer Survivorship 22
Dragon Boating for Breast Cancer Survivors ..................................................... 25
Psychosocial Outcomes and Breast Cancer Dragon Boating ............................. 27
   Summary of literature on psychosocial outcomes ............................................ 31
   Summary ........................................................................................................ 32

Chapter 3
Methodology ......................................................................................................... 34
Starting Point: Preliminary “Analytic Framework” .............................................. 34
The Qualitative Research Approach ................................................................... 35
Critical Health Promotion Approach .................................................................. 36
Interpretive Description Design ........................................................................... 37
Benefits and Limitations of my Approach .......................................................... 38
Sampling ............................................................................................................. 40
Data Collection .................................................................................................... 41
The Process of Interviewing ................................................................................ 42
Interviewer Role ................................................................................................... 43
Ethical Considerations ......................................................................................... 44
Chapter 6

Discussion ................................................................. 111

Section One: Themes .................................................. 111
Moving past isolation — networks of like-minded support ............. 112
Taking control ............................................................. 115
Journey into adventure ................................................ 118
Affirmative outlook ..................................................... 122
Confronting painful experience ....................................... 124
Rebuilding identity ..................................................... 127
Spiritual engagement .................................................. 130

Section Two: Connections Across Themes .......................... 134
Meaning ....................................................................... 136
a) Worthwhile project ................................................ 136
b) Reframing ............................................................... 136
c) Structure ............................................................... 137
d) Myths ................................................................ 137
e) Metaphors ............................................................... 138
Psychosocial growth ..................................................... 139
a) Turning points ......................................................... 140
b) Active engagement ................................................ 140
c) Fit with basic principles of PTG ................................. 141
d) Disagreement with PTG ........................................... 141
e) Community ............................................................. 142
f) Summary of psychosocial growth ............................... 144

Section Three: Reflections .............................................. 144
On endurance .............................................................. 144
On “becoming” ........................................... 145
On insiders and outsiders ........................................... 148

Section Four: Limitations and Directions for Future Research .................... 149

Section Five: Clinical Implications ................................................... 151

Section Six: Conclusion – Closing Statement ........................................... 152

References ........................................................................... 154

Appendices
  Appendix A: Certificate of Approval ........................................... 164
  Appendix B: Participant Recruitment Notice ................................... 165
  Appendix C: Participant Consent Form ......................................... 166
  Appendix D: Interview Guide ...................................................... 168
  Appendix E: List of 7 Themes ...................................................... 169
  Appendix F: List of Subthemes Which Support Each Theme ............. 170
  Appendix G: Sharing the Wisdom ................................................ 171
  Appendix H: Typical Dragon Boat ................................................. 173
LIST OF TABLES

Table One: Moving Past Isolation – Networks of Like-minded Support .............. 65
Table Two: Taking Control ............................................................................. 72
Table Three: Journey into Adventure .......................................................... 77
Table Four: Affirmative Outlook ................................................................. 86
Table Five: Confronting Painful Experience ............................................... 92
Table Six: Rebuilding Identity ................................................................. 98
Table Seven: Spiritual Engagement ............................................................ 104
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Dedication

To Marion Shermak.
She has never been up the creek without a paddle.

To Pearl, Mary, and Marion (my Mom) for their relentless efforts to improve the quality of life of women coping with breast cancer in their small community, as well as the rest of Vancouver Island. And thanks for inspiring me to try and do the same.
CHAPTER 1
Introduction

Both the incidence of breast cancer disease and the rate of survival are increasing in North America today (Arman & Rehnsfeldt, 2003). One in nine women will experience breast cancer in her lifetime and breast cancer is the most frequently diagnosed cancer among Canadian women (Canadian Cancer Society, 2005a). Because of improved detection methods, mortality rates have dropped 20% since 1986 (Canadian Cancer Society, 2005a). In Canada there are a large number of women who will become, or are already, survivors of breast cancer. It is increasingly being recognized that cancer is a chronic disease, with long lasting medical ramifications for survivors (IOM, 2005). Despite the prevalence of breast cancer, and possible impact on the well-being of survivors, post-treatment options are still limited, especially in small communities. In such a societal context breast cancer dragon boating teams have the potential to be an important resource for survivors. Yet there have been few studies to investigate psychosocial benefits of the breast cancer/dragon boating connection. This exploratory, qualitative study was an opportunity to explore the lived experience of six women who partake in breast cancer dragon boating and are in the process of restructuring their lives post-cancer.

In the opening chapter, I describe my personal process of coming to investigate psychosocial elements of the breast cancer dragon boating experience. I then provide a brief historical overview of the emergence of breast cancer dragon boating teams. Then I discuss the rationale and research problem, followed by a definition of terms. I go on to present a few key assumptions that I held going into the research. The chapter ends with a brief summary.

Out of Deep Waters: How I Came to Explore the Topic

When I was a young woman living in a rural community, I first became aware of the complex needs of women with breast cancer. I was my Mother’s primary caregiver through a bout with breast cancer that required her to have a lumpectomy and to undergo
radiation therapy. In the corridors of Victoria’s Royal Jubilee Hospital we encountered other women with breast cancer who came from a number of tiny communities like ours and required medical care in urban centers. All the women we met were consumed by questions about cancer just as we were, and there was much uncertainty as to the future, including what would life be like after treatments, once one was “back home.”

In my Mother’s case, life after her treatments was marked by a storm of emotional upheaval and chronic pain issues. Severe depression followed her cancer treatments, and her efforts to manage various physiological ailments. I witnessed the isolation she felt in her small community, where few women openly identified as cancer survivors. She struggled to make sense of what had happened to her and what would come next. Eventually she did find a volunteer-run support group and also took an active role in local advocacy efforts.

Although my Mother started to heal she became frustrated by how, little was being done to change or simply address the lived experience of women with breast cancer. And I remember the hope that came to her when she heard of breast cancer dragon boating, a new activity that had started in Vancouver and had expanded to Victoria. Driven to have a team for her local area, my Mother helped form the first small-scale breast cancer dragon boating society in British Columbia. She saw in breast cancer dragon boating a wide-reaching way to connect with fellow survivors in her area and an active means to strike back at cancer by raising awareness. She had hope that others would not have the struggles that she had had with breast cancer and post-treatments.

The collective breast cancer dragon boating experience of my Mother and her teammates seemed to equal a return to life, a moving forward with enjoying life. At my Mother’s second festival with her new team, I walked at her side when the team marched down from the warm-up area to the boats. All around us people cheered, and people ran out of the crowd to pat the paddlers on the back. I thought it was because most people hadn’t seen breast cancer dragon boaters before, but looking back I now wonder if it was because the sight of middle aged to elderly women wearing gaudy pink sports uniforms was such a big shift from how women with breast cancer had been portrayed as sickly chemotherapy patients with no hair, or worse, no portrayal at all. As with many of the women around her my Mother was glowing, a far cry from how ragged she had seemed
just a short time before. At the time I wondered how my Mother’s meaningful engagement with breast cancer dragon boating compared with the experiences of other survivors.

That was over ten years ago and since then I have had the privilege to be part of the development of breast cancer dragon boating into an international sport. I have witnessed the journey of several breast cancer survivor paddler friends over the years, and the highs and lows of being a breast cancer dragon boater. I have also sensed a change in small communities where both non-profit services and government regulated cancer supports, such as health authority outpatient programs, have been limited. The presence of breast cancer dragon boat societies provides not only opportunities for survivors physically well enough to race, but also role models for community members and a rank of volunteers for community outreach. The “gaps,” or lack of survivor supports in these communities, do not seem as wide now.

Entering my Master of Social Work I did not intend to research breast cancer dragon boating, but many questions arose since my Mother had just dealt with a cancer recurrence. I began to wonder whether cancer supports in smaller communities had significantly changed and what exactly did breast cancer dragon boating mean to the paddlers themselves. I had been removed from the breast cancer dragon boating community for the previous two years, and this distance allowed me to turn a critical eye to breast cancer dragon boating. Given the experience of my Mother and associates it seemed that documentation of breast cancer dragon boat experiences was warranted, perhaps even necessary, if there were even the slightest chance positive psychosocial outcomes for survivors were involved. My interest in this topic was sustained by the fact that, within the social work discipline, personal experience and insight are a valid resource for conceiving a research project.

Before deciding on a formal research topic I sought advice of women in the breast cancer dragon boating community, and individuals skilled in qualitative research. The broad academic area of my research, psychosocial issues and breast cancer dragon boating, was brought forward to a group of the original members from my Mother’s team, who in turn provided a range of recommendations. I also spoke individually with two team founders and long time paddlers whom I respected for their commitment to the
development of the sport. I presented my preliminary research ideas, and inquired about areas they would like to see addressed by research. With one of the founders, who was also a graduate student and healthcare professional, I solicited discussion on the notion of psychosocial growth following trauma, including mention of the posttraumatic growth model (Tedeschi & Calhoun, 2004), which I felt might have relevance to my broad topic of interest. To gain a different perspective I spoke with a novice paddler from a large urban team. This fieldwork was in addition to speaking with members of my supportive thesis committee and graduate students who had completed their own qualitative research projects. Such exploratory work convinced me of the soundness of my preliminary ideas and I began to formulate a research question.

**Paddles Up: The Emergence of Breast Cancer Dragon Boating**

It is generally accepted that dragon boating began more than 2500 years ago in south central China (Dragon Boat, 2008). Rooted in sacred Chinese traditions modern dragon boating includes a number of highly ritualized traditions, some steeped in myth or folklore and others in cycles of the seasons. Notably, legends concerning the celestial Chinese dragon and poet Qu Yuan’s suicide prominently shape the current state of modern dragon boating ritual and sport. For instance, the modern awakening of the dragon or eye-dotting ceremony at festivals involves both an altar honouring the five directions, including their connection to nature, and the blessing of the dragon spirit in each vessel so they may awaken, usually conducted by a Taoist priest (Barker, 1996).

Dragon boating is no longer confined to Asia nor specialized clubs worldwide and is the fastest growing team sport in North America. Notably, Canada’s West Coast is a world hot spot for dragon boating (ScienceDaily, 2008). Dragon boating consists of a practice season that is intended to be preparatory for participation in dragon boat festivals, and races whether at a local, provincial or international level. Dragon boat festivals are elaborate affairs combining competitive racing with Chinese cultural events and rites. Not all teams move past a practice season, to a competition or festival season where they partake in timed races organized by various dragon boat sporting bodies. At festivals or other organized meets in British Columbia, dragon boat races are usually 2 to
4 minutes long, depending on distances that can range between 200 and 1000 meters (False Creek Racing Canoe Club, 2006).

The dragon boat is a paddle-craft, which is human powered using a distinctive stroke. In British Columbia fiberglass is the primary boat material of choice, replacing the ancient Chinese tradition of teak. There is no typical size of dragon boat. However, “Six-Sixteen” (2006) boats, premium racing boats in British Columbia, are 48 feet long. Most West Coast dragon boats are larger than Asian equivalents for two main reasons: increased stability in inclement weather and higher volume of paddlers to accommodate the sport’s popularity. For festivals, ornate traditional style drums are added to boats, often replacing empty ice cream buckets; prows and sterns are outfitted with colourful dragon head and tail pieces. The dragon boat paddle features a T-grip and the blade width is usually 18 centimeters.

A West Coast dragon boat is typically crewed by 20 to 24 paddlers seated in pairs, with a steersperson at the back of the boat and a drummer at the front who beats out the paddling stroke (see Appendix H). As regulated by GO Paddling and Rowing Association of Canada (Nanaimo Dragon Boat Festival Society, 2006) a crew must have a minimum of 20 paddlers to race in festivals, but the typical size is expected to be 22. In addition, most dragon boat teams have “spares,” or spare paddlers. Each team has a paddler who acts as a captain. She or he provides leadership and motivation for the crew.

The sport places vigorous demands on paddlers, because discipline, commitment, and passion are required for optimum sport performance. Each team member must adhere to demanding physical training schedules, learn dozens of call commands to operate the boat, be able to work in perfect synchronicity with fellow paddlers to propel the boat effectively, and master the dragon boat paddling stroke which is counter-intuitive to the more familiar canoe paddling style. The process of effectively executing the dragon boat stroke to achieve high speeds is described thus: “the blade of the paddle must hit the water in a horizontal position with a quick, backward pull, an action that requires considerable trunk and upper extremity strength,” (Unruh & Elvin, 2004, p. 139).

Because of the physical demands of the sport and that paddling synchronicity is imperative, dragon boat clubs place large emphasis on building “team.” Pre-race or practice warm ups involve multiple repetitions of various exercises often punctuated by
team chants or/and “power” phrases, meant to unite paddlers towards a common goal. Teams often invest considerable time creating team names, paddling uniforms, and for competitions team paraphernalia that again reinforce shared goals. Examples of team paraphernalia may include; brightly coloured wigs; feather boas worn by the drummer or/and steersperson; and bright war paint or/and temporary tattoos on the face or/and arms. A key part of dragon boat festivals are paddler dances and team tents, both environments where teams bond as a unit.

In 1996, the first breast cancer dragon boat team Abreast in a Boat was formed in Vancouver, British Columbia. The sport of dragon boating was chosen by Dr. Don McKenzie (1998) to test the hypothesis that upper body exercise, even of a strenuous nature, was beneficial to breast cancer survivors and, contrary to standard medical assumptions, did not increase health risks, in particular lymphedema. The research yielded anecdotal evidence that participants experienced considerable improvement to their physical health as expected, but also their mental health (McKenzie, 1998). Part of participation on Abreast in a Boat required that paddlers would do community outreach for other survivors. As the resulting word-of-mouth stories of Abreast in a Boat spread through the breast cancer survivor community, efforts by survivors to create other teams in British Columbia grew, gradually leading to a global social movement.

Today in British Columbia there are only two breast cancer dragon boat teams that have a highly formalized organization structure: Vancouver’s Abreast in a Boat and Victoria’s Island Breaststrokers. Abreast in a Boat is a special case in that it is the original team and has a number of resources not available to other teams, including the involvement of professional medical and training staff. However, for both the Victoria and Vancouver teams there is a level of professionalism, as seen in crew outfitting, team management and corporate sponsorship, that is not found in other breast cancer dragon boat teams. All other teams in British Columbia are located in small cities or towns. These teams are run by minimally structured non-profit societies and rely heavily on community funding and volunteerism to maintain operations. In this study I refer to these teams as small-scale dragon boat teams.

Standards of participation for breast cancer dragon boat teams vary widely between teams; however there are a few common practices. Individual teams set their
own schedules for practice based largely on how competitive the team is, or how involved they are in efforts to achieve awards. Highly competitive teams often practice year round and at least twice a week, with extra practices added close to the festival season. Outside of this elite group, typical breast cancer dragon boat teams paddle two or three times a week starting in late spring and ending in late August. On all breast cancer dragon boat teams, participation is not restricted to sport specific activities, such as practice sessions and races. There are a number of community volunteerism roles, for the purpose of breast cancer awareness and/or fundraising. Depending on the individual team, there may be any number of roles unrelated to sports, roles which are either required or requested of paddlers. It should be noted that all breast cancer dragon boat teams make allowances for medical issues, although standards vary between teams.

Breast cancer dragon boating team subculture mirrors that of dragon boating, but with an emphasis on the colour pink or "Abreast in a Boat fuchsia" and other elements specific to breast cancer. At dragon boating festivals breast cancer paddlers are often distinctive for their pink war paint; pink feather boas; pink ribbons; and ornate paddle art depicting themes of personal transformation since cancer, for example a pink butterfly or flying dragons with pink scales. Breast cancer dragon boat subculture has become a large part of dragon boat festivals in recent years, with many festivals holding increasingly ornate carnation ceremonies to honour women with breast cancer and smaller scale events such as Nanaimo’s candlelight vigil.

**Rationale**

There is a need for increased recognition of the support that women with breast cancer require after the end of their active treatment phase. With the growing recognition of cancer as a chronic disease, there has been an increase in attention paid to the lived experience of cancer survivorship. Breast cancer survivors are a relatively well studied population of cancer survivors, including in the broad area of psychosocial adjustment to trauma. Among the issues faced by women with breast cancer are that survivors are left with emotional memories of treatment and concerns about cancer recurrence (Thomas-MacLean, 2004). Despite increased understanding of survivor issues, there is still a poor
picture of how women who have had breast cancer are faring once active medical involvement ceases. Cancer survivorship overall is not a well defined concept and there is a poor understanding of psychosocial concerns and realities (Parry, 2007).

In Canada when women with breast cancer leave active treatment, they fall outside of coordinated care efforts for cancer patients. Regarding cancer in general, Canada currently has no integrated strategy for cancer control (Fitch, 2006), and no standardized post-treatment procedures at a federal or provincial level. Mitchell and Nielsen (2002) noted that women with breast cancer had a range of post-treatment needs that were not being met by the established medical system, a problem also pointed out by McKenzie (1998). In an extensive review document on clinical practice guidelines for the care and treatment of women with breast cancer released by the Canadian Medical Association Journal (Steering Committee, 2005) the only option provided for long-term survivors was a listing of drugs for chronic pain management.

As I discovered, as a counselling intern at BC Cancer Agency, many survivors rely on a range of non-profit services and peer advice when they have reached the end of active cancer treatment. In my experience, survivors were somewhat satisfied with these supports, but in times of distress often expressed a wish for additional services.

The lack of supports for survivors has the potential to complicate their initial recovery and the ability to cope successfully with further challenges.

In such a societal context, breast cancer dragon boating has the potential to be an important community resource for women who have survived breast cancer. The first breast cancer dragon boating team was formed in part with therapeutic intent: to address physical rehabilitation needs of survivors. Breast cancer dragon boating sport has rapidly expanded since the original team. As of November 2005 there were 49 breast cancer teams across Canada, and dozens of teams exist internationally. In Canada, diverse communities have, or are in the process of, establishing breast cancer survivor teams. Breast cancer dragon boat teams exist in places where often the only formal support for long-term cancer survivors is a local general practitioner and/or a volunteer-run support group. What is the meaning of breast cancer dragon boating teams to women who have few community resources?
Before I began the study I was beginning to realize that the potential of dragon boating to be a valuable support for survivors is even greater when one considers the anecdotal evidence. Such evidence portrays the beneficial role of breast cancer dragon boating in creating positive personal change. All studies on the psychosocial impact of dragon boating suggest that paddlers enjoy positive psychosocial benefits from team participation and better adjustment to cancer related issues, even in some cases to the extent of experiencing a sense of an enhanced life, post-trauma. I began to see that in general breast cancer dragon boating appeared to be a means for survivors to actively confront the aftereffects of cancer treatment and to develop a positive and vibrant sense of self. Therefore I became interested in investigating the potential of breast cancer dragon boating participation to enhance recovery after cancer.

**Statement of the Problem**

In this study I set out to explore the following research question: What are the experiences of women who take part in breast cancer dragon boating? A focus of this research was to expand understanding on dragon boating and its potential for encouraging psychosocial growth for breast cancer survivors. A second focus was to understand the meaning of dragon boating for paddlers in smaller communities, where post-treatment cancer wellness options were limited. It has been found that rural breast cancer survivors face supportive care challenges related to being in small communities (Gray, James, Manthorne, Gould, & Fitch, 2004). It was my hope that the understanding generated by the research question would illuminate the nature of breast cancer dragon boating as a post-treatment resource for women.

Embedded in my research question were two implicit commitments: first; to acknowledge the complexity of cancer survivor experiences, not only those that conform to social norms of positive accounts of cancer survivorship, those “most comfortable” to hear about, and second; to watch for the spiritual dimension of human experience that is common post-trauma and often part of overall psychosocial wellness, but not necessarily recognized by researchers. These commitments stem from the need for a balanced and
comprehensive perspective towards issues of cancer survivorship (Arman & Rehnsfeldt, 2003).

**Definition of Terms**

First, I provide a comprehensive overview of breast cancer survivorship. Second, I provide other terms used throughout this study.

**Section one: Breast cancer survivorship**

The concept of adult cancer survivorship is relatively new in North America. Understanding of who is a survivor and what are his or hers wellness needs is a rapidly evolving topic because as cancer control strategies improve there is a growing population of survivors to draw knowledge from. Typically, a person is considered to be a cancer survivor from the time of diagnosis to the rest of his or her life (National Coalition for Cancer Survivorship, 2006). Up until recently the term cancer survivor was restricted to individuals who had lived for more than five years after initial diagnosis and showed no symptoms of active recurrence (Rowland, 2006). The new definition marks a shift towards recognizing cancer as a chronic disease that can have long lasting complications.

The concept of “breast cancer survivorship” is not restricted to women, with a small percentage of cases occurring in men. However, for the purposes of this study “breast cancer survivor” is discussed in terms of issues faced by female survivors who
dragon boat.

Because breast cancer survivorship is a predominantly female-specific health concern that involves unique social issues which separate it from general cancer survivorship, including negative stigmatization and restricted social roles. Over the last thirty years, the negative stigmatization that accompanied a breast cancer diagnosis has greatly decreased (Sinding & Gray, 2005). The dominant social role currently available to women with breast cancer is what Sinding and Gray (2005) call “spunky survivorship,” (p. 148) or the expectation that women will joyfully embrace life after cancer. Cancer survivors are subject to overly positive social discourses, and women with breast cancer often face pervasive stereotypes of how they should live out their life post-cancer.
(Wilkinson, 2001). A notable example of this is “breast cancer awareness” month which is held each October throughout North America. Critics have suggested this month might better be called “national breast cancer industry” month as the focus is not on prevention or cure, but on marketing products to survivors, such as cancer-specific make-ups, jewelry, and wigs (Breast Cancer Action, 2007). In this study it was not assumed that the experiences of women with breast cancer are shared with other survivors of other cancers.

I acknowledge that within professional healthcare contexts there is increasing debate about the correctness of “survivor” as a term for patients who have had cancer. One argument is that the term “survivor” is passive, implying no responsibility and perhaps “witness” would more accurately reflect survivor experience (Frank, 1997). Another argument is that the term is inaccurate because it implies the end of the disease, and a complete return to health pre-cancer, which is often not the case (Sinding, & Gray, 2005). I agree with the notion that cancer is ongoing, and entails active engagement. My use of the word “survivor” in this study was not meant to imply that cancer is not a current or real issue for the women in my study. As there is currently not an agreed upon alternative, for the sake of clarity I chose to use the term “survivor” in this study.

Section two: Definition of terms used

The following definitions are offered to ensure accurate interpretation of the terminology used in this study:

**Dragon boat** – The dragon boat is a paddle-craft, which is human powered using a distinctive stroke (see Appendix H). For festivals, ornate traditional drums are added and prows and sterns of boats are outfitted with colourful head and tail pieces.

**Dragon boat team/crew** – A West Coast dragon boat is typically crewed by 20 to 24 paddlers seated in pairs, with a steersperson at the back of the boat and a drummer at the front who beats out the paddling stroke (see Appendix H). Each team has a paddler who acts as a captain, she or he provides leadership and inspiration for their crew. Team membership requires conformation to rigorous team training principles.
**Dragon boat sport** – It is generally accepted that dragon boating began more than 2500 years ago in south central China (Dragon Boat, 2008). Dragon boating is the fastest growing team sport in North America. Dragon boat races are usually 2 to 4 minutes long, depending on distances that range between 200 and 1000 meters (False Creek Racing Canoe Club, 2006).

**Posttraumatic growth model (PTG)** – A theoretical model of psychosocial growth as the result of trauma. Coined by Tedeschi and Calhoun (1996) posttraumatic growth assumes that trauma or stressful life events are not necessarily followed by negative outcomes, but that coping with trauma often leads individuals to experience significant personal growth. The model rejects the view of trauma as uniformly leading to dysfunction and other negative effects. Tedeschi and Calhoun (2004) have since developed a model that illustrates the processes of posttraumatic growth. The model postulates that growth following a trauma is not a given and entails active involvement on the part of the survivor. E. Taylor (2000) references the theory presented by Tedeschi and Calhoun (2004) as a general model of growth.

**Psychosocial health** – Psychosocial health is the conceptualization of health as being comprised of more than physiological issues. Elements include: psychological, social, biological, and spiritual. In this framework health, illness, and illness recovery are considered within a holistic or whole body focus. In other words, health factors are not limited to physiological causes.

**Psychosocial growth** – Within my study this phrase is used to express positive changes following trauma. The concept is inclusive of a number of models describing transformation or meaningful personal change after trauma (e.g. S. Taylor, 1983, E. Taylor, 2000, Arman & Rehnsfeldt, 2003, Tedeschi & Calhoun, 2004).

**Small-scale breast cancer dragon boat team** – All but two teams in British Columbia are found in small cities or towns. These teams are run by minimally structured non-profit societies and rely heavily on community funding and volunteerism to maintain operations. In this study I refer to these teams as small-scale dragon boat teams.
Spirituality – Spirituality is a poorly understood and difficult to define element of psychosocial health, also expressed as “psychosocialspiritual.” Although spirituality and religion are often used interchangeably, for many people they have different meanings (National Cancer Institute, 2007). For the purposes of this study I considered spirituality to be a deeper, more meaningful engagement with everyday life, often connected with a wider search for meaning and purpose. In this study I held the belief that a critical element of spirituality is “connectedness and being in relationship with the inanimate and animate; in the larger universe” (Canadian Society for Spirituality and Social Work, 2007, Principles section, bullet 2, pt. 2). Related to connection, Chiu (2000) described spirituality in the context of the breast cancer experience as, “an evolution to a wider realm” (p. 519), meaning a connectedness with or awareness of issues beyond pragmatic daily concerns. As Downey (cited in Puchalski, 2000, Defining Spirituality section, para. 1) defines spirituality, it is "an awareness that there are levels of reality not immediately apparent."

Suffering – Many breast cancer survivors experience suffering. The concept of suffering is not restricted to the physical body. “Suffering occurs in the whole person, as a state of distress induced by the threat of loss of intactness or disintegration from whatever cause” (Arman & Rehnsfeldt, 2003, p. 511). Suffering is a complex process that is more than a psychological response and “poses existential problems of identity and continuity of self” (Charmaz, 1999, p. 364). In other words, suffering challenges an individual’s sense of who he or she is.

Support group – For the purposes of this study a support group is not considered to be a place where people receive psychotherapy, but a circle of individuals who share a common medical condition and meet to discuss health-related concerns. The Canadian Cancer Society (2005b) offers peer run support groups, including Reach for Recovery for breast cancer survivors, in many communities where the study took place.

Trauma – Many cancer survivors have experienced trauma. Trauma can be defined as a circumstance that significantly challenges the adaptive abilities of an individual and alters her ideas about her place in the world (Janoff-Bulman, as cited in
Tedeschi & Calhoun, 2004). Trauma can have long-term symptoms and effects on thoughts, emotions, and behaviours; e.g. flashbacks and reliving the event (Herman, 1997).

Assumptions

I believe that research conducted with breast cancer survivors needs to be done with an understanding of the social forces impacting survivors of this condition. As with other marginalized groups, there is often a divide between social subject positions and lived experience. It was with a certain amount of trepidation that I decided to research breast cancer dragon boating, as I know this activity may potentially enforce the social “pink washing” (Basen, 2004) or the misrepresentation of lived experience, of women who have been diagnosed with cancer. Regarding the battle and sporting metaphors that infuse socially accepted cancer narratives, breast cancer dragon boaters exemplify both warrior and hero. I believe breast cancer dragon boating is indeed a double-edged sword: it can both empower women and reinforce restrictive social stereotypes on breast cancer survivorship. Throughout this study, by building rapport and being emotionally supportive, I have attempted to create space for participants to share their stories, as I did not wish to restrict them to stereotypical breast cancer survivorship.

As part of my belief in psychosocial wellness, I also felt it would be an unbalanced study if I did not allow for the possibility of spirituality in participant stories. Spirituality is an often overlooked element of wellness in the healthcare field (Meraviglia, 2006). Brennan (2001) argues that existing literature on survivors and spirituality speaks to, “the profound relevance of these issues to the ‘lived experience’ of people with cancer.” As a qualitative researcher I wanted to make as much space for participant stories as possible, and acknowledging spirituality as a potential part of psychosocial experiences was an extension of that commitment.

In Chapter 3, I explain how my assumptions affected the method of this study.
Summary

I have now shown how I arrived at the focus of this study. Through this process I realized the importance of clarifying the lived experience of breast cancer survivors and the societal value of this work. Embarking on this study I hoped to learn why some breast cancer survivors became dragon boaters, the meaning of the activity in their lives, and if they experienced personal changes, what the change process was for them. In Chapter 2, I review the literature concerning dynamics of breast cancer survivorship, with a focus on dragon boating, and psychosocial wellness and growth.
CHAPTER 2
Literature Review

The purpose of this chapter is to review literature that explores the psychosocial experiences of breast cancer dragon boat paddlers, inclusive of change processes. The chapter begins with three sections that together provide a picture of the lived experience of breast cancer: the evolving notion of cancer survivorship; an introductory discussion on the nature of breast cancer and psychosocial wellness; and an overview of the social context of breast cancer. I then discuss the need for research that situates breast cancer survivors as the experts in regard to their own experiences. In the next section, I discuss literature concerning psychosocial growth, including the post-traumatic growth model, which is one explanatory framework for understanding positive and negative change experiences for cancer survivorship. Next, I discuss the research on physiological and psychosocial dimensions of breast cancer dragon boat paddling. The chapter concludes with a summary of the literature regarding psychosocial outcomes and change for breast cancer survivor dragon boat paddlers.

Redefining Cancer Survivorship

Julia Rowland (2006), director of the cancer survivorship office at the U.S. National Cancer Institute asserts that both treatment and research need to keep pace with the ever-expanding population of cancer survivors. For instance, many trajectories delineating the clinical course of cancer place little emphasis on the events and processes of long-term survival (e.g. Veach, Nicholas, & Barton, 2002).

With advances in early detection and cancer treatment a new paradigm of cancer survivorship is gradually emerging in North America (IOM, 2005). Adult cancer survivors are now part of the social landscape, and their growing numbers have raised questions and concerns over their health issues and requirements. Attention is being paid to who are cancer survivors, what their needs are, and embracing the need for redefining the notion of survivorship in general (IOM, 2005). A growing number of health researchers have argued the need for a health promotion approach to survivorship, one
with the goal of optimizing health after cancer treatment (Rowland, 2006). The emerging paradigm on cancer survivorship considers a wide range of health factors: psychosocial elements in addition to physical ones.

No longer is the term “survivor” reserved for those who have lived cancer-free for five years, as was historically the case. Within a psychosocial definition, survivorship becomes a process that starts with diagnosis (Dow, 1991, as cited in Thewes, Butow, Girgis, & Pendlebury, 2004). Likewise, cancer is often now framed as a chronic disease, meaning the illness is prolonged, and does not resolve spontaneously (Stanton, Revenzen & Tennen, 2007). The prolonged course of illness associated with chronic diseases “results in extended pain and suffering and decreased quality of life,” (Centers for Disease Control, 2005, Chronic Disease Overview section, para. 1). Seen within the framework of chronic disease, cancer impacts the health of survivors long after the end of initial treatment.

**Breast Cancer and Psychosocial Wellness**

Breast cancer can be a “jarring” medical condition; unlike some other illnesses breast cancer is not usually experienced gradually and a diagnosis of the disease is often unexpected (Thomas-Maclean, 2004, p. 633). Survivors often report that the general experience of being diagnosed with breast cancer is one of losing personal control over life and entering into suffering (Thomas-Maclean, 2004).

In an important qualitative metasynthesis on the lived experience of breast cancer, Arman and Rehnsfeldt (2003) provide a vibrant picture of living with breast cancer from the time of diagnosis to long-term survivorship. The authors found in their review of literature that women described the initial breast cancer experience with words like "shock," "loss," "uncertainty," and overall disruption of life. Breast cancer typically was viewed as a "life threat." Within the reviewed literature it was clear that women coping with breast cancer endured considerable suffering across all dimensions of their life, but many women eventually reached a turning point, and found ways to discover possible meaning in their experience. Facing their new reality and the changes in their life the
women then made steps towards reclaiming a sense of wellness in their lives, even in some cases to the level of profound personal transformation or growth.

The authors noted that the breast cancer experience in general fits well with the ontological concept of suffering, where suffering is not restricted to the physical body but occurs within the whole person in all aspects of her being. Human suffering is an integral part of life, and is not the polar opposite to health. What is key is that suffering becomes bearable so the survivor can continue with her life. At the heart of Arman and Rehnsfeldt’s review is an appreciation of the complexity of the breast cancer condition, and recognition that the condition is neither marked exclusively by positive transformation after cancer nor by severe dysfunction.

Another psychosocial element that is part of the dynamic picture of breast cancer survivorship is the immediacy of the memories of treatment. With long-term survivors, even decades after their diagnosis, memories of cancer diagnosis and treatment can be unsettling (Thomas-MacLean, 2004). Time does not necessarily reduce the resonance of painful trauma (Herman, 1997). Breast cancer survivors have reported feeling strong emotions around medical treatments simply by reflecting back on those experiences (Thomas-MacLean, 2004). Breast cancer survivors, therefore, are not only at risk of lingering physiological concerns from treatment, but also psychosocial concerns.

Within the healthcare field there is a growing recognition of the importance of spirituality in psychosocial wellness for cancer survivors. Brennan (2001) asserts, “spiritual/existential questions are a vitally important and already somewhat developed area within the field of psychosocial oncology,” (p.13).

Spirituality is a problematic concept as there is no consensus as to its definition or key elements of presentation. Many definitions of spirituality within healthcare, related to cancer or otherwise, discuss changed meaning or altered beliefs. For example, spirituality is “the need to find meaning, purpose, and fulfillment in life, suffering and the death, and the need for hope and the will to live, and the need for belief and faith in self, and/or ultimate reality,” (Ross, 1995, p. 457). Susan Folkman (personal communication, April 1, 2006) notes that a complication with attempting to capture spirituality is that it is “infusing.” Spirituality is not limited to one dimension of a person’s life.
Regardless of exact conceptualization, cancer has the potential to cause individuals to reevaluate their spirituality or/and religious beliefs. For instance, E. Taylor (2000) found that women with breast cancer who had processed the traumatic elements of their disease experienced an “intensified spiritual awareness” or a sense of deeper dimensions of reality, which often coexisted with a sense of inner peace. Spirituality is also a known means of coping with cancer (National Cancer Institute, 2008). In general, spirituality is another element in the experiences of breast cancer survivors.

A growing interest in the area of psychosocial wellness and breast cancer concerns the nature of what Stanton, Danoff-Burg, and Huggins (2002) term, “adaptive survivorship,” or survivorship characterized by positive adjustment. It is known that the passing of time alone does not mean better long-term adjustment from breast cancer (Helgeson, Snyder, & Seltman, 2004). Also there is marked variability in how individuals cope with breast cancer. However, the bulk of existing research has focused on the initial adjustment period to cancer, neglecting aspects of long-term adjustment to cancer and the examination of the survival experience (Helgeson, et al., 2004). Additionally, few research studies have considered the needs of breast cancer survivors who live in rural areas (Gray et al., 2004). Overall, research that adds to the knowledge of the lived experience of long-term survivors of cancer, including breast cancer, is needed.

The Social Context of Breast Cancer: A Brief Introduction to Dominant Discourses

In order to understand fully the lived experience of women who have had breast cancer, it is important to recognize the modern social context that women with breast cancer live in and how it potentially impacts their daily lives. Cancer survivorship in general has a high public profile today. Dominant discourses of survivorship typically place the cancer survivor in one of two positions: having returned to pre-cancer health or made better from their cancer experience (Sinding & Gray, 2005). Cancer discourses are part of popular culture, part of the world that women with breast cancer live in.

Unlike in the recent past, breast cancer is no longer subject to widespread secrecy and stigma. This is in part because breast cancer is no longer seen as immediately connected to death. Over the past two decades the societal perception of breast cancer has
become upbeat (Gray, Sinding, & Fitch, 2001) and breast cancer has become a dominant disease on the cultural map (Ehrenreich, 2001). Part of the “success” of breast cancer is its bland nature when compared to socially problematic diseases like AIDS (Ehrenreich, 2001) and diseases like hepatitis C, which are widely perceived to be physically unpleasant. With regard to the hierarchy of cancers, breast cancer is privileged with public attention and funding dollars. Breast cancer is now out in the open and a recognizable feature on the social landscape.

Breast cancer survivors are subject to a number of additional social discourses of cancer specific to women that ultimately obscure and invalidate personal experience. Much has been written about how breast cancer is unique from other cancers because of the intersection between gender issues and expectations of mainstream cancer culture, (e.g. Ehrenreich, 2001; Wilkinson, 2001; Broom, 2001; Sinding & Gray, 2005). Breast cancer is a type of female-specific condition, and represents “disordered femininity,” which negatively impacts the lived experience of women (Broom, 2001, p. 256).

Wilkinson (2001) documents the two main social discourses that target women: concealment and blame and responsibility. First, women with breast cancer face the expectation that they are “healthy” following treatment and will “cheerfully” resume social obligations. Part of this is the expectation that women will conceal any scarring or disfiguration that by its nature would negatively impact their perceived womanhood. Second, women are encouraged to “think positive” and when they fail they are assigned blame for any health issues. This is a problem with all cancer survivorship, but mainstream notions on breast cancer are permeated with relentless optimism and narratives of courage (Broom, 2001).

Consistent with Wilkinson’s (2001) commentary, Sinding and Gray (2005) documented differences between social prescriptions of survivorship and the lived experience of breast cancer survivors. When women were asked to describe the social images and messages they faced, they spoke of the expectation that cancer is “over”; they were assigned responsibility for their cancer (e.g., if they didn’t watch what they ate their cancer may return); and they were told often of how their survivorship was an heroic accomplishment. In direct contrast to these social expectations, women felt that their cancer was not over but ongoing; they did not feel responsible or in a position of control
over their cancer; and they made distinctions between cancer as a matter of daily survival and pride through acts they had chosen to take on. The message from Sinding and Gray’s (2005) study was that women were subject to social expectations of “spunky survivorship,” (p. 148) which was often a struggle for women to reconcile with their own notions of their disease process and recovery.

In creating a research study involving breast cancer survivors I believed it was necessary to acknowledge discourses that are often implicit in our society, in an effort to capture the lived experience of survivors.

**Participant Accounts in Breast Cancer Research**

Historically, there has been a significant lack of breast cancer research that has considered the perspective or lived experience of the patient or survivor (Thomas-MacLean, 2004). Research has largely reflected the opinions of medical experts, a trend that is beginning to shift. Arman and Rehnsfeldt (2003) observed that over the previous eleven years breast cancer research has increasingly been conducted from a variety of perspectives, including that of the patient. This trend parallels the emergence in Canada of a cancer patient rights movement, where cancer survivors have demanded increased participation in their medical care (Gray, 1992). If we are to truly understand the needs of women with breast cancer the trend of valuing survivor experience needs to be supported.

There has also been a tradition in cancer research to neglect the idea that breast cancer may involve unique concerns, different than those caused by other cancers (Arman, & Rehnsfeldt, 2003). Breast cancer targets visible parts of the female anatomy that help define gender construction for women in contemporary North American culture. The perceived threat to femininity varies for women, but it is common for breast cancer patients to face pressure from social circles and the medical community to maintain and/or restore aspects of womanhood following treatments that alter body image. Breast cancer survivors are subject to “pink-washing” (Basen, 2004), or making invisible the negative aspects of breast cancer by means of exaggerating the positive, especially through commercial marketing. The failure in research to elaborate unique psychosocial dimensions of breast cancer disease may further obscure the experiences of survivors.
With qualitative research the philosophical underpinnings of this paradigm allow for a more comprehensive understanding of participant experience. Qualitative design looks at "the whole picture," of experience and is not seeking to "prove something or to control people" (Janesick, 2000, p. 385). Qualitative inquiry also seeks to understand, "the meanings individuals assign to experience" (Berg, 2004, p.7). A benefit of this approach with cancer survivors is that, "qualitative studies afford researchers an opportunity to fully evaluate cancer meanings. They can offer a unique perspective on survivorship and provide a rich and coherent picture of individual cancer experiences" (Foley et al., 2006, p. 249). Such understanding is tempered by the fact that qualitative studies cannot completely project the voice of participants, because it is acknowledged researchers cannot be fully objective and their individual perspectives are part of the research mix.

**Psychosocial Growth: The Posttraumatic Growth Model and Cancer Survivorship**

Initially, I wanted to explore how women were changed by the experience of breast cancer dragon boating. As I explored the literature I found work by researchers exploring positive change, such as Tedeschi and Calhoun (2004), were most informative and helpful.

The adjustment process from cancer, including breast cancer, has been subjected to a number of unrealistic assumptions. An unbalanced view of cancer recovery has emerged from a tendency of past research studies to focus solely on the stressful aspects of cancer as a trauma and the potential for dysfunction (Cordova, Cunnigham, Carlson, & Andrykowski, 2001a). In direct contrast, other studies have enforced the "tyranny of positive thinking" (Holland & Lewis, 2001); here patients are placed in the position at having to focus on positive elements of cancer to ensure optimum wellness, for example by avoiding open discussion of tragic elements of their experience. Trauma, such as cancer, is a complex and nuanced experience that to be understood needs to be considered from a multidimensional approach to adjustment (Bellizzi & Blank, 2006). A multidimensional approach attempts to capture a comprehensive picture of growth versus one that focuses on single or few elements of the experience.
Parkes (1971, as cited in Cordova et al., 2001a, p. 176) coined the phrase “psychosocial transition” to emphasize the need for a broad conceptualization of adjustment to trauma. Within this view, trauma involved both positive and negative outcomes.

Adding to the idea of trauma as a nuanced experience S. Taylor (1983) proposed a theory of “cognitive adaptation to life-threatening events” that highlighted complex processes involved with trauma recovery. S. Taylor (1983) argued that adjustment to trauma revolves around three themes: searching for meaning in the traumatic experience; attempts to gain “mastery” or control over the traumatic event or/and life in general; and restoring self-esteem through reevaluation of trauma. A strength of S. Taylor’s theory is the emphasis on active engagement by the trauma survivor in complex, processes that are often ongoing. Importantly, this theory “views people as adaptable, self-protective, and functional in the face of setbacks,” (S. Taylor, 1983, p. 1170). S. Taylor’s theory presented views that were uncommon at the time and made clear a large gap in trauma understanding, which in turn opened up new lines of research.

Building on the notion of psychosocial transition and allied concepts, Tedeschi and Calhoun’s (2004) posttraumatic growth model (PTG) allows for a dynamic conceptualization of trauma as process. Within the PTG model trauma can be defined as a circumstance that significantly challenges the adaptive abilities of an individual and alters her ideas about her place in the world (Janoff-Bulman, as cited in Tedeschi & Calhoun, 2004, p. 5). Inherent with the PTG model is the rejection of the traditional view that a highly stressful life event or trauma has primarily negative outcomes, such as mental disorders. Instead trauma is viewed as setting in motion a “rebuilding” process and is a chance for new possibilities to emerge. “The frightening and confusing aftermath of trauma, where fundamental assumptions are severely challenged, can be fertile ground for unexpected outcomes,” (Tedeschi & Calhoun, 2004, p. 1). One of the original intents behind the PTG model was to “further our understanding of the natural processes people use as they struggle with the aftermath of trauma to derive meaning, feel wiser, and face uncertain futures with more confidence” (Tedeschi & Calhoun, 1996, p. 469).

Posttraumatic growth does not mean a return to the way a person was pre-trauma but instead means a significant development of self (Tedeschi & Calhoun, 2004). The
domains of the PTG model include: greater appreciation for life and changed set of priorities; more intimate relationships with others; increased recognition of personal strength; recognition of new possibilities for one’s life; and spiritual development, which can include greater engagement with existential issues (Tedeschi & Calhoun, 2004). The acknowledgement of spiritual issues, an often ignored psychosocial element, is testament to the multidimensional nature of the PTG model. The domains in general are broad umbrellas for the diversity of positive aspects that can result from trauma.

In considering change and growth from trauma I thought about the ongoing nature of these events. Posttraumatic growth has been conceptualized as both a process and/or an outcome. Tedeschi and Calhoun (2004) argue it is both. Viewing the model as a process allows for a clearer recognition that posttraumatic growth is not static, but an ongoing development. A limitation in my view of conceptualizing posttraumatic growth as a process is that it also makes it more complex, hence harder to define. However, in qualitative research there is methodological freedom to operate outside clear-cut definitions or binaries (Thomas-Maclean, 2005). For the purposes of this study it is my view posttraumatic growth and adjustment to trauma in general is a process.

Within the model, posttraumatic growth does not emerge from the trauma itself, but from the survivor’s process of suffering (Tedeschi & Calhoun, 2004). Growth often results when one’s assumptive world is challenged and then there is an active struggle with one’s new reality. Adjustment to trauma is an act of becoming, of active steps to adjust to emerging issues (Arman & Rehnsfeldt, 2003). Breast cancer is among the traumas known to be a catalyst for posttraumatic growth (Cordova, et al., 2001a).

The need for active engagement with trauma for psychosocial growth is highlighted in E. Taylor (2000)’s model of transforming tragedy. Phases of growth are named for the broad actions they involve. Encountering darkness involves facing difficult questions, such as “why” things happened. Converting darkness involves a shift in focus to what options are available for recovery. Encountering light involves coming to see the significance in tragedy and valuing some elements of experience as positive. Reflecting light involves taking actions, such as volunteerism, that reflect the interior growth one has experienced. Phases do not necessarily occur in fixed stages, and growth is often a
spiraling process of assessment and adjustment. E. Taylor’s model emphasizes how positive meaning from growth is a dynamic process of personal engagement.

I recognized a limitation that some aspects of the theory underlying the posttraumatic growth model conformed to traditional models of health that did not hold a holistic focus. The domain of spiritual development focused more on religiosity, which in my experience is common within traditional medical model conceptualizations of health. Additionally, the PTG model did not elaborate on the role of community and posttraumatic growth. From my personal experience and from existing literature I recognized that breast cancer dragon boating was an activity that could be considered a community enterprise and certainly was interconnected with various other communities. How did the role of community come into play with participant experience? With the posttraumatic growth model, of most use to my understanding of trauma was the broad elaboration of the process by which experience with distress could potentially lead to growth and possibly wisdom.

The theories and models of psychosocial growth and trauma enriched my knowledge of trauma, offering an alternative to the view of trauma as producing dysfunction. In approaching my research study, these theories furthered my understanding of trauma as more than tragedy, and of the potential for personal growth in dragon boating or even possible failures of the sport in providing growth for paddlers.

**Dragon Boating for Breast Cancer Survivors**

The first breast cancer dragon boating studies explored the ability of breast cancer survivors to exercise safely and not diminish their physical wellbeing, such as suffering lymphedema. Traditionally breast cancer survivors who have had axillary lymph nodes removed and/or radiation have been warned by medical professionals to avoid various upper body exercises or activities (Harris & Niesen-Vertommen, 2000). The counter-argument is that restricting physical activity of breast cancer survivors is detrimental to their quality of life (Harris & Niesen-Vertommen, 2000) and compromises physical recovery (McKenzie, 1998). There is ongoing debate in the medical community about the risk factors, such as physical activity, for lymphedema in breast cancer survivors, in part
because of a lack of randomized control studies (Unruh & Elvin, 2004) and few standardized care protocols for survivors.

Breast cancer dragon boating is the product of research designed to challenge the medical assumption that repetitive or vigorous arm movement and/or upper body exercise is connected with lymphedema and other adverse side effects in breast cancer survivors. In 1996 the sport of dragon boating was chosen by Dr. McKenzie (1998), a sports medicine researcher at the University of British Columbia, to test the hypothesis that upper body exercise, even of a strenuous nature, was beneficial to the health of breast cancer survivors. Dr. McKenzie, while working on anecdotal evidence from his medical practice and emerging medical research, recognized the potential role of exercise in successful recovery from breast cancer. The study involved the creation of the first all breast cancer dragon boat team in the world, Abreast in a Boat. The research yielded anecdotal evidence that participants experienced considerable improvement not only to their physical health as theorized, but also their mental health (McKenzie, 1998).

Further challenging what they call the “myth of exercise-induced lymphedema,” (p. 95) Harris and Niesen-Vertommen (2000) found that women who received treatment for breast cancer could safely engage in strenuous upper body activity, including dragon boating. None of the research participants in this statistical analysis of case reports experienced a significant increase in arm circumference, a sign of lymphedema, over the course of the study.

Both of the physiological studies of breast cancer dragon boating allude to the psychosocial impact of the sport. McKenzie (1998) noted, “The impact of this experience on the women has been overwhelming, the physical changes barely keeping pace with the changes in the psyche,” (p. 377). D. McKenzie (personal communication, November 10, 2005) continues to assert his belief in the positive benefits of the sport for mental and social wellbeing. Harris and Niesen-Vertommen (2000) stated that women with breast cancer face a frightening medical experience that compromises their quality of life, and to limit recreational activities without sound evidence was a further blow to their emotional wellbeing. The evidence from these studies points to the value of creating research studies that focus on investigating the psychosocial impact of breast cancer dragon
boating. However, these studies only provide anecdotal knowledge on psychosocial elements.

**Psychosocial Outcomes and Breast Cancer Dragon Boating**

D. McKenzie (personal communication, November 10, 2005) noted that there was concrete evidence of the positive physiological benefits of breast cancer dragon boating and that the next challenge for researchers was to elaborate psychosocial dimensions of the sport.

Mitchell and Nielsen (2002) were the first researchers to focus on the broad area of psychosocial issues and breast cancer dragon boating. In their pilot study they used a participatory research design with 6 paddlers from both urban and rural communities in Ontario. Their purpose was to gain a better understanding of the meaning and psychosocial impact of breast cancer dragon boating. Findings suggested dragon boating was associated with positive, beneficial psychological recovery from cancer. For instance, all participants discussed improved emotional and physical health. This research supported McKenzie’s (1998) assertions of psychosocial benefits and breast cancer dragon boating. Being a preliminary study and the first study to focus on what women were gaining psychosocially from breast cancer dragon boating, it created a multitude of possibilities for future research; the authors themselves noted a significant need for further research.

With a theoretical emphasis on group processes McNicholl and Doyle (2003) undertook a qualitative study to produce a snapshot of the experience of being an Abreast in a Boat team member. Utilizing focus groups, this study produced 2 complex sets of findings that encapsulated what dragon boating had come to mean for most members of the original breast cancer team: in essence an uplifting and rewarding life after cancer. Notably, in their team environment paddlers enjoyed an unspoken understanding of the cancer experience and team participation lead them to accepting the fact they had had cancer. The study of McNicholl and Doyle also was the first study to find and directly discuss spiritual benefits from breast cancer dragon boat team participation. As data from
the McNicholl and Doyle study is specific to elaborating the Abreast in a Boat team experience, the findings do not necessarily apply to other teams.

Building directly on Mitchell and Nielsen’s (2002) work, Unruh and Elvin (2004) conducted a qualitative pilot study that sought in-depth insight into the meaningfulness of breast cancer dragon boating to the lives of three paddlers, who were from the Maritimes. Unruh and Elvin’s study used thematic analysis and was rooted in the philosophical base of occupational therapy. In their study dragon boating was conceptualized as a “meaningful occupation” with the potential to transform a negative experience (breast cancer) into something survivors would deem as positive. The finding that dragon boating is an energizing framework for a psychosocially improved life after cancer raised questions for further research on psychosocial growth through dragon boating. A methodological concern with the study was that the researchers felt the interview process did not achieve deep data, because of time constraints and the skill set of the interviewers (A. Unruh, personal communication, November 10, 2006).

The most data-intensive study of breast cancer dragon boating to the present was by a research collective based out of the School of Human Kinetics at the University of British Columbia. Both quantitative and qualitative research was used to explore psychosocial effects and breast cancer dragon boating, with attention also paid to the sport aspects of participation. Data was collected from Abreast in a Boat team members over a fixed period of time and from hundreds of paddlers from an international meet. In a summary report from a subsection of this yet unpublished data, Sabiston, McDonough, and Crocker (2004), explain how a grounded theory analysis of interview material from 15 novices and 20 veterans of Abreast in a Boat provided reasons for participation and psychosocial benefits derived from team participation, notably social support for cancer related issues. Although not part of research goals, the findings of this study fit with four domains of the posttraumatic growth model, with the exception of spiritual development (M. McDonough, personal communication, March 31, 2006). Data interpretation was heavily influenced by sports medicine, from the same faculty as sport founder Dr. Don McKenzie, and “psychosocial” data was often linked with physiological processes.

Sabiston et al. (2004) have shown that although the overall experience of dragon boating is a positive one for most paddlers, there are also clear negative outcomes of the
breast cancer dragon boating experience. Negative outcomes included in their study were: being socially excluded by peers on the team and being emotionally overwhelmed by the constant presence of breast cancer disease in the dragon boating environment. This finding reflects a need for balanced perspectives in cancer research. Arman and Rehnsfeldt (2003) have noted that cancer research needs to encompass the full range of patient experience, not only the positive. This supports my initial concept, of change processes experienced by trauma survivors, for the study.

Falling outside of the studies that informed the construction of my study, three additional studies on breast cancer dragon boating and psychosocial concerns have been published recently.

Parry (2007) working within a feminist paradigm used a creative analytic practice to create representations of “lived experience” of survivors engaged with breast cancer dragon boat racing. Framing dragon boating as a leisure pursuit and focusing on the concept of survivorship, she interviewed 11 women and 1 man. Participants were recruited from a large team from Southern Ontario. Parry’s findings document improved quality of life in the form of changed notion of self, identity and wellness. Although the representations Parry created offer a rich interpretation of the data it is often confusing as to whether experiences were held by a few or many of the women involved. Building on this study Parry (2008) used a constant comparison method to demonstrate how dragon boating was key to participant healing after cancer, impacting three broad areas of wellness: emotional connectedness to others, improved physicality, including being more athletic, and spiritual awakening, often equaling greater appreciation of life and a sense of being alive. Parry noted that her research is restricted to Ontario, and because breast cancer dragon boating is a worldwide sport there is a need for research both internationally, and within countries, for example other provinces of Canada.

To explore the psychosocial impact of breast cancer dragon boat participation on women who have had breast cancer, Mitchell, Yakiwchuk, Griffin, Gray and Fitch (2007) interviewed 10 novice paddlers from Ontario. A purpose of the study was to elaborate Mitchell and Nielson’s (2002) pilot study on psychosocial factors. Using a constructivist qualitative approach, researchers interviewed women before and after their first season of breast cancer dragon boating. Comparison of pre and post season themes revealed that all
the women regardless of backgrounds or level of team participation benefited in positive ways from participation. Benefits included: awakening of self, including greater appreciation of life; finding a common bond with others who had breast cancer; regaining a sense of control over life; and uplifting of emotions and general enjoyment.

Interestingly, the dramatic improvement in psychosocial wellness reported by participants occurred over a very short time span. Researchers noted the “psychosocial completeness” of the dragon boating activity and that, “survivor dragon boating is a unique activity in that it holistically combines all the individual elements identified in the psychosocial literature reported to benefit women with breast cancer,” (p. 135). Although, this study provides the most complete psychosocial picture of breast cancer survivor dragon boating to date, all of the participants had been diagnosed with cancer within four years of the interview, meaning the views of long-term survivors were not represented. Further 8 out of 10 participants had athletic backgrounds, which in my experience is atypical of the larger breast cancer dragon boating paddling community.

The importance of spirituality in dragon boating is a recurrent, but poorly elaborated, narrative in the existing literature. Paddlers found dragon boating to be a vision of hope for life after cancer; the activity was part of a more conscious life resulting from having faced their mortality (Mitchell & Nielsen, 2002). Participants of one study reported that the experience of paddling is spiritual by its very nature and there are mythic qualities to the sport of breast cancer dragon boating, such as the notion of racing against the dragon that is cancer (McNicoll & Doyle, 2003). Unruh and Elvin (2004) found that dragon boating was deeply meaningful or spiritual to participants. A theme in the interviews with paddlers from this study was transcendence or meaningful recovery over the cancer experience. Unruh and Elvin also had incomplete data on the importance of symbols and rituals in dragon boating to participants, and Unruh expressed a lingering critical curiosity about their psychosocial importance (A. Unruh, personal communication, November 10, 2006). Unruh and Elvin’s general findings parallel McNicoll and Doyle (2003) who documented that paddlers in their study found dragon boating a transcendental and mystical experience, meaning it had elements beyond the corporeal. Finally, Parry’s (2008) “spiritual awakening” finding revealed, “how dragon boating reminded the women of the wonders of everyday life and fortunate they were to
be alive,” (p. 230). Although findings suggest a spiritual aspect to breast cancer dragon boating for paddlers, this issue has not been a focus of any studies to date nor is the issue clearly understood.

**Summary of literature on psychosocial outcomes**

The existing research suggests that there is potential for dragon boating to be a viable post-cancer treatment resource for women, but that further investigation is needed. Mitchell and Nielsen’s (2002) study supports the idea that breast cancer dragon boating is a means to manage the anxiety that often follows the end of active medical treatment and improve the general quality of life of survivors. Unruh and Elvin (2004) noted that a practice implication of their study was that “leisure occupations may have an extremely valuable role as coping strategies that promote health and well-being in daily life,” (p. 13). Mitchell et al. (2007) titled their study “Survivor dragon boating: a vehicle to reclaim and enhance life after treatment for breast cancer” because of the psychosocial healing experienced by their participants. Further, participants appreciated the support offered by dragon boating because the lack of focus on cancer-specific issues made it unique in comparison to other peer groups. Instead, it offered a setting for connection based on shared experience. However, the limited amount of research is not conclusive.

Mitchell and Nielsen (2002) emphasized there is significant need for more research on breast cancer dragon boating and psychosocial issues. Since that inaugural study there have been six additional studies. However, existing research-generated knowledge largely comes from a similar background as the original physiological studies. Five out of seven studies were generated from medicine based or recreational stances: occupational therapy; human kinetics; recreation and leisure studies; and hospital based oncology. The existing studies often retain an underlying emphasis on the sport aspect of dragon boating and its physical benefits. Additionally, keeping in mind that regional and organizational variables can impact how paddlers frame their experience, existing studies do not illuminate the range of possible experiences. Five of the studies were done with Eastern Canada teams, four of those from Ontario, and two were with the original team, Vancouver’s Abreast in a Boat. No studies have illuminated the experience of rural teams nor focused on average teams from Western Canada.
A number of the studies I reviewed either alluded to or found “psychosocial benefits” and “personal change” which occurred from breast cancer dragon boating participation, but this has not been a primary focus of any existing studies. Broad general areas of psychosocial wellness have either been explored with treatment goals in mind or from intellectual curiosity over meaning of the activity for women. Throughout all the existing studies I saw threads of psychosocial growth, and was struck by how common the experience was. Because growth is such a broad area within psychosocial wellness, I was left wondering about the details of change processes for paddlers.

Summary

In this chapter I have reviewed research on the experiences of breast cancer survivors in general and on psychosocial outcomes associated with breast cancer dragon boating in particular. I have come to value efforts to capture the “lived experience” of survivors, for research to support the stories women have to tell. From my review of dragon boating specific studies I also came to see how psychosocial growth is often a significant narrative in the stories of women who have become breast cancer dragon boat paddlers. Further, I could see that the body of research on psychosocial growth and cancer could act as a starting point for the construction of my study on psychosocial experiences and breast cancer dragon boat paddlers.

As the area of psychosocial research and breast cancer dragon boating is in its infancy I see the value in pursuing a study that further explores and adds to this broad field of understanding. Considering that most of the existing psychosocial studies retain an emphasis on the sport aspect of dragon boating and its physical benefits, I could see the benefit of a study designed with the goals of social science in mind, and the contribution of a contrasting professional lens. Further, the current research does not provide perspectives from across Canada, for example small communities nor average Western Canadian teams. This is particularly important because most breast cancer dragon boat teams in Canada are located in smaller communities. From the current body of research I could also see the need to explore matters of spirituality and add to existing knowledge. Findings from existing psychosocial studies on breast cancer dragon boating
partially support the understanding of Tedeschi and Calhoun (2004) that trauma survivors in general often experience spiritual questioning and growth, though there is a need for further exploration. In my study I hope to address gaps in existing psychosocial breast cancer dragon boating research by elaborating on both change processes and the experiences of paddlers from small communities in Western Canada.

In the next chapter I explain my methodology. I outline the qualitative and interpretative descriptive approaches that I used to design a study to explore the experiences of breast cancer dragon boaters.
CHAPTER 3
Methodology

In this chapter I outline why I have chosen to use a qualitative research paradigm allied with critical health promotion in my study. I provide the preliminary analytic framework that was the starting point for this study. I describe my research design, interpretive description, which is a newly developed method that has resulted from debate of what constitutes qualitative research. I then document the processes of my study: sampling, data collection, analysis, and steps to ensure validity. A summary concludes this section.

Starting Point — Preliminary “Analytic Framework”

Within interpretive description an informal analytic framework is often the foundation to begin a research study (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). With interpretive description, a researcher does not bracket existing knowledge, but instead engages in a critical review of both clinical experience and existing research. This framework makes explicit the biases and theoretical assumptions that will influence research design (Thorne et al., 1997). An analytic framework orients decisions at the start of the study, but needs to be flexible as to yield to the outcomes of data collection and analysis. The analytic framework is a solid starting point for research, not a formal structure that dictates inquiry. With good research the framework will often be challenged during the research process.

In examining my personal experiences with breast cancer dragon boating I was mindful of the need to make explicit my role as an insider. There would be differences between my perceptions and those of participants. I would be challenged to make the familiar unfamiliar. When a qualitative researcher is an insider to her research context self-exploration is crucial, and the following question should be revisited continually: “Am I talking about them or am I talking about me?” (Ely, 1991, p. 125). I recognized the need to cultivate awareness of my perspectives throughout the research study.
Nine years of participation in dragon boating festivals, team meetings, fundraising rallies, and emotional support for women on my Mother’s team gave me a sense of the social context of the sport. The available research on breast cancer dragon boating confirmed many of the field experiences I had had, but also raised questions about psychosocial issues that I had never critically considered before. Of note was the prominence of personal growth narratives despite the diverse nature of breast cancer dragon boating experiences for women. And I remembered how in my small community and neighboring communities that before there was a breast cancer dragon boat team, breast cancer survivors were isolated from both the medical community and other breast cancer survivors. Breast cancer dragon boating had brought opportunity and hope, even to women who could not be active paddlers.

I knew that I wanted to do a study with breast cancer dragon boaters, but I needed to devise a research question applicable to the current state of the activity. I assumed that there was need for more community supports for breast cancer survivors and that there was potential in breast cancer dragon boating societies to be a meaningful wellness option for the diversity of survivors in their perspective communities. Further, I had encountered the posttraumatic growth theory and I wondered whether it would help me to understand some of the experiences I would see in the field. Regardless of my beliefs, what was the reality in the communities I would be conducting research in?

The Qualitative Research Approach

Qualitative research methods have a flexibility that opens possibilities beyond those offered by quantitative means. Unlike quantitative research, which is positivistic and bound by dictates of statistical probability, qualitative research examines nuances of human experience that are not easily quantifiable. The essence of good qualitative research establishes procedures that are a balance of rigorous and open-ended, and that invoke a sense of the complexity of the social context under examination (Flick, 2006). A qualitative approach allows for surprises and unexpected outcomes to be discovered (Ely, Vinz, Downing, & Anzul, 2001). Overall, the qualitative approach allowed me as a
researcher the freedom to develop a comprehensive understanding of the participants and the social context of their experiences.

Embedded in a qualitative or naturalistic approach is an examination of lived experience. Qualitative research is often a search to understand meaning unique to each participant and to engage her perspectives on issues related to the study (Janesick, 2000). The emphasis on participant perspective allowed me greater access to their point of view and worked well with my intent to explore the personal narratives of breast cancer dragon boat paddlers. In this study individuals with experiences relevant to study guidelines were able to share their perspectives (Sherman & Webb, 1988, as cited in Ely, 1991).

**Critical Health Promotion Approach**

The philosophy underlying my research is critical health promotion. In the view of Cook (2005) a critical approach to health promotion is an alternative to positivist notions of health, notably the emphasis on individual lifestyle factors. Over the past decade there has been a movement within health promotion to apply constructivist perspectives to health and to shift away from a reliance on traditional medical models of wellness, that place onus on the individual to achieve wellness. Within a critical perspective, health is now framed as a sociopolitical phenomenon. The wellness of individuals is considered with a contextual perspective, looking beyond the individual to social, political and economic factors (Cook, 2005). In this way health is reconceptualized from traditional models, and it is possible to capture the complex dimensions of health (Robertson & Minkler, 1994).

Critical health promotion is rooted in critical social science perspective (CSSP). Two important elements within CSSP are power issues and a dialectic view. Regarding power, there is no casual acceptance within CSSP of what is generally thought to be 'true' or 'real.' Within the new health promotion movement power issues are increasingly made explicit, allowing for a focus on empowerment or the positive changing of power relations for an individual. This is done in part by making space for the voices of the disenfranchised or any other source of alternative voices in debates on health (Poland, 1993). Within CSSP it is also important to recognize that the spheres of the macro-level
and the micro-level are "in a `dialectical' relationship with each other, each informs, produces, and reproduces the other," (Eakin, Robertson, Poland, Coburn, & Edwards, 1996, p. 159). It is not a matter of either/or, consideration of both social structure and individual action together needs to be considered for maximum insight.

Utilization of CSSP begins "with a `reflexive' posture towards knowledge and the research process," (Eakin et al., 1996). Researchers who assume a reflexive stance recognize they are not objective nor operating outside of the world they study. Knowledge is subjective, dependent on the perspective one takes (Rubin, & Rubin, 2005). The challenge of reflexivity is to make explicit the underlying assumptions and ideologies that so often are taken as 'truths.' An outcome of reflexivity is discovering alternative ways of viewing `reality.' In other words, "space is opened up for seeing that things could be otherwise, and for potential change," (Eakin et al., 1996, p. 158).

I identify with the CSSP approach because a researcher operating within it "views human beings as being creative, adaptive, and having much unrealized potential," (Allain, 2005, p. 25). Despite the potential people carry there is the hazard of becoming trapped in social relationships and meanings. If isolated and mired in dysfunctional social trappings, such as social myths, individuals can lose hope and sight of their potential for control over their lives. Connection with other marginalized individuals in similar situations can be a remedy for such despair (Neuman, 1994). A CSSP researcher operates within the philosophy that people can work together for change at a social level.

**Interpretive Description Design**

As part of the trend in the latter 20th century of research-related perspectives moving away from notions of truth to notions of significance of meaning (Howard, 1991), interpretive description allows researchers to explore diverse elements of lived experience.

Thorne, Reimer Kirkham, and O'Flynn-Magee (2004) state that interpretive description design is grounded in key principles of naturalistic inquiry outlined by Lincoln and Guba (1985). These are research axioms with which I strongly identify as a researcher. First, there is no singular, factual reality; instead there are multiple
constructed realities. Thus reality is subjective and contextual. Second, there is an interaction between the researcher and participant, and they influence each other. The two are inseparable, and this interconnection needs to be acknowledged. Third, a theory chosen in advance of a study could not address the multiple realities that a researcher encounters in the field and this is why theory needs to be grounded in the data.

Interpretive description design, which features an array of data collection and analysis methods, is held together by this epistemological foundation.

Interpretive description is intended for qualitative inquiry within applied or practice-based disciplines, particularly health care related fields. Interpretive description was designed to be a qualitative health research method that was responsive to the questions put forward by those from practice-based disciplines, without the hazard of mixing traditional methods to meet research needs (Thorne et al., 2004). Specifically interpretive description is part of a movement begun by nurses to, “articulate distinct methodological approaches designed to fit the kinds of complex experiential questions that they and other applied health researchers might be inclined to ask,” (Thorne et al., 2004, p. 1).

An advantage of this design is a balanced consideration for the theoretical and the practical. Interpretive description is rooted in the nursing field, which is a pragmatic profession, where researchers are concerned with connecting their studies back to the well being of the groups of people they serve. The pragmatic aim of nursing science is demonstrated by one of the discipline’s main knowledge domains of inquiry: how individuals adapt and respond to wellness and illness (Thorne, 1991). Overall, interpretive description is not concerned with abstract theorizing, but with developing relational and practical knowledge.

Benefits and Limitations of my Approach

In general, interpretive description was a solid fit with my research goals. A researcher can, “use interpretive descriptive approach to develop knowledge about human health and illness experience phenomena without sacrificing the theoretical or
methodological integrity that the traditional qualitative approaches provide,” (Thorne et al., 1997, p. 169).

Choosing interpretive description as my design allowed me both to explore and to interpret levels of deep meaning within participant accounts. Interpretive description fits with my research purpose, because it is designed for use with smaller scale qualitative studies. Further, traditional descriptive approaches in qualitative research limit the level of interpretation of the data, for example Sandelowski’s (2000) qualitative description design. Interpretive description design acknowledges the inclination to analyze, typical of qualitative researchers in practice-based fields (Thorne et al., 2004). With interpretive description I had the methodological freedom to analyze data to deeper levels, and thus to generate an interpretive account of the participants’ experiences.

Another key benefit was the inclusion of non-traditional data sources. A tenet of interpretative description is, “we believe that the judicious application of a range of data sources can add considerable strength to the usual data sources of interviews and observations for the purposes of generating practice knowledge,” (Thorne et al., 1997, p. 174). For instance, a range of lay and/or clinical documents can be used which provide a strong conceptual background to both study construction and analysis. I had the flexibility to utilize an informative data source, even if it was outside traditional sources. This was particularly important considering much of the material documenting breast cancer dragon boating falls outside academic or research circles.

A limitation of the interpretive description approach is that it is a recently created research design and is still being refined. The design is increasingly recognized across a number of disciplines, but currently is most practiced by a regionally-bound group of nursing researchers.

Further, as with any qualitative design, results from interpretive description studies do not generalize to the external population from which the participants were drawn. However, findings do add to the theoretical understanding of the experiences of participants, in my case breast cancer dragon boaters.
Sampling

As consistent with both qualitative and interpretive description design, purposeful sampling was used (Thorne et al., 2004). With purposeful sampling the goal is to find information-rich cases who will elaborate areas of interest (Patton, 2002). According to J. Morse (personal communication, August 12, 2006), in qualitative research bias must be used by researchers to connect with individuals who have the experiences we wish to study. That is, "we deliberately select the best case, and the participants who are maximally experienced, rather than having "average" experiences," (J. Morse, personal communication, August 12, 2006). I sought women who had the lived experience to answer my research questions. I developed criteria for study inclusion: participants needed to be women over the age of eighteen, who were current breast cancer dragon boaters, and who spoke English fluently. I also had the goal of finding women who were "good informants" (Morse, 2006), in that they not only were experts in my research topic, but they were able to articulate and express the depths of these narratives.

Snowball sampling, a form of purposeful sampling (Patton, 2002), was used to recruit participants. To avoid conflict of interest and to increase my ability to remain open to surprises, I intentionally sought breast cancer dragon boat teams where I did not know any of the team members. From my existing breast cancer dragon boating associates, I learned the names of the official contacts from two breast cancer dragon boating teams from small communities on central Vancouver Island and the Sunshine Coast. I approached the team contacts about possible recruitment of paddlers for my study, providing details of who I was as a researcher and printed information on the study. Team contacts provided names of paddlers who fit with parameters of my study.

I contacted possible participants by email, where I outlined the goals of my study and invited contact by telephone if interested. In the telephone call I roughly evaluated whether the women had a basic level of experience with survivor dragon boating sufficient to speak about it, and had the potential capacity to be a "good informant" (Morse, 2006). All the women I spoke with appeared to be reasonable candidates and in this way three participants were selected from each team, for a total of six.
Data Collection

Interviews were my primary means of collecting data. Interviewing is one of the typical data collection methods employed in interpretive description design (Thorne et al., 2004). With qualitative research the investigator collects representations not actual events, and interviews are a common way to gather accounts (Morse & Richards, 2002). The goal of interviewing is to gain insight into the perspectives of others, and it is assumed that such perspectives are both meaningful and knowable (Patton, 2002). As qualitative interviewing is an interactive process, the interviewer must balance skills and techniques with subjective personal qualities, such as an interest in the subject. Technical interviewing skills alone will not produce quality information.

The interview format used was semi-structured. In part I was able to utilize this approach because I had a basic level of understanding of the topic and could develop questions in advance (Morse & Richards, 2002). The semi-structured format allows an interviewer the flexibility to digress as need be from the interview guide, but also allows for predetermined topics and questions (Berg, 2004). Aspects of my study involved topics outside of common conversation, such as spirituality, and I needed a means to facilitate exploratory dialogue. As advised by Ely et al. (2001, p. 237) I considered the interview guide to be a “provisional outline” to be used more to extend conversation on issues of concern to the study than to format conversation from the beginning of the interview to the end.

In practice, interview questions were exploratory; broad and open-ended. “How a question is worded and asked affects how the interviewee responds,” (Patton 2002, p. 353). Open-ended questions are not “yes or no,” so they do not inadvertently guide a participant’s response (Glesne, 2006). Open-ended questioning allows for surprises to be encountered and when combined with the act of listening, can lead to valuable information and narratives the researcher could not have anticipated (Ely et al., 2001). In addition to this standard, an opening question was designed to gently ease dialogue to a deeper level by offering a topic that could be easily discussed by participants (S. Cadell, personal communication, November 8, 2005): “Please tell me about your experience of becoming a breast cancer dragon boat paddler.”
Within the structure of interpretive description design is the recognition that over-reliance on interview data inhibits a comprehensive research scope. Common problems with interviewing are a neglect of the material world in which participants are part and an unrealistic view that interview data is fully representative of participants' lived experience (Thorne et al., 2004). As advised by Thorne et al. (2004) interview data was supplemented with field logs, participant observation, and photographs. Of note, I attended a major dragon boat festival on Vancouver Island where both teams involved with this study were competing. I coordinated with participants and had an all-access pass that allowed me to follow and interact with participants throughout the entire festival.

**The Process of Interviewing**

Six interviews were conducted over a six-month period. Prior to setting up each interview, the participant and I discussed the study purpose and goals over the telephone. I explained to each participant the nature of the study and she had the chance to clarify any questions or concerns. During this initial contact I asked questions to ensure participants met the sampling criteria for the study. For example, "are you actively involved with the breast cancer dragon boat team at this time?" Interviews were scheduled at a mutually agreed time, and when I asked about a private setting preferable to them, all participants chose their home.

At the time of the interview the purpose of the study was reviewed in relation to the interview guide. Information on confidentiality was provided, including data storage and representation of data in the thesis, a public document. In conversation with participants it became clear that they appreciated offers of confidentiality, but the women realized that as members of a small community in a unique activity that confidentiality was limited. After a discussion about confidentiality, I checked that the issue was understood and there were no further questions, at which point the participant was asked to sign a consent form.

The interview using a semi-structured format took between one and two hours. The interview guide was used to engage discussion and assist the participant in sharing her narrative. Effort was made to guide, not lead participants, and provide space for
participants to have their say (Morse & Richards, 2002). The same exploratory questions
were asked of all participants, to ensure areas of interest to the research were addressed.
However, each participant brought her own view or perspective to the interview and
accommodations were made to assist, not prohibit, storytelling. The questions and their
order were adjusted according to context, and narrative flow. With a few of the
participants, a number of the interview questions were only used for clarification as
participants had dealt in detail with those topics during the natural flow of conversation.
Further, interview questions were slightly revised throughout the interview process to
reflect my growing understanding of the process and to reflect feedback from
participants.

To support the interview process probes were used. One example from interview
notes is a clarifying probe, “When you say ___ (e.g. magic of dragon boating), can you
say a little bit more about what you mean?” I also carefully used silence, a type of probe,
to encourage participants to take the time to formulate their thoughts (Glesne, 2006).

Initially in the interview process, I was most interested in the period of time when
participants became a breast cancer dragon boater. However, participants began their
stories with their cancer treatment. I came to understand that the story of coping with
cancer was essential for understanding the meaning of dragon boating to them, and I
made a particular point to make space for these narratives.

Equipment used in the interviewing process varied because of technical
difficulties. The primary platform was Audacity sound editor software, version 1.2.6,
utilized on a Mac iBook G4 laptop. Interviews were stored in password-protected files in
WAV format. In the case of technical failure, which occurred twice, data was recorded on
a Sony microcassette recorder (Model M-470), and later transferred into WAV files to
allow for digital playback. All data, regardless of recording method, was played back for
transcription and/or review through QuickTime Player, version 7.1.3.

**Interviewer Role**

As previously discussed, with qualitative research the interviewer plays an
important and interactive role. The qualitative researcher is an instrument of analysis and
her responsiveness at all stages of research determines rigor. Further, in a study investigating events surrounding trauma strong emotions may accompany narratives of events and researchers have stressed that an interviewer needs to create an environment of trust (Allain, 2005, p. 34).

Part of both building trust and being a valid instrument of research is having familiarity with the experiences under study (Miles & Huberman, 1984). I have a personal history and academic interest in the dynamics of breast cancer survivorship. I have acted as my Mother's personal caregiver through two bouts of breast cancer. I have been with her as support "staff" throughout her efforts to start a breast cancer dragon boat team and her subsequent years as a lead stroke for several local and international teams. Regarding breast cancer survivorship, as well as trauma and grief in general, I have completed numerous academic courses and have taken advantage of professional educational opportunities. In the past my work as a crisis counsellor and chronic disease self-management facilitator taught me that clients are the experts concerning their own experiences. Survivors of trauma have developed individual coping strategies and have numerous strengths gained from their experiences. The evolving knowledge and experience I bring with me to a given situation is more useful as a starting point for discovery rather than assumptions about anticipated norms.

In this study my personal background meant we had "common ground" which was useful in building and maintaining trust with participants. However, once established I worked at setting aside much of this experience to make room for the stories that were shared with me.

**Ethical Considerations**

As an interviewer, I was sensitive to the fact my study topic might open exploration of painful memories of trauma for participants.

A specific intent behind the open questions and informal probes used in interviews was to meet a personal goal of doing no harm during the interview process. Open questions not only encourage participants to provide detailed descriptions of their
experience, but in the process facilitate empowerment as there was no attempt on my part to dictate their story for them.

When participants spoke of their cancer experiences I was careful to use language and frame probes in a manner conducive to thoughtful discussion. I wanted each participant to realize that her knowledge and strengths were respected, that her interview participation had the potential to assist other women. At times, I offered participants the opportunity to take a break and reminded them they could end the interview at any time. I made sure to watch for facial expressions, and other nonverbal cues of distress or concern. I also asked participants how they were doing emotionally from time to time, and checked on their comfort level with the interview process.

At the end of each interview, we debriefed the experience, an ethical process advocated by researchers such as Allain (2005). This was an informal process, usually involving casual conversation on what the experience was like for the participant. I asserted participants were free to email me if they had any concerns or further questions. I was sure to thank each participant for her assistance.

Data Analysis

Transcription

For the first three interviews a professional did the work of transcription. Digital WAV files of each interview were transferred onto a disc, which was then used by the transcriptionist to produce a transcript file. In each transcript the participant’s name was not used and the individual was referred to as “participant.” Completed transcripts were couriered to me in the form of a disc. To ensure confidentiality all files were password protected. A disadvantage of using the professional transcriptionist was that there was a block of time after each interview where I was removed from the data analysis process: I did not engage in the replay of interview data which is part of transcription nor did I have a completed transcript to review shortly after completing each interview. To immerse myself in the data I had to engage in extensive replay of the interviews at the time of transcript delivery.
I transcribed the final three interviews myself, at which time I assigned participants pseudonyms to preserve confidentiality. As well, I altered or omitted identifying information in transcripts such as town names, team names, and names of fellow teammates. I also expanded the notation system used by the transcriptionist, to better represent nonlinguistic features of each interview. Creation and consistent use of a notation system allows for better preservation of linguistic and emotional nuances that are often lost when an oral interview is transcribed into text (Sandelowski, 1994). For brief pauses in dialogue three dots were used and for lengthy pauses additional dots were added depending on the length of the pause. Laughter, crying, sighs and periods of silence were included in round parentheses. For example:

D: “It is hard. It is really hard, it’s an emotional thing again because you are really up here .. you are happy and your excited but there is also a sadness ... I guess sadness being why you had to go through what you did to be able to feel that way now (silence)”

Backup copies of transcribed text were kept on a memory stick and in print form, until analysis was complete. Transcriptions have been kept confidential: computer files are password protected and printed material has been kept in a locked drawer. At such time as the data is no longer required for the purposes of this study and when I am no longer required to retain data by University of British Columbia ethics standards, I will destroy printed material and delete computer files.

The analysis process

With qualitative research design data analysis is not a distinct stage in research, but a “reflexive activity” that informs the research process from the time of the first interview (Coffey & Atkinson, 1996). Analysis involves constant questioning and re-evaluating that is responsive to the emerging events in the research process. With analysis the researcher must distance herself from preliminary assumptions and ideas, by remaining critical and forging pathways that challenge, not reinforce, initial theorizing (Thorne et al., 1997).

Solid data analysis involves the expansion of ideas over time and process. I used a system of memos and a journal to engage in a dialogue with myself over questions,
insights, and concerns. These written records document an inductive process of critically engaging with the data. Further, my field notes and reflexive journal have allowed me to trace the development of abstractions in the analysis process (Thorne et al., 2004). My process of examination and re-examination led me to schedule gaps of time between interviews, so that new observations and information could be used to inform the data analysis process. In particular, I spaced each of the final three interviews about a month apart from each other, in order to take stock of saturation levels in certain themes, and identify gaps in understanding.

With interpretive description the actual system of coding or organizing is less important than whether the research is guided by “processes of intellectual inquiry,” (Thorne et al., 2004, p. 12). The analytic process needs to be one of constantly questioning, and reevaluating. However, Thorne (2000) advises a constant comparative approach when reaching the stage of interpreting raw data.

The formal system of data analysis I used was primarily influenced by a variation of the constant comparative method described by Ely et al. (2001). This system allows for a higher level of analysis as consistent with interpretive description. Following completion of each participant transcript, I would review lines of text and underline portions that had broad relevance or meaning to the research question. Text where I sensed importance to the study but could not yet explain were included. From underlined text, I selected chunks that were the smallest possible unit of meaning, which varied from a couple words to a couple of sentences. An example of an average meaning unit was, “But of course you know getting a boat and life jackets and every – how are we going to do that?” These meaning units, highlighted in yellow, were retained in a block of text that preserved the immediate context of the unit, a process suggested by J. Morse (personal communication, June 27, 2006). For each participant, a meaning unit document was created to store these new representations of the data.

The next step in analysis was to build preliminary categories using each meaning unit document, remaining at an individual participant level. Portions of text were reread over a period of time and informal margin notes were added (Ely et al., 2001). From this process meaning units were labeled with codes. A particular meaning unit might be assigned more than one code if it had multiple connotations. Codes were not formal
These could change as understanding of data shifted. Coded meaning units were next grouped together by cutting and pasting statements into new category documents for each participant.

Throughout the coding and subsequent categorization process I continuously used Thorne et al.’s (2004) questions for examination: “Why is this here? Why not something else? And what does it mean?” (p. 12). Such questions helped to shift understanding of the data from a literal level to an interpretative one.

Through reflection and comparison of tentative categories across all participant narratives, I gradually identified patterns that would form the basis of themes. Following advice from J. Morse (personal communication, June 30, 2006) I did not assume that themes would emerge and instead I engaged in an active search, where I took her approach of thinking, and thinking harder. This is consistent with Ely et al.’s (2001) assertion that themes can only be developed over time and through much deliberation. While reviewing the text of tentative categories I made detailed notes of impressions and refined categories as their meanings became clearer. Immersed in this process I began to recognize key patterns for each participant and patterns shared across participants.

Not until all interviews were completed did I formally evaluate themes. When creating themes I continually revisited three questions for critical review: 1.) Is it important enough to stand on its own? 2.) Is it the same kind of theme as the other themes? For example, level of abstraction. 3.) Does this answer the research question? Through this process of analyzing and re-analyzing themes were slowly refined.

I made lists of themes for each participant and compared those lists to each other, keeping in mind key quotes that helped define each theme. Then I began to create documents for each theme, by combining similar categories from all participants. These new documents uniting individual data illuminated a few meaning units and/or categories that needed further evaluation or clarification of meaning. It became apparent that some themes and subthemes were shared by a majority of participants, while some were unique to one participant, but invaluable in documenting the experiences of breast cancer dragon boaters.
Themes and their supporting subthemes were never fixed in the thesis process, and became more defined during the writing of the results chapter.

Validity

Because naturalistic research design is emergent, validity cannot be ascertained with objective measures available to quantitative studies. With interpretive description quality of the study is largely determined by attention to rigor during the research process and then the articulate reporting of that process (Thorne et al., 1997). The logical processes that developed the findings must be made explicit. This methodology section and its subsections help to achieve these standards.

A verification strategy for validity is that good qualitative research is dependent on investigator responsiveness at all levels of the study, and the lack therefore is arguably the greatest hidden threat to rigor (Morse, Barrett, Mayan, Olson, & Spiers, 2002). In regards to responsiveness, as the qualitative research process is highly emergent, the research is only as good as the researcher. The qualitative researcher must be creative, sensitive, flexible and have a high level of technical skill (Morse et al., 2002). To maintain my underlying curiosity for the topic I tried to avoid burn-out by keeping to a thesis work schedule that included mandatory break periods, and non-academic activities, such as backcountry wilderness excursions. To maintain responsiveness by increasing skill or knowledge level, I attended a week-long qualitative research training workshop (6th Annual Thinking Qualitatively Workshop Series presented by The International Institute for Qualitative Methodology: University of Alberta), sought conversation with qualitative researchers in the field (e.g., Sally Thorne, Don McKenzie, Adele Rich, Janice Morse, Anita Unruh, Susan Folkman), attended cancer related conferences (e.g., The 2nd International Cancer Rehabilitation Conference presented by Interprofessional Continuing Education: University of British Columbia), and presented original research at conferences (e.g. The 4th International Multidisciplinary Conference on Spirituality and Health presented by Interprofessional Continuing Education: University of British Columbia). Overall, I appreciated the need for approaching research in an engaging not disinterested way.
A further means to ensure validity during the process of the study is to collect and analyze data concurrently (Morse et al., 2002). Morse et al. (2002) note that concurrent collection and analysis of data, “forms a mutual interaction between what is known and what one needs to know,” (Verification Strategies subsection, para. 4). One specific example in my study was that I scheduled blocks of time between interviews, to have the space to reflect on new information. For instance, my first three participants all spoke in some depth about fears and I came to watch for the topic in future interviews, and to ask probes around any fear related issues. Overall, I ensured data collection and analysis were interactive processes that together deepened my understanding of data.

Member checking is another means to demonstrate or verify that results reflect participant experience and that a researcher has not skewed results (Thorne et al., 1997). Member checking is accomplished by requesting participant feedback on research findings. Within interpretive description design it is advised that “beginning conceptualizations representing the entire sample,” versus raw data from individuals, be presented to research participants for “critical consideration,” (Thorne et al., 1997, p. 175). Once I completed a first draft of my results section I emailed copies to all participants, and also the introduction section for the sake of providing context. Unfortunately, one participant did not provide feedback. Having some understanding of her current circumstances I believe this is because of her busy schedule. Participant feedback indicated that findings reflected their experiences accurately: either to an adequate level or very well. One participant in particular felt the findings represented her perfectly, and she wished to share copies of the thesis with other survivors, as part of her advocacy efforts. A few suggestions for correction were offered and I made these minor adjustments to ensure the final product of the thesis was the best fit as possible with participant experience.

As it is not possible to eliminate personal bias, the researcher must also account for the influence of bias (Dreher, 1994, as cited in Thorne et al., 1997, p. 175). Throughout this thesis document I have made clear my history with breast cancer dragon boating in an effort to be empirically honest and transparent. My goal has been to utilize this background only as a point of connection to my study. Journaling throughout the
research process has helped me to remain self-aware and to recognize and confront assumptions.

Summary

In this chapter, I have described my approach, which combines qualitative research methods with critical health promotion. Having outlined the interpretive description design that has guided the steps of the research process, I then addressed benefits and limitations of this approach. I described both data collection and analysis strategies. Finally, I provided a discussion on standards of validity and how I incorporated these in my project. In the next chapter I introduce the participants and provide in-depth information on both group and individual characteristics.
CHAPTER 4

An Introduction to the Participants

In this chapter, I introduce the six women and their experiences of moving past cancer treatment to claiming a new life after trauma.

The first section is a review of group characteristics. The subsequent section is a brief overview of each participant’s individual process of change.

The presented narratives are based solely on interview transcripts and do not include interpretation or analytical discussion.

Ideally, this chapter will help readers to perceive the women in this study as a limited cross-section of Canadian women: distinct and diverse individuals, who share a common experience of surviving breast cancer and who are taking steps to thrive, post-trauma.

Section One: Group Description

This section provides a group description of the six participants. Each participant included in the study was referred by the team contact from each of the two breast cancer dragon boat teams. The section includes group characteristics, both similarities and differences.

The participants were six adult women, who ranged in age from early forties to early sixties. Four were married, one was widowed and one was single. Two of the women had a family history of cancer. All six participants were Caucasian and from Canadian or European ancestry.

Prior to dragon boating, four out of six participants did not have a sporting or physically active background. One participant had been very physically active throughout her life, and identified as being a long-time athlete. One other participant had been moderately active, with a keen interest in fitness.

At the time of the interviews the participants were all active members of breast cancer dragon boat teams in small communities located on Vancouver Island and the Sunshine Coast. Active participation was not restricted to paddling positions. One woman
was a tiller, and one was a drummer/paddler. Most of the women had been diagnosed with cancer within five years of the interviewing session, although one woman had had cancer fourteen years ago.

As is typical with a group of breast cancer survivors, types of treatment experienced and their duration varied with each woman. For some participants, treatment was restricted to a lumpectomy. For others it included a cluster of treatments, such as mastectomy, chemotherapy, and plastic surgery. Unprompted, a central part of the narratives shared by the women were vivid details of their cancer treatment experience and the emotional resonance of that period of their life. I noticed that the levels of emotional pain, trauma and shame that participants expressed seemed to be higher for women who had aggressive treatments and who perceived their cancer as being intrusive.

There was also variety in how well participants were socially integrated in their perspective communities. Three of the women had an entrenched history within their local community, with family and long-time friends there. In comparison, three of the women expressed having limited social supports. One woman was recently widowed and her adult children had moved away. She also reported having few friends outside of dragon boating. One woman was married but had no children and a small circle of friends. Another woman was single, with no family in the immediate area.

None of the women in this study had access to a dragon boat team in their community at the time of ending cancer treatment. Breast cancer dragon boating is a new sport and until recently was not well established outside large urban centers in British Columbia. Three women started breast cancer dragon boating with a club in a neighboring community. Five of the women interviewed were involved at some level with founding teams in their local community. One woman did not have the opportunity to join a club, despite the wish to do so, until recently moving to a community where one existed.

I was deeply moved by the candor the women showed in sharing their efforts to achieve a renewed life after cancer. A part of being a breast cancer dragon boater is openly sharing one’s experiences with others. Only one participant had never spoken publicly in great depth about her cancer experience before the research interview. The women told me they were glad to have the opportunity to help other women through our
discussion. Often the research interviews seemed to be an extension of the social advocacy that was an integral part of the women’s breast cancer dragon boating experiences.

Section Two: Summary of the Experience of each Participant

Each profile provides a brief overview of the participants and their experience while transitioning from being a breast cancer survivor to a breast cancer survivor dragon boater. All statements are based on data from interview transcripts. In each profile heading is a quote from that participant, taken from raw transcripts and to a degree summarizes the experience of that participant. Names and locations have been altered to help ensure confidentiality.

Sarah: “Now the journey is an adventure”

Sarah, at the time of the interview, was in her mid-forties, making her the youngest participant. She and her husband formed a cohesive family unit, as they had no children and few family members live in their area. She described herself as an athletic person, who had recently settled into her desired career of fitness instructor. She came from a working-class background.

Sarah was diagnosed with breast cancer five years prior to the interview. Cancer caught her by surprise. She recalled being in the best shape of her life, a fit individual who had never been to a hospital for any kind of treatment. Nor did she have a family history of cancer.

Like all the women in this study her treatment required consultation with experts outside of her community. Ultimately, she underwent a lumpectomy and required six months of chemotherapy. She also became part of an ongoing research project that allows her to receive strict monitoring for future signs of cancer. She has not suffered a recurrence at the time of this writing.

Sarah discussed how cancer was a major turning point because it exposed her to the realities of serious illness. For her cancer was very much perceived as a brush with death and this lead her to reconsider life priorities. While still in treatment at BC Cancer
Agency she began to search for meaningful ways to move on with her life as a cancer survivor. This path led her to become aware of breast cancer dragon boating.

Breast cancer dragon boating would become a key part of Sarah’s recovery. As there was no team in her local area, she joined a neighboring town’s team upon returning home from treatment. In dragon boating she found a means to realize her hope of an active life after cancer and came to enjoy a renewed sense of life. Sarah became strongly committed to her new sport and was instrumental in the formation of a team in her own community. At this time, she is involved with the development of an all-cancer team in her community.

Related to cancer treatment Sarah has issues with her right side and arm. She currently does not have problems with active lymphedema.

At the time of the interview Sarah had been a dragon boater for four years.

Callie: “Made me sit back”

Callie was in her late forties, and a trained professional who worked in criminal science. She lived with her husband and had two grown children. Her background was mainstream middle-class.

She was first diagnosed with cancer seven years prior to her interview. She had a lumpectomy, and radiation. Her treatments occurred over a ten month period. Callie suffered a mild recurrence shortly after her first sets of treatment. She approached cancer as she has dealt with everything in her life: efficiently and promptly.

Cancer was one of the few instances of significant adversity in Callie’s life. Callie described herself, as well as the members of her immediate family, as very competitive and she had always strived for and achieved increasingly larger goals.

With her cancer recovery she strove to get “that healthy feeling back” and “back to normal,” meaning her stable life. Part of this was to help start and then paddle for her town’s breast cancer dragon boat team. However, she ended up going through a time of intense reflection and learning. Cancer, then dragon boating, made her “sit back” and consider how she wanted to live the rest of her life and what really mattered.
Being in the breast cancer dragon boating team environment had led Callie to appreciate the adversity others have gone through, and she described herself as “more empathetic.” She said, “You get in their shoes and you feel different.”

Today, breast cancer dragon boating is proof for Callie; she is back to her active self. Cancer need not be a source of shame, but pride.

Callie is athletic and in good physical shape, she did not discuss any significant ongoing complications from cancer treatment.

At the time of the interview Callie had been a dragon boater for four years.

Nel: “I’m the dragon lady now”

Nel was a woman in her early fifties who had taken early retirement due to medical concerns. She lived alone, and was unmarried. She had adult children from a former marriage, yet she rarely saw them as they lived in distant communities. She was mainstream middle-class.

Nel spoke of an extensive family history of cancer. There were cancer histories on both her mother’s and father’s side of the family. Nel tested positive for more than one mutant gene related to familial breast cancer. Her brother and sister also have had breast cancer. In total, Nel had a history of ovarian, uterine and three occurrences of breast cancer.

Nel described her first occurrence of breast cancer as “uneventful.” She received no treatments other than a lumpectomy that left her with a small scar.

Her first recurrence in 2001 was far more traumatic. She was made aware that she would lose her breast and sought out means “to kind of say good bye” and had a special portrait of herself done because “I needed to capture me before.” In the end she required a mastectomy, chemotherapy and plastic surgery. The mastectomy involved removal of significant tissue leading to extensive reconstructive plastic surgery to close the wound. She also received months of preventative chemotherapy. After the surgery, “the first thing you do is look down and obviously... it’s gone.” During chemotherapy her spouse of more than a decade years ended their relationship. It was this batch of breast cancer treatments in 2001 that shattered her confidence, and made her feel as if she was “really ugly” and unfeminine.
During this period of intense loss she first reached out to survivor communities for support, a decision that would lead her to discover the new sport of breast cancer dragon boating. Inquiring about dragon boats in her community she connected with Sarah and then Nel joined the efforts to form a team for their area. Her assistance in starting a team would soon be just one of the ways she found meaning in her cancer experience through social advocacy and volunteerism.

The day before her new team was to have a public launching event for their first boat she learned she had breast cancer again. Despite being fearful, Nel made the effort to put her worries “out of mind” and still sat on the drum for the boat launch, feeling like a “stronger person” for it. With her team officially founded she began her next round of breast cancer treatments, which involved the removal of her remaining breast then complete breast reconstruction.

Her medical recovery from her last bout of breast cancer was facilitated by her new dragon boat team members and a previous team she had paddled for. Team members continue to provide key emotional support.

As a direct result to invasive surgeries to her chest, Nel has little to no feeling in parts of her left arm, and generally the arm is weak. Being left-handed this was a considerable obstacle for her in general and becoming a dragon boater. She said the arm feels somewhat better thanks to dragon boating participation.

Through dragon boating, she described herself as moving past the pain of cancer and becoming her community’s “dragon lady.”

At the time of the interview Nel had been actively involved with dragon boating for almost four years.

**Heather: “Not standing out as somebody different”**

Heather is a former long-term care worker, in her early sixties. She and her husband recently retired to the West Coast from Ontario. Heather is solidly middle-class.

Breast cancer was something part of Heather’s past, something she had dealt with “long ago.” She was diagnosed sixteen years ago and underwent radiation therapy as part of treatment. She described her experience as having been “isolating,” as the breast cancer culture now evident in mainstream Canadian society was nonexistent. Further, the
approach to treatment and care she had faced was solely within a classic medical model, with no focus on wellness or holistic treatments.

A large part of joining a breast cancer team at this stage of her life came down to finally having access to one and the chance to be part of a collective that shared the breast cancer experience. Being with other survivors gave Heather the freedom to try out new activities and engage in various outings without “standing out as somebody different, somebody who can’t do something.” She could become physically and emotionally stronger in a safe, supportive peer environment.

Heather spoke of “being in the worst shape of her life” when starting dragon boating. It was unclear how many of her current health issues were directly related to cancer or not.

When I last spoke to Heather she had decided to resign from breast cancer dragon boating. She made the decision that it no longer met her needs, and she was going to move on to a mixed dragon boat team (survivors/general paddlers & male/female paddlers).

At the time of the interview Heather had almost completed her first season of dragon boating.

**Dee: “Never give up”**

Dee was almost sixty at the interview. Both Dee and her husband are retired; they have lived in their community for a number of years. Dee is solidly middle-class.

She was diagnosed with cancer when she was 51, and it was a shock that caused her to become “extremely angry.” She had thought of herself as being in good health, and she couldn’t understand the diagnosis. Her anger built as treatments became complicated. Radiation therapy plans were disrupted as she had also been diagnosed with shingles; she had to endure a wait for treatment and then still suffered burns. Overall, radiation followed by chemotherapy consumed a year.

The anger and intense hurt she felt continued with her long after treatment, and at the time of her “five-year anniversary” she was involved in a cancer related wellness program in her community. During this time she met a woman who was trying to start a breast cancer dragon boat team in their area. She initially was reluctant to take part in
creating the team, because of a fear of drowning and never having participated in sports. However, she began to develop close friendships with her would-be teammates and wanted to be part of “the fun” they were having.

Becoming a breast cancer dragon boater for Dee was a slow process of confronting a list of fears and other emotional hurdles. To overcome a fear of drowning she made a commitment to pool training, although at first she could only get to the door of the facility, then later down the stairs. Finally she could do a lap of the pool. Being with peers helped Dee normalize her experience and to help others. Through helping a teammate her anger over having cancer finally faded.

Today Dee has been voted her team’s captain and serves as an ambassador for breast cancer dragon boating in her area.

Dee told me how to be a dragon boater she has had to work through complications with one of her arms, which has been an issue since cancer treatments. She experiences pain, it often “hurts bad” after paddling, but credits dragon boating with making it somewhat better.

At the time of the interview Dee had been involved with dragon boating for four years.

Trudy: “Do all I can”

Trudy is in her late-fifties. She is a recent widow, who is still employed. Unlike the other participants she identified with a religion; she is Roman Catholic. She has a middle-class background.

Trudy was diagnosed with cancer in 1999. She did not share details of her treatment, and generally made it clear she wanted to talk about her cancer history only in generalities. Trudy has a family history of cancer.

The last few years for Trudy had been a struggle, with a continuing arc of crises. She had coped with several family members being ill from cancer in recent years. Her own diagnosis of cancer came within one year of her husband’s passing away also from cancer. With her husband’s passing she had to make numerous adjustments to her financial and social lifestyle. At the time of our interview she was enveloped in another
personal crisis, and she often spontaneously broke out in tears. Regarding all the changes in her life she said, laughing, "God will only give you what you can handle, but enough."

Because of her family history with cancer, Trudy was committed to “do all she could” regarding her own cancer and becoming healthier, including physically stronger.

Trudy became a dragon boater somewhat accidentally, as involvement in a local wellness program for survivors led her to be part of a group of women who ended up forming the first breast cancer team in their area. Breast cancer dragon boating was an enjoyable experience for her, one with plenty of new experiences that kept her engaged. Being part of the dragon boat team also provided her essential social support for coping with all the turmoil in her life. She credited teammates with always being there for her.

Although her dealings with cancer have led her to “become braver,” in many ways she was consumed by grief. Perhaps because of the ongoing upheavals she faced, Trudy was unlike other participants because she seemed to be actively struggling with cancer-related issues at the time of our interview. Although she had engaged in some healing, she was overwhelmed by the circumstances of her life, her cancer history being just one facet.

Trudy suffers from lymphedema and when she first started dragon boating she had to wear an armband, although she “believes” her condition is “sort of a little better with paddling.” Trudy also has memory issues, which from my personal experience are common with breast cancer survivors.

At the time of the interview Trudy had been involved with dragon boating for almost five years.

Summary

In this chapter I have introduced the six women who volunteered to provide data for the study concerning their experiences with breast cancer dragon boating. In Chapter five I provide a review of the context of cancer for participants and I present the findings of this study.
CHAPTER 5
Results

In this chapter, I present an overview of the context of cancer for my participants, followed by presentation of the themes that were important in the participants’ experiences. I provide tables which illustrate each theme and its subthemes.

From the interview data seven themes emerged, each containing a number of subthemes. The themes are: moving past isolation, networks of like minded support; taking control; journey into adventure; affirmative outlook; confronting painful experience; rebuilding identity; and spiritual engagement.

Data revealed seven themes, with “moving past isolation – networks of like-minded support” and “taking control” being of most importance in terms of elaborating participant experience. All the themes were part of a much larger, dynamic picture of conscious engagement with life after trauma, often leading to psychosocial growth.

Dee said of dragon boating, “is not all about physical strength, it’s about the emotional strength too, we draw a lot on our inner selves to get out there.”

In understanding the collective meaning of the themes, each one can be likened to a dragon boat stroke. Just as each stroke is part of the larger picture of boat propulsion, each theme was part of the larger picture of psychosocial wellness for participants. The trajectory of a dragon boat is never linear, and neither was the path of cancer recovery for the women in this study. Each dragon boat stroke contributes to the whole, as did each of these themes in participant recovery from the trauma of cancer, particularly to finding meaning and psychosocial growth.

Theme and subtheme names utilize in whole or part actual participant words. There are two exceptions which instead are derived from participant experiences: the subtheme of “resisting” (listed under the theme of taking control) and the theme of “confronting painful experience.”

Quotations used to illustrate points are taken directly from transcripts.
Section One: The Context of Cancer

Because of cancer, life changed dramatically for participants. The diagnosis of cancer set in motion a series of new experiences for all the women, eventually including dragon boating. In Sarah’s words, “the whole world just turned upside down.” Nel described the morning of her mastectomy as “very surreal” because she knew after the surgeries “things were going to be different.” Within participant stories was a thread of disruption: of perceived self, of normal feelings, of the pace of change in their lives, and of routine.

Many of the women spoke of how at the time of their diagnosis they had believed themselves to be in good health. Sarah said, “I was working as a fitness instructor ... I thought I was in the best shape of my life.” Likewise with Dee: “I had just turned fifty-one. I thought ‘No, I lead a good lifestyle; I don’t drink; I don’t smoke; I like my meals but um aside from that I try to keep physically active.’ ” Cancer arrived as a surprise.

Intense feelings arose from the cancer diagnosis for all participants. Shock and disbelief were common elements in the stories of participants. Dee had always thought of cancer as a “death sentence.” About being diagnosed, she remembered,

When he says “Yes, you have breast cancer and you have these choices” ... you don’t think about the choices; all you think about is how you are going to fulfill, the best way to fulfill those days that you might have left; that was for me was the first thing I thought about.

Sarah said, “This was my attitude by the way .... I didn’t believe it for the longest time.” Many participants also faced a quick transition from diagnosis to active treatment, from the perception of healthy to ill. Nel found herself facing major surgeries only days after her diagnosis: “It was kind of like, you know, a little bit of shock.” In considering her mammogram, Sarah said, “I wasn’t going to [have the test] .... and ah ... five days later I was under the knife.”

Anger was another common emotion. “When I was diagnosed with cancer, I was extremely angry,” said Dee. Trudy’s face clenched at the memory of her diagnosis. Her first response to the news had been, “the anger just came just like that!” and she snapped her fingers for emphasis. Participants spoke of how anger often came from a sense of unfairness.
Callie found herself “consumed” by the thought of cancer: “The weird thing is, you get diagnosed and everything you see is breast cancer.” “Further, when I first got it - was like everything ‘green’ ... you know I wouldn’t ... go near certain places that ... may have toxins and ... oh I just went bizarre.”

Part of the seeming unreality of their situation was that the routine of regular life was being replaced by medical procedures. All of the women spoke of months of their life being committed to treatments and they all spoke of their efforts to regain routine after the completion of medical care. Callie said,

I got diagnosed in January of 2000 .... Great, you know; everything good is going to happen to me – anyway there you go ... So, by the time I’d gone through everything ... October came.

The process of adjustment is captured in the words of Dee:

Then, of course, you come home and you have a good cry and then you start to see the bigger picture, and well you know it might not be so bad, so-and-so maybe has done this, and then it evolves from there ....

For participants in my study, breast cancer dragon boating became a part of the “evolving” process of recovery from cancer.

Section Two: Themes

Moving past isolation – networks of like-minded support

The theme of “moving past isolation – networks of like-minded support” is similar to other themes as it demonstrates deeper personal growth over time, such as changes in feelings of control over life, and awareness of spiritual dimensions in daily life, facilitated by engagement in breast cancer dragon boating.

Although participants were not asked about social support, it became clear that forming enduring social connections with fellow survivors and community allies was a critical aspect of personal growth and healing for all of them. While sharing their experiences, participants reflected on feelings of “isolation” upon completing cancer treatment and the often challenging process of seeking support and building new connections in their local communities. They also discussed how their support needs shifted as they progressed in their cancer recovery, from establishing connection with
other survivors to finding survivors actively pursuing wellness. They spoke of becoming conscious of their complex social support needs and the personal importance of obtaining them.

A key part of dragon boat was new social connections. About dragon boating, Callie said,

You get thrown into this circle with people that you don’t know … and - and there are some people that you don’t get along with … in - in that same circle but … they are people that … you’ve come to know because of this disease.

Sub-themes include: contained support system; understanding; team: the whole is greater than parts; and support from the public. See Table One.

**Contained support system.** From the time of leaving active medical treatment, participants became aware that they needed to expand their emotional support networks. For all of them the means to obtain this was not readily apparent. Participants discussed how, in their small communities, there were few options, and for many of the women breast cancer dragon boating societies had not yet been formed. A first step was often to join the local Canadian Cancer Society support group; however the women who did this emphasized that the support group was limited as it dealt more with the immediate trauma of treatment and not with the needs of women who had moved past this.

Breast cancer dragon boating consists of a uniquely tight group as it combines a team oriented sports environment with a shared disease experience. An emotional disease experience was mixed with a goal driven sport. Callie, a long time athlete and team player, said “the difference with the dragon boat is everyone has had to overcome the same obstacle so that it’s an immediate bond when you get on that boat.” Heather told me that dragon boating is different from other groups because it is the “kind of group where everyone is very much in sync, you know, so you become very close to those people.” Within that closeness there was “a safe space” to express feelings and concerns. Callie described how if someone has a bad day they can bring that to the team and work it out. She said, “We paddle along and it’s good; a lot of ideas get sorted out there in that boat.”
<table>
<thead>
<tr>
<th>SUBTHEME: Contained Support System</th>
<th>H: “kind of group where everyone’s very much in sync.”</th>
<th>N: “you’ve got this mini support system.”</th>
<th>D: “If I run into problems … I’ve got ladies there that I can call.”</th>
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<tr>
<td>SUBTHEME: Understanding</td>
<td>D: “I’m accepted as I am, for who I am.”</td>
<td>C: “I was looking for people [text removed] who had been through it, and I found them.” “These women, they know what it is like.”</td>
<td>H: “an unwritten code, that you understand”</td>
</tr>
<tr>
<td>SUBTHEME: Team – the whole is greater than the parts</td>
<td>D: “We make one another stronger.”</td>
<td>S: “There’s magic there … we all get together and something silly happens.”</td>
<td>D: “[we are] from twenty-two different walks of life, and yet we all share.”</td>
</tr>
<tr>
<td>SUBTHEME: Support from the public</td>
<td>D: “People you don’t know are there, supporting you [at festivals].”</td>
<td>C: “It’s amazing, the support; you almost feel cheeky after awhile.”</td>
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Dragon boating was appealing to participants because, as Nel said, “the dragon boat couldn’t be any more positive … you’ve got this mini support system.” Likewise, Heather said, “I have found a great support system; maybe that is the best way to say it, a really great support system.” Participants expressed numerous supportive elements in being a dragon boater, including: “encouragement,” “patience,” “fun,” and “positive outlook.” Dee felt her team offered unconditional support. She said, “They are willing to listen,” and “they definitely want to hear if you are having a problem, how they can help you.”

Support from team members was not restricted to team related activities. Dee said, “Even outside of paddling, we are there for one another.” She elaborated,

Our lives don’t revolve around one another except when we are paddling … but I know that if I run into problems tomorrow that I’ve got ladies there that I can call … and [they] will be there to support me.

Nel talked about how when she suffered a recurrence requiring extensive surgeries team members did everything from “bring me dinner” to “walk my dog.” Similarly Sarah described how she was supported through a personal tragedy:

“When my brother’s plane went in and everybody died off on [name of place] … both teams were here … [her team’s parent team] was here … first night … all the way from [neighbouring community]. … And I had two dragon boat teams at my house …. For weeks helping out, making sure I was okay … so … that’s the kind of thing that happens too…. it’s not just boating.”

Many women found the support system of the team acted as a buffer against the fear of cancer recurrence. Sarah said a recurrence would require her “to dig deep,” but she’d be able to because, “you have all these people that are dragon boaters … aren’t going to let you do it any other way [dig deep].” Dee said, “I think if I had a re-diagnosis today I would handle it … because I know sort of what to expect and I also have the team behind me.” Unlike her first cancer experience, Sarah was confident that if she had to “I won’t do it alone again … all of it.”

For some of the participants the circle of support offered by dragon boating was perceived as a family system. These participants had few family members in their community and found close ties they needed. Dee referred to her teammates as “sisters” She said, “we’re like sisters, we are like extended family,” and “I have family that don’t
know me that well.” Callie talked about an East Indian team member who had been shunned by her family after her cancer experience: “we became her family,” and that the entire team rallied around her until her death. With Nel, dragon boating has become such an important resource that she stayed in her community to be part of that: “it’s what kept me in town too, you know – I don’t have family here or anything.” In dragon boating Trudy had found an “emotional anchor;” she valued the friendships on the team above all and relied on them in crisis, “especially with me living alone.”

Understanding. Throughout interviews women spoke of the sense of “understanding” they had from being a dragon boater. A significant part of the appeal of the breast cancer dragon boating team was immersion in a network of people who understood the breast cancer experience from a first-hand perspective, and were also committed to enhancing wellness. All of the participants spoke about efforts to find women who had shared experience, which was a challenge in their small communities. Before engaging in dragon boating, the women recalled having feelings of isolation and being compelled to seek like-minded women who had survived breast cancer.

When asked about the meaning of breast cancer dragon boating many women spoke of the new meaningful social connections they gained through becoming a dragon boater. Callie said she valued, “the friendships that you made that you wouldn’t have made [otherwise],” Further, “if I didn’t have breast cancer I wouldn’t have it’s really sad when you think of it but I probably wouldn’t have been in the same circle as them.” Sarah said, “It’s magic ... I mean I met the greatest people ... I meet the most amazing people.” Nel said a big part of the meaning of the boat was, “I never would have had that [friendships] without the boat.” Dee said,

I think if I hadn’t had cancer I probably wouldn’t known these people yet I would have missed out on a lot; I feel I would have missed out on something really special by not knowing them because they are great ladies.

In reflecting on how she felt just before becoming a dragon boater, Sarah spoke of becoming frustrated by the transition back into her local community following treatment in Victoria and a growing sense of isolation, “you do feel like you’re all by yourself at times when you go through everything.” The support group she found in her community
was a step forward but she said "I thought I was all by myself ... until I found dragon boating." The intensity of the team experience and community activities led her to firmly believe, "You're never alone once you're a dragon boater."

All of the women spoke of how friends and family, unlike dragon boating peers, could not relate to their experience. Callie said when she finished treatment the support from her family gradually stopped, the attitude being:

We'll get on with life the way it used to be ... although for them it goes back to the way it used to be – for you it doesn't – it does but not entirely .... because you never get over the fact that you have had this.

Dee understood the lack of empathy often showed to women with breast cancer, "I would never have understood, being a spectator on the shore ten years ago."

Many of the women had initially found understanding within their local support group, but had since outgrown it for a number of reasons. Callie said of the support group that it was a like an "AA meeting" where people kept reliving their cancer and "it's a good thing when you first get breast cancer ... because you go there and you see that people that have survived it ... but after a while." Callie said she felt guilty when the support group no longer met her needs, but the facilitator helped her realize, "if you don't come back to the meeting, she's done her job; you don't need that ... blanket of security anymore ... you need to get out on the water and - and give'er." Nel said the difference between the groups for her was, "the physical aspect [of cancer] is not really talked about much on the boat ... it's more the emotional, how empowered we feel." Women on the team did not base discussion on breast cancer issues but instead built friendships based on an implicit understanding of shared history.

Callie said regarding the boat, "I was looking for people who were like me ... who had been through it and ... I found them ... all of them." She went on to add, "Someone else can sympathize with you but they just don't know it the same," and "these women they know what it is like." Related, Heather spoke of how, because of the shared experience of team members, there was "an unwritten code that you understand." Heather added, "plus mentally being in a boat with all of the other people who have had the same thing, so you can all relate to one another, on one level or another, and, ah ... I don't know I just feel really comfortable there."
Participants revealed that being on the dragon boat team meant not only that there was a shared cancer history, but there was acceptance of the lasting impact of the disease. Part of why Heather felt comfortable on the team was because: “You’re not standing out as somebody different, you know; as somebody who can’t do something.” Further, “if you have a bad day ... take your paddle in and relax ... you know, you deal with whatever comes along.” Trudy liked the fact that cancer was “no big deal” and, “we can joke about things that we went through.”

Dee’s feeling of acceptance from her team was a new and liberating experience. She spoke of how for her entire life she felt like an “outsider” and now “I am accepted as I am, for who I am.”

**Team: The whole is greater than parts.** The women spoke of how individual interactions with team members equaled a collective process that was both meaningful and dynamic. Heather said,

> It is not only a group, but I mean you could go to a group, a gardening club, but then you can go home and do your own garden; but this is the kind of group where you all have got to be very much in tune with one another.

The chemistry among teammates was valued by all the women in the study. Dee spoke of “her love of” her teammates, and Heather struggled to articulate her relationship with her teammates, “I enjoy the other paddlers, but it is more than that.” While Sarah spoke of the “magic” that happened when her team was together. Callie spoke of how, “I loved that fact that you’re all in synch because you’ve all had this disease.” The terms “camaraderie” and “common bond” were used frequently by the women to describe why dragon boating was meaningful to them.

The rapport between teammates helped participants to move past team infighting, what Dee called, “our battles.” Even though there might be conflict among team members, Sarah discussed how “there is magic there ... we all get together and something silly happens.” Sarah also said teammates were able to put the team first, “everybody may be bitching but if somebody’s in trouble they’d all be together on it.”

Interview data revealed that the ability of the women to function as a team despite difference, also applied to the fact that the paddlers were often of different social
backgrounds from each other. Dee talked about how, “we have 22 people on the boat at any given night, we have 22 different personalities, 22 different walks of life, and yet we all share.” It was typical on both teams in my study that women varied widely in terms of age, education, and social status. Breast cancer and interest in dragon boating were the common factors. Overall, “together we make it work,” Dee said.

Throughout interviews participants spoke of how, in Dee’s words, “we make one another stronger … I had my story, other ladies have their stories.” Participants discussed how being among teammates was “inspiring.” The following quotation from Trudy is a good example:

There are a couple ladies in our boat that are terrified of the water and they are like in our boat (?) … They took lessons and stuff … to get more confidence; that was neat. They sort of inspired me, like no big deal [that] you can only a swim a bit.

Callie spoke of being inspired by older paddlers. She said, “The ones I had the most admiration for are our older women that are in their seventies … and they are just givin’ ’er, out there.” Part of her admiration was that she perceived these women to have faced great adversity:

the way the treatment is now I mean it’s - it’s like day and night – twenty years ago [if] they had a - a tumor – your breast was off – there was no questions asked – now they’ve got so many things out there that you can do.

**Support from the public.** The participants not only found support within their individual teams, but described how by being a breast cancer dragon boater they found themselves in a position to receive support from their local community and groups associated with breast cancer dragon boat racing.

The women spoke of how breast cancer was a disease and social cause that people were open to embrace, and as dragon boaters they benefited from this. Dee said, “there is not the support for other types of cancer that there is for breast cancer.” Nel recognized that in her community “we’ve got a good affiliation of breast cancer supporters.” Regarding that same community Callie said, “It’s amazing the support; you almost feel cheeky after awhile.”

The public support for breast cancer extended to efforts by Callie, Sarah, and Nel to start a dragon boat team in their community. Callie said, “We brought the idea up here
and it just took off and within 3 months we had a boat ... our community is amazing when it comes to that.” When the team boat was commissioned, the mammogram technician from the hospital dotted the eyes, as Nel said, “She’s now like our mascot ... she has been such a wonderful support.”

As breast cancer dragon boaters the women were inundated with encouragement at festivals, and other public events. Callie said, “You feel this connection that people are there for you.” Feeling somewhat overwhelmed, Dee described how “people you don’t know are there supporting you, people you may never see again” and this included other paddlers, “all those team members you have respect from, isn’t that awesome?” Both Dee and Callie also enjoyed a sense of “acknowledgment” for what they had been through with cancer.

Taking control

In the following section, data is presented that supports the theme of “taking control.” Efforts to gain a level of control over their lives, real or perceived, were discussed by all participants. Participants described efforts to regain a sense of control throughout their cancer trajectory, beginning with diagnosis and continuing to the present time, even in cases where it had been several years since treatment.

Part of the process of establishing control, was finding new “power” and “strength” in contrast to the vulnerabilities associated with cancer. “Being a breast cancer paddler,” for Dee, “means that I can get out there and bomb the torpedoes and just go straight ahead (clapping noise, from hitting her palm with her fist), that I am able to.” Nel said of cancer recovery that “what I kept coming back to was the boat and how strong it made me feel,” and “I just feel so much power.” Sarah said the meaning of the boat to her was, “I ain’t taking this [cancer] lying down and that [boating] is all you have to do.” Further, “strength and power that’s what it means.” The sub-themes of reaching out; putting herself first; and resisting illustrate the typical ways participants established degrees of control. See Table Two.
<table>
<thead>
<tr>
<th>THEME: TAKING CONTROL</th>
<th>Some examples from subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SUBTHEME</strong></td>
<td><strong>N:</strong> “To take control of my life again, whereas I was feeling that I’d lost control of it.” “I just feel so much power.”</td>
</tr>
<tr>
<td>Reaching out</td>
<td><strong>S:</strong></td>
</tr>
<tr>
<td><strong>SUBTHEME</strong></td>
<td><strong>N:</strong> “That’s how the boat is; it’s on my terms.”</td>
</tr>
<tr>
<td>Putting herself first</td>
<td><strong>S:</strong> “I do it [dragon boating] for me … the health aspects.”</td>
</tr>
<tr>
<td><strong>SUBTHEME</strong></td>
<td><strong>D:</strong> “I don’t have to baby myself and say, ‘Oh, I can no longer do such and such because I have breast cancer.’”</td>
</tr>
<tr>
<td>Resisting</td>
<td><strong>S:</strong> “The bottom line was ‘You’re not supposed to do anything after breast cancer’. …” (Nevertheless, she did dragon boating).</td>
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</tbody>
</table>
Reaching out. A command often heard on the boat is, “reach,” meaning for the paddler to extend their paddling reach far forward to gain a deeper stroke in order to increase boat speed. Women in my study also “reached” in all aspects of their life to gain a sense of control.

On the way to becoming a dragon boater and acting in that function, the women sought and also created a number of opportunities that helped them to move past the cancer experience. With cancer, Dee said, “so much is taken out of your control, the only control you have is to get on with it.” Important to all participants was to “do something,” or to be actively engaged in their recovery process.

Efforts to take control were often small, non-dramatic and built on one another. For example, when Nel discovered breast cancer dragon boating at a festival in Victoria she “brought a book back [home]” to learn more. Then at her local support group she asked women, “if anybody had ever heard about dragon boats and was anybody interested in dragon boats?” From there she found a contact, “I met S. I’m you know bald and she looks at me and I’m going I hear you know about dragon boats.” Small active steps eventually lead Nel to significant changes.

In contrast to the cancer experience, being a dragon boater was an active role the women equaled with “power” and “strength.” In seeking out dragon boating Nel wanted, “to take control of my life again … whereas I was feeling that I’d lost control of it.” “It’s [dragon boating] a good way to get the horrible disease and just say you know I’ve had enough of you,” emphasized Callie. Sarah said, “every time we strike those paddles in the water … we’re beating cancer.” Dee spoke of how, “I have control over myself in the boat; no one else has control of me in that boat except myself.”

While staying at a cancer lodge Sarah recalled feeling compelled by a need to take an active role, to no longer be a patient: “I said well what are we going to do when this is over, she [roommate] says well I heard about dragon boating, okay we could do that.” There was no team in Sarah’s community, but she managed to find one within a reasonable driving distance. She went on to co-create a team in her community.

After addressing a number of issues through a support group, Callie had felt, “it’s not what I need anymore.” Acting on that, “I’d never even heard of dragon boating but I wanted to do something.” Boating appealed because, “the dragon boating people are
more aggressive; they take life more by the shoulders and give it a good shake ... the support [group] people are gentler.” Driving Callie was a need to not discuss issues any longer, but to take action.

With cancer Nel said, “I felt what I needed to do was to somehow turn this situation that was kind of a negative situation ... somehow I needed to make it positive.” When she heard about dragon boating, “I thought well maybe that is the only thing available.” In conversation Nel framed dragon boating as an opportunity to turn her life around.

Putting herself first. Interviews revealed that life after cancer meant a greater emphasis on self for participants, of which breast cancer dragon boating was “an extension.” Most participants worked on engaging life on their own terms. Personal boundaries were often newly important, a means to preserve new priorities. For Callie, Nel, Sarah and Heather prioritizing self was a significant part of their efforts to establish a sense of control.

Callie remembered feeling uncomfortable with her old support group, “I just couldn’t handle discussing it, rehashing it over and over so I quit.” Her decision put her in a position to find a better fit for her emotional needs.

Callie had made a series of decisions that ensured that she had the best outcomes possible regarding her cancer, “I was in really good health when I first started [dragon boating] because I made sure I was in good health before I had my surgery.”

Having struggled over an extensive period of time with cancer related complications, the boat had special significance to Nel. She said, “That’s how the boat is, it’s like on my terms.” Being a paddler allowed her to do things her way, take a non-passive position and fulfill her goals.

Although dragon boating had initially helped Sarah to find “strength” after cancer, her commitment to staying a team member was soon tested by interpersonal conflict. Her choice was to establish strong personal boundaries as a team member, because she did not want to quit the team. She had new resolve, “I do it for me ... that’s how I look at it now, is ... not going to let one or two people take away what I love.” She added, “I do it for me ... the health aspects.”
Heather had joined breast cancer dragon boating to meet wellness goals. For instance, regarding the risk of recurrence, “I wanna be fit, ‘cause I want to have the strength to combat it [cancer].” When breast cancer dragon boating began to negatively impact her health, she chose to quit the team. She wrote me to say that, “I do not think an all women’s team is for me; it has made me anxious about going to practice, and that is really not the point of taking care of oneself.” Despite enjoying the sport, she chose to put her health needs first.

**Resisting.** The data revealed a number of acts of resistance, as participants adjusted to life with cancer. Wade (1997) postulates than whenever individuals are oppressed they will find a way to resist their treatment, whether in the form of thought or action. Participants described numerous ways that felt they were treated unfairly and the ways they responded to such treatment. Notably, for Sarah, Callie and Dee dragon boating was a purposeful way to resist medical and social opinion about how a survivor of breast cancer was to act.

Sarah remembered how in the recent past, breast cancer was never openly discussed, “nobody talked about it.” She knew very little about breast cancer at the time she was diagnosed with the condition. When she completed surgery she was given instructions on recovery. She was told not to “lift your arm up this high” and advised to “wear a glove on your right hand,” to help prevent lymphedema.

For Sarah, dragon boating was “the best thing that came out,” because it opened up many possibilities. She talked about how her Mother had spent years in bed with rheumatoid arthritis under advice of doctors. Sarah remembered after completing her cancer treatments, “The bottom line was you’re not supposed to do anything after breast cancer” and “you wouldn’t be able to do all sorts of different things.” Sarah physically shuddered at the thought of a limited lifestyle, “that’s all I want to be doing is nothing.” Sarah felt “lucky” to have dragon boating as she had first thought that having cancer she might have a fate similar to her Mother’s.

Sarah’s sentiments were similar to that of Dee. Dee talked about social perceptions of her friends about cancer, saying “you say ‘well yes, I’ve had breast cancer’
and they immediately zero in on your breasts, like somehow you are going to look
different on the outside.” Dee said,

    Being a breast cancer paddler for me means that even though I had breast cancer
I’m able to go out there, and I’m able to do that, I’m able to be physically active
...... that’s what it means ... [S: Am I hearing like a statement ...]
Yes you are. (silence).

Dee added, “I don’t have to sit at home and hide away. I don’t have to baby myself and
say oh I can no longer do such and such because I had breast cancer.”

Callie also struggled with social expectations of her after she completed breast
cancer treatment. “You get this stigma when you have breast cancer ... people kind of
look at you sideways or they put you on a pedestal.” Callie argued surviving breast
cancer was no better or worse than surviving any other condition, “I don’t like to see it be
sectioned off like that, that we’re something marvelous because we’ve come through it,
right?” Regarding preferential treatment she said, “I didn’t feel I needed the recognition
or deserved the recognition that people were giving me – it was like well wait a minute
it’s still me,” and “this is what I’ve had and it’s over with.” She remembered how friends
would say things like, “oh my god I can’t believe what you’ve been through.” Being a
dragon boater was positive for Callie as it gave her a chance to be the athletic person she
had been before cancer and to “prove it.”

**Journey into adventure**

The theme, “journey into adventure” arose from participants’ descriptions of how
dragon boating was part of engaging a purposeful life as a cancer survivor. The women
often expressed a distinct sense of purpose and that life was embedded with renewed
meaning, both of which called for finding ways to live life to the fullest. Sub-themes for
this theme are: quest; renewed life; love of paddling; and social advocacy – giving back.
See Table Three.
<table>
<thead>
<tr>
<th>SUBTHEME:</th>
<th>N:</th>
<th>D:</th>
<th>C:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quest</td>
<td>“I went on this quest to find it [femininity] again”</td>
<td>“[To] become stronger within myself, emotionally stronger”</td>
<td>“[Dragon boating] is a very healthy way to get through breast cancer.”</td>
</tr>
<tr>
<td>Renewed Life</td>
<td>“[Dragon boating] has brought some life back to my life” “I’ve got spirit.”</td>
<td>“It’s like a new life; you’ve survived breast cancer”</td>
<td>“…. So now the journey has turned into adventure.”</td>
</tr>
<tr>
<td>Love of paddling</td>
<td>“I’m doing what I love to do [when paddling].” “I feel so much ‘wow!’ when I’m in the boat.”</td>
<td>“It [dragon boating] all comes from your heart.”</td>
<td>“I love it” “It’s just a good feeling [text removed], love of the water.”</td>
</tr>
<tr>
<td>Social Advocacy – Giving Back</td>
<td>“It’s how you can help other people, how you can get them on board.”</td>
<td>“…. just to help others really, and to have fun while doing it.”</td>
<td>“I want to help people. I’m trying to give back because who am I? I want to bring a smile back to people’s faces.”</td>
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</table>
**Quest.** Interviews with my participants revealed that dragon boating was often an integral part of a lengthy and purposeful search to fulfill a sense of loss after cancer.

Following her cancer experience, Sarah set goals to go beyond the restoration of her well-being, to some kind of personal betterment. With joining a dragon boat team Sarah said “the idea is to just get back to the way you once were ... even better and stronger.” Her philosophy was: “So you made it ... oh my God, you’re not going to stop now; are you crazy?” The dragon for Sarah was symbolic of her goals, “what does the dragon represent? Power, strength and magic ... and that’s what we want.” Sarah was able to move past cancer, “beating cancer” with every paddling stroke.

Callie had similar needs to Sarah. Callie wanted to get “back to normal” after cancer. Considering the possibility of dragon boating, Callie foresaw a dynamic experience that combined her love of sports with connecting with other survivors. By dragon boating:

I expected to get back that healthy feeling I’d had before ... I .... got sick because there was a period of time when you get sick that you feel really unhealthy ... because you you’ve had a disease right ... so I think I felt that I was going to be healthy again.

She said the dragon boat is “a very healthy way to get through your breast cancer.”

Both Heather and Callie expressed a need to find women who shared the common experience of breast cancer. Heather said, “It really was sort of finding a group I had something in common with; when I was in Ontario I was always part of the breast cancer society.” About the transition from her breast cancer support group into dragon boating, Callie said, “I was looking for people who were like me, who had been through it ... and I found them.”

Entering dragon boating Dee hoped to “become stronger within myself and I don’t mean physically stronger but emotionally stronger.” She went on to describe in detail how in the five years since her cancer diagnosis she had experienced turbulent emotions and had been quite agitated by a number of chronic symptoms. She said “I didn’t go in [to boating] with expectations,” but ultimately even to paddle meant “hoping that I could overcome my fear of water, to be in the boat.” Her initial wellness goals soon expanded to challenging a phobia.
Cancer had been an extremely disrupting experience for Nel, with multiple and aggressive surgeries. For Nel a devastating loss was her sense of womanhood, in part because of her mastectomy, “you feel mutilated … you feel that this feminine thing is gone … I went on this quest to - to find it again.” Breast cancer dragon boating was one of several experiences she tried, including “belly dancing”. She ultimately chose the boat because of “how empowered” she felt. Further, “the boat is all about choosing to find your life again.”

For Trudy dragon boating was a response to all she’d been though with her own cancer and that of loved ones, “cancer is so much through my family; so determined to you know fight this; do what I can do and all I can do (laughing). I knew a part of that had to be more healthier.”

For Heather and Dee dragon boating was in some ways a quest unto itself. Heather said, “It was something I wanted to do for a long time but I had never really been in a community that it was really close.” Moving to a new community she joined a team immediately. Despite her fear of water, Dee liked the paddlers on the team she helped fundraise for and she saw “the fun” they had. Dee recalled thinking, “I want to be a part of that.”

Renewed life. With dragon boating, the women spoke of embracing life, more than a simple return to life. Both psychosocial and physical wellness elements of life were enhanced. Following cancer treatment, life was no longer taken for granted and dragon boating was an engaging extension of this that made participants feel as if they were living life to the fullest.

Nel said with dragon boating, “it has brought some life back to my life.” Nel had thought cancer was a negative experience, and it was through dragon boating she found positives like “lifelong friends,” and new strength. She said, “it’s the dragon boat for me … it gave me back my life.” Further, “I’ve got spirit.”

For Sarah breast cancer dragon boating embodied new life after cancer. Sarah described being faced with potentially limiting circumstances: medical instructions restricting physical activity and general uneasiness about what the fallout of cancer could be. Since becoming a paddler, “now the journey has turned into adventure … so that’s
what dragon boating is – it’s my adventure.” Further, “let the adventure begin … jumping into a dragon boat really shocks.” Her new philosophy was, “what’s the adventure today … because it’s not life – it’s an adventure now … not a journey already did that.” The Victoria Dragon Boat festival was a symbol for Sarah of this new life:

The Victoria Dragon Boat Festival means so much to me because on August 15th of 2002 I was standing on stage getting a silver medal for [team name] … and the year before that, I had just finished radiation.

She also credited dragon boating for greatly advanced her professional goal of becoming a personal trainer. She said, “It really got me to do what I want to do in life.” She was not only alive after cancer, emotionally as well as physically, but more alive than before the disease and dragon boating. She said a meaningful life was “probably lost before hand anyway,” and now “life was better than before.”

Since dragon boating Sarah felt she had “HEALTH” aspects restored or created new in her life. Sarah explained that this acronym loosely equaled: “happiness;” “excitement/energy;” “adventure;” “love & laughter;” “tears” [of joy or hard work or shared emotion]; and “hope.” Watching other breast cancer dragon boaters, she said “wow, look at all that life – isn’t that cool,” and “you see a whole new life … because we all know where we have been.”

Trudy told me the story of how she helped name her team, which roughly equaled reaching for life, and how it related to her own experience. She described the process by which she and her teammates decided they wanted a name that captured their shared purpose, “it was sort of like what we felt we were doing, almost like a new life, you survived breast cancer right.” She looked forward to being on her new team, “it was sort of like an adventure because you know we were the first one in [our community].” Being a dragon boater Trudy reflected how her life has been “improved,” in large part to being physically active again.

Being a dragon boater to Callie meant that she had come back to her life after cancer. She said,

it was proof to me that that my life was back to normal because I was doing things that I had done before … so I had this little hiccup [cancer] … and then now because I was dragon boating I had to be well … you know because I was doing things that I did before [active living].
In her efforts be healthy again, “I think the dragon boating really helped that … get you feeling like you’re just normal again.” A part of this was that she credited the dragon boat for helping her have a new attitude towards her breast cancer: “I talk about it, I read about it but I’m not consumed with it anymore.”

Callie, Sarah and Trudy spoke of dragon boating as public proof of wellbeing after cancer. Structured breast-cancer activities like dragon boating, as well as breast cancer society events, were considered by Sarah means “to prove a point” that there is meaningful life after cancer. Callie said dragon boating was a way for her and other survivors to, “show the rest of the world and themselves that they are just like you, they may have been sick, but by god they’re going to kick your butt on the water.” Trudy talked about the public nature of dragon boating, and how dragon boating meant, “to show myself and others there is active life after breast cancer.” Dragon boating was a way to turn her personal commitment to “do what I can do and all I can do” against cancer into a public statement.

**Love of paddling.** All participants discussed a love of paddling and other elements of breast cancer dragon boating. With her voice full of emotion, Dee told me,

> I was bitten big time (laughing). I *love* paddling, I truly do, even in adverse conditions when it is in pouring rain and because of the radiation my lungs are so bad almost every year I end up with pneumonia and if it rains and I get cold and wet but *it doesn’t matter*, I’m doing what I love to do.

Dee also had to negotiate her fear of drowning, “once I got into the *boat* I *loved* the paddling end of it, I did not like um, the water when the water was slopping over you.” She said, “I feel so much *wow*, I *really* feel alive when I am in that boat.”

In the middle of listing ways breast cancer dragon boating improved her daily life, Trudy stopped suddenly, and after a pause said, “And I *enjoy* it.”

Callie compared breast cancer dragon boating to other sports in which she had participated:

> I … have taken to and I - I love it same as I like kayaking … and sailing and - and … you know bike riding or anything like that …. But the difference with the dragon boat is that they’re all like me; you know, they’re all exactly like me.
Callie was at a loss for words about what it felt like to participate in dragon boating, she said, “it was just … I don’t know,” then “it’s just it’s a good feeling – I mean it’s … you know what it’s like right?” She went on to say,

I don't know if it’s the love of the water … or … the fact that you all have a common bond … or you’re trying to prove something … I think it’s those three things.

In speaking about everything she does as a dragon boater, Sarah said, “it all comes from your heart.” Describing her role on the boat she said, “I love tilling… yeah I really do – it’s fun.” Her attraction to dragon boating included the “excitement/energy” aspects.

First reading of dragon boating in a book, Nel thought, “It seemed pretty cool.” Nel revealed how “I was never athletic… if you had said to me years ago you know you’re going to be on a dragon boat … you know competing you know … like forget it.” Now a seasoned drummer and paddler, Nel says,

It’s [breast cancer dragon boating] what’s kept me in town too, you know, like I - I don’t have family here or anything like that but I mean the whole thought of leaving … my dragon boat is (laughing) is forget it.

Further, she adds, “you cannot have a down day when - when you’re on a dragon boat.”

With breast cancer dragon boating, Heather found both a distraction and a way to play:

I think it is the nature of who you’ve become after you’ve had an episode with cancer … you want to have fun too, I like [that] there is a lot of singing that goes on, and the tapping of the paddles on the boat, and forgetting in that moment what is going on with you.

Social advocacy – giving back. For five of the participants, the renewed sense of purpose they felt was strongly connected with a need to “give back” by assisting other survivors of cancer, which the breast cancer dragon boating role satisfied. Sarah said dragon boating is “about bring a life back” to other survivors. Callie asserted, “It’s how you can help other people, how you can get them on board, how you can get them to the same place you are right now”

From discussion with participants it became clear how breast cancer dragon boating was part of a network of breast cancer support in the small communities the
women came from, and participants noted numerous opportunities to volunteer. As a
dragon boater Nel volunteered at the local hospital to visit women when they have had
mastectomies. Part of her function was “to let them know where they can get help and
support.” As part of their team’s fundraising mandate Dee, Heather, and Trudy had
structured volunteer functions in their small community, such as a role in community
festivals. Dee said, “we sort of feel we are giving back a little bit too.”

Heather spoke at length about the connection between advocacy and breast cancer
dragon boating:

When I grew up, when my grandmother died of cancer we couldn’t even say that
she died of cancer, you know, because it was a terrible word then; you don’t want
that, um, but, just to help others really, and have fun while doing it I think that is
what dragon boating is all about. It’s just like accepting that you’ve had this
disease or that somebody might be going through it right now.

Sarah used her breast cancer dragon boating role to create numerous ways for her
to “give back.” Through her public profile as a paddler she was able to share her personal
story of cancer, “every year it’s something that somebody asks me to write about.” She
often agreed to participate in research studies, like mine, because, “an awful lot of people
that already suffered … that I have outlived so they deserve to know that.” Likewise,
when I asked her if she would like to review the findings from the study she said, “I’m
always interested in anything for the cause.” Regarding volunteerism, she said, “I’m an
ambassador for the BC Cancer Foundation up here in the North.” Further, “for the last
five years I do all the warm ups” prior to the breast cancer races at major festivals.
Throughout the interview Sarah brought up key points that were part of her previous
advocacy efforts, and she was very emotionally engaged as she communicated her points.

A driving factor in Sarah’s involvement with dragon boating was, “I want to help
people … I’m trying to give back ‘cause who am I?” When she started paddling there
was no team in her area and she set out to change that, “if C. [neighbouring community]
has one, we have one because traveling back and forth was too hard and people couldn’t
do it,” especially women still undergoing treatment and those who were parents with
young children. In addition, about the pre-race warms ups she did for her team and
others, she did it “because I want to bring a smile back to people’s faces.”
Speaking about volunteerism and dragon boating, Nel said, "This is my purpose." After repeated bouts with cancer, Nel spoke of how "I finally did get angry at God ...and I said all right, you know, like why me?" She said, "I do believe I was answered ... so that I could help other women ... um so now I ... co-facilitate support groups and - and or do the hospital visitation." With dragon boating she has been able to fully satisfy this calling, "I’m busier now than when I was working (laughing) ... sometimes I think oh my (laughing) goodness." Nel said,

I’m right out there in the public now and I’m quite an advocate for ... breast cancer ... you know for ... um women to ... learn how to do ... proper self exams and ... to rally for a cure and all of that ...I don’t ever want anyone to forget ... that is on that dragon boat team ... why we are there.

For both Nel and Dee a goal was to spread the word of how beneficial they found dragon boating. Nel said “I wish I could convince everybody who goes through breast cancer to get on a dragon boat.” Dee told me she had no time to volunteer outside of dragon boating as the boat kept her so busy, and yet she was available as part of her role to talk with other survivors. She said,

I would hope ... [text removed] that I can put that into words and feelings if another lady comes along and is thinking about joining our boat, I hope that I can express to her the joy and the enjoyment that I get and I sincerely hope she would get.

Sarah, Callie and Nel all were among the founders of their dragon boat team and all were part of new efforts to extend the benefits of breast cancer dragon boating to other cancer survivors. All three were part of an effort to create an all-cancer team in their area. Nel said, “why just breast cancer?” then: “I mean cancer’s cancer it can be a struggle no mater where you get it.” Likewise, Sarah said that with cancer: “there is no difference – cancer is cancer ... it’ll attack anything and it’s not prejudiced.” Sarah’s new goal was to “let everybody try it [dragon boating].”

The reciprocal nature of supporting others is demonstrated in Dee’s story. Dee struggled with anger in the years after her cancer treatment. One of the ways dragon boat involvement helped her resolve this anger was assisting a co-paddler, “I supported her and in supporting her it helped me to get over some of my anger, and frustration.”
Affirmative outlook

In the following section the theme of “affirmative outlook” is presented. Interview data revealed that through coping with turbulent change participants had developed new outlooks on life, outlooks which were assertive and benefited the new wellness goals participants had. Being part of the breast cancer dragon boating environment refined and solidified these outlooks. For instance, Dee credited eight years of survival from cancer and her subsequent experiences for the fact, “I just have a whole different outlook on life.” When Callie considered the benefits of breast cancer dragon boating she said, “I just think it’s a really, really healthy outlook,” and a means for women to improve wellness.

Sub-themes are: letting go; never giving up; try anything; and hopeful reframing. See Table Four.

Letting go. Most of the women spoke of having developed new priorities and with them a willingness to let go of matters they now deemed trivial. The outlook of letting go was of particular importance in a team environment, where interpersonal issues existed. Letting go was often a substantial challenge, but when met allowed participants a greater peace of mind.

Dee mentioned the new peace in her life through “letting go” and it is something she has “adapted … to lots of stuff now.” She said,

With the cancer and joining the dragon boat, the two together, cancer has taught me that you live for today and don’t sweat tomorrow because tomorrow takes care of itself and going into the dragon boat I guess is a reaffirmation of that.

Since becoming a paddler she has learned to let go when something doesn’t go right. In the past, “I really gnawed over it and fretted on it,” even the “simplest little thing.” She doesn’t “brood” as much. She says that now she tells herself, “it is out of your control; just let it go; tomorrow’s another day … and it took a lot for me to find that in myself, an awful lot.” She talked about now accepting trivial things like waiting for a busy traffic light, “there was a time I would get impatient but I don’t anymore.”
### Table Four

**THEME: AFFIRMATIVE OUTLOOK**

Some examples from subthemes

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<th>SUBTHEME:</th>
<th>D:</th>
<th>S:</th>
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<tbody>
<tr>
<td>Letting go</td>
<td>“Just let it go. Tomorrow is another day, and it took a lot to find that in myself.”</td>
<td>“I just go with the flow this year.”</td>
<td>“You have to paddle as fast as your slowest paddler” “[so now I am] a team player … no longer stressing over [being] competitive”</td>
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<td>Never giving up</td>
<td>C: “If you lose a race, you get back in the boat.”</td>
<td>S: “You just have to dig for it.” (Her metaphor “dig” is a dragon boating term).</td>
<td>D: “Being a dragon boater [made me be]” “a never-give-up sort of woman.”</td>
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<tr>
<td>Try anything</td>
<td>H: “[The dragon boating group] is a new challenge for me.”</td>
<td>T: “I’ve gotten braver [since cancer]” “It doesn’t hurt to try anything.”</td>
<td>S: “I do it all the time now. I just take on anything.”</td>
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<tr>
<td>Hopeful reframing</td>
<td>S: “I take every situation and figure something out, make it positive. … That has a lot to do with it, your mindset.”</td>
<td>T: “On the boat, we can joke about things we went through, and we do.”</td>
<td>D: “I’ve never looked back; I keep looking to see the future.” “The positive is what keeps you going.”</td>
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When acclimatizing to the dragon boating environment, Sarah first began to realize she would have to make choices as to her level of involvement. She said, 

So many people take it seriously and I won’t do that, because it just brings me down so I’ll just take it as an adventure ... and say okay well that’s one thing to do – let’s move on....

Further: “I find that a shame that they [teammates]... get upset about stupid things ... oh I can’t take it anymore ... you just go .... Was it that important?” Sarah spoke passionately about dragon boating, but also recognized the hazards of overextending herself. When her team did not register for a major festival after numerous group discussions, “they just made a mistake and I let them .... I could have fought it but said “nah”.” She refused to risk a large conflict, so she registered herself as a spare for another team. She avoids team in-fighting, “I don’t try to fight it because it’s something you have to work through.” Sarah had done a lot for the team, but now, “I just go with the flow this year – I show up and that’s all I have to do this year.”

Callie remembered shifting her priorities. She said, “Things that were so important to me before are just not important.” Reflection was important for her, “if something isn’t going my way ... I will assess it now and think okay is this really important to me, is this going to be worth stressing over?” If something is not crucial, she now feels she can “back away from it and carry on.” She said that she used to have the need to “kind of have control of everything but I don’t need that now.” With dragon boating she had to confront the fact that in her family, “we’re just really competitive people (laughing).” It was significant “for me to take on a team ... where ... all of a sudden you have to paddle as fast as your slowest paddler.” With dragon boating, it “makes me be ... you have to be a team player.” She has struggled to no longer need “control over people.” In general, she was still adjusting to her new ideals and acknowledged, “I like to say it but I probably still want a little bit of control [over life].”

Never giving up. The mindset of “never giving up,” a type of perseverance or “fighting spirit,” is an essential element of breast cancer dragon boating culture. However, for a number of the participants this concept was described to have deep personal significance.
For Callie, who had breast cancer twice, she said an intersection between cancer and dragon boating was that “you just keep plodding along till you get it right.” She said, “if you lose a race you get back in the boat and you try harder next time . . . if you get breast cancer and you get it again you know you get out there you try harder next time.” Overall, “when things go wrong you just get back in that boat and just do it again right?”

Sarah talked about the importance of not taking cancer or any other major challenge, “lying down.” She was “frustrated” by the dynamics of her team, but she refused to quit, saying dragon boating was a good experience and sometimes, “you just have to dig for it.” Through journaling during and after cancer treatment Sarah also came to realize, “when you feel your best you have to pull – drive yourself back in and do it again, that’s the hard part.”

Being part of a dragon boat has made Dee strive to be a “never give up sort of a woman.” With cancer she first learned the value of “keep fighting.” With dragon boating she looked up to women on the team who were going through big challenges and she “wanted to be like them.” It has reinforced the need to “never take on a defeatist attitude.” The boat has taught her “to keep trying,” and most important: “you can apply that to your everyday life, not just on the dragon boat, and not just because you are a breast cancer survivor dragon boat paddler, you never give up.” “Never give up” had become a personal mantra for Dee.

Dragon boating was a key part of Nel’s efforts to endure and then recover from intensive cancer treatments. Using new personal power from being on the team Nel did not shy away from insisting on certain standards for her breast reconstruction surgery, even though “it took a little bit of a battle.” After her surgeries, she “remained on the drum” of her team and she mentioned how it facilitated her healing process.

The challenging dragon boat environment fostered participants to develop or refine the outlook of “never giving up.” Dee described how races could be grueling both because of being exposed to weather out on the boat, “[out on the water, waiting for a race to start] sitting there on Sunday in all that heat in Nanaimo oh it was awful,” and adjusting to race regulations meant for top athletes, “[at the end of a race] we didn’t even get a chance to get a drink of water or even a bathroom break, we just turned right around [to race again].” Related to expectations on physical fitness, Heather spoke of her team’s
standards of training, including off-season training regimes, “they want to have you as strong as possible (laughing).” Participants also had to negotiate working with fellow team members towards goals. Trudy reflected on the team motto of: “love, laughter, and active life,” saying “the love part we all have to work on all the time, especially when trying to organize something (laughing).” Overall, being a dragon boater required endurance, and the ability to “keep telling yourself you can do it,” in Dee’s words, was refined by participation. I observed that developing this ability was necessary if one was to become a long-term paddler.

**Try anything.** Another outlook described by participants was to try anything or a willingness to take risks. Entering dragon boating for all the women involved risk, whether they were new to sports, afraid of drowning, new at being a team member or other reasons. The ability to take such a risk and to continue taking risks was a key part of growth narratives, especially as described by Sarah, Nel and Trudy.

Joining breast cancer dragon boating was a large risk in unto itself for Heather. She had to work up, “courage to join.” She said, “I’m not a group person; this is the first time I’ve actually been involved in a group. And it usually scares me and sometimes I think that is the reason I can’t remember directions that I am being given because I’m scared because I don’t like being in a group.” Being on the team “is a new challenge for me.”

Life after cancer for Sarah meant, “I’m not going to hide anymore … I’m going to do this and I’m going to do that … and take more chances.” She had been a “shy” person at the time of her teams’ creation but volunteered to be tiller, a person who helps lead the team by steering the boat and yelling commands. Explaining why she said, “I just was going through hell so I would try anything.” After recovering from cancer, Sarah’s attitude stayed with her, “I do it all the time now, I just take on anything.” She had also developed boundaries to protect herself, “I’m willing to say no, but I take it on if I want it … I just grab it.”

Cancer had caused Nel to withdraw from life, but because of dragon boating, “I’m certainly a lot more outgoing.” When she started with the team, “it’s funny you know I mean I was pretty timid you know at first and - and now you know I mean we just
kind of hop in and .... and away you go.” She now even felt confident enough to expose what she had thought was a great weakness, saying that she was willing to “flash my new breasts (laughing) to everybody that wants to see them.”

Trudy expressed a love of “trying new things,” that has been enhanced with recent life experiences. Trudy had dealt with cancer, the loss of her husband, change of home, and joining a sports team (her breast cancer dragon boat team). Through all these changes if, “I get the opportunity to try something, to go somewhere, if I am able to do I’m going to do that sort of thing as long as I can ... you don’t know if you are going to have that time.” She confessed to not being comfortable with the water, but she still did “not hesitate” to try dragon boating, in part because of new courage that has been building in her. “I’m not really brave or stuff but I’ve gotten braver in the last while just being sick and cancer and ... it doesn’t hurt to try anything (laughing) as long as you do it safely.”

**Hopeful reframing.** All of the women in my study made efforts to take a positive or hopeful “spin” on their circumstances. Sarah asserted that when it came to life after cancer, “I think that has a lot to do with it ... too is your mindset.” A common strategy was humour, especially finding the lighter side of a bad situation. For some participants reframing was part of a personal strategy for healthful recovery and living.

Part of Dee’s outlook on her life since cancer, was to frame her disease as being in the past. She asserted, “For myself I had cancer, I don’t have cancer.” Her life was now about possibilities, “I have never looked back I keep looking to see the future.”

Some participants brought up the need for thinking positively, which has become a common part of breast cancer culture and dragon boating. Nel said,

... one of the things they say is that ... to get through cancer you really have to have a positive attitude ... and ... you know I really believe that that’s what got me through and why I’m still here ... even after five times with - with cancer.

Part of the appeal of dragon boating for Nel was, “to me the - the dragon boat couldn’t be any more positive.” As a paddler Dee has a new focus on “looking for the positive” and refuses to dwell on “what ifs.” She said she left a different peer group because, “the negativity is what kills you, the positive is what keeps you going, and I wasn’t seeing that with that group.”
“Spinning the perspective” of her circumstances was of particular importance to Sarah. Demonstrating that she has been positive throughout her cancer experience, she read from one of her journals on what treatments were like: “it’s raining here … but I feel really good … I’ll take no hair … and feeling good.” Now with dragon boating even more so, Sarah said, “they call me Mary Poppins. (In) the worse situation… my glass is always half full …. I take every situation and figure something out, make it positive.” Her perspective in life was, “all I have to do is just … take reality and put a spin on it.” Her loyalty to breast cancer dragon boating was in large part due to its reinforcement of her philosophy. Regarding her team experience, “other than that [infighting] I can’t think of anything … all I can think of is positive, nothing but positive.” Because of dragon boating, “hope at the end [of cancer] … and even that’s getting better.”

Reframing often took the form of humour and the willingness to make light of difficult situations. Humour was part of what Trudy valued with her team, “even on the boat sometimes we can joke about things that we went through, and we do.” Reflecting back on her chemotherapy experience Sarah now laughed, “it has its perks – you see it is one of the few times you get new hair darker and it’s a good permanent, it is nice and curly for at least 6 months.” Sarah carried that humour over when interacting with team members, “with somebody who gets started the first thing I say is … ah so … look, when’s your treatment over because we don’t want it to interfere with the dragon boating (laughing).” Dee considered all that she had been through and decided she was now very capable, “so as long as I can swing my leg over the side of the boat I’m on it (laughing).”

Confronting painful experience

The “safe” and supportive environment of breast cancer dragon boating offered the women a context within which they could directly confront a range of painful experiences. Breast cancer dragon boating participation was sometimes a source of new painful emotions, but participants reported support in place to deal with such issues. Through addressing painful experiences the women were further opened to personal change and growth.

Subthemes are: honouring loss; facing fears; and emotional release. See Table Five.
### Table Five

#### THEME: CONFRONTING PAINFUL EXPERIENCE

Some examples from subthemes

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<th>SUBTHEME:</th>
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<tr>
<td>Honouring loss</td>
<td>&quot;The people that didn’t make it, you’re offering something to them.&quot;</td>
<td>&quot;[At dragon boating festivals], you start thinking of the true reason [cancer] why you are actually there.&quot;</td>
<td>&quot;I’m not just there for me. I’m there for my sisters [women with breast cancer].&quot;</td>
<td>&quot;[Regarding the appeal of dragon boating], it meets a lot of fears. Even I had fears.&quot;</td>
<td>&quot;[Regarding the carnation ceremony] it’s always so emotional. We’ve had one [team] member that died.&quot;</td>
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<td>Facing fears</td>
<td>&quot;A lot of fears I had to overcome, in order to stay in that boat.&quot;</td>
<td>&quot;[Regarding the carnation ceremony] it’s always so emotional. We’ve had one [team] member that died.&quot;</td>
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<td>Emotional release</td>
<td>&quot;The boat addresses more the <em>emotional</em> need.&quot;</td>
<td>&quot;It’s cleansing when you can cry and cry [with teammates].&quot;</td>
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Honouring loss. The interview data revealed that for all participants, breast cancer dragon boating provided a context in which to honour both the larger breast cancer community and their own personal experience. As dragon boaters the women could openly address personal losses around cancer and pay respect to other women who had lost their struggle with breast cancer. Notably within breast cancer dragon boating there were both organized and informal remembrance activities for women with breast cancer, the most salient being the carnation ceremony.

To be in dragon boating was to face the realities of cancer. Reminders exist throughout the physical environment. For example, one team I interviewed was sponsored by a major breast cancer society and participants mentioned the large pink ribbon embroidered on the sleeve of the uniform.

The carnation ceremony or toss, a remembrance event held at major festivals to honour all women who have had breast cancer, was a structured way for the women to not only connect but actively engage with their loss histories.

Participants were able to express grief over losing loved ones and friends to cancer. Participants spoke of not throwing carnations for themselves, but for women who have lost their struggle with breast cancer. Nel described the carnation ceremony as “the paying of respect to those that lost their struggle with breast cancer.” Callie said it was about offering, “to the people that didn’t make it ... you’re offering something them.” Nel spoke emotionally about how,

I’m not just there for me ... I’m there for my sisters who have had to battle this, for my Mom; I’m there for the women that we have lost on our team ... you just never forget them.

Dee said, “For myself and several in the boat we are not throwing the carnation for ourselves; we are throwing the carnation for someone we love dear, who has gone.”

The carnation ceremony also caused the women to remember why they had come to be on a dragon boat in the first place and a means of giving thanks for having survived cancer. At festivals Dee said she would be focused on competing until assembling for the carnation ceremony then, “you start thinking of the true reason that you maybe put aside for a short time, why you are actually there.”
Part of being in dragon boating was not only honouring previous losses but learning to deal with the fact that new friends gained in dragon boating were at risk for cancer recurrence. Referring to the loss of a couple teammates, Dee said quietly, “our family dwindles and our family gets larger.” Callie talked about the impact of the recent death of a teammate, “it was a big loss to us … not in the physics of the team, but in the stability and the kind of the emotion of the team; everybody felt her loss.” However, participants spoke of the supports in place to deal with the losses that inherently came with being on a team of cancer survivors: Dee described how group crying was accepted, even encouraged, by teammates and Sarah, Callie, and Nel spoke of ways their team had devised to honour lost teammates, such as plaques on the boat and a private team remembrance activity while out in the boat.

Facing fears. A surprising finding was that throughout the interviews participants described how breast cancer dragon boating participation helped them to face a diverse range of fears. Participants described two general types of fears they encountered: long standing personal ones and cancer-related. Personal fears mainly consisted of phobias, whether of water/drowning or social, including discomfort in groups. Unprompted discussion of fears was a recurring topic. Women provided examples of the many ways dragon boating participation put them in the direct path of those fears, and helping them to move past fears to new freedom.

All of the women spoke of how being a dragon boater required them to face at least one kind of fear. Dee said, “There were a lot of things, lot of fears that I had to overcome in order to stay in the boat.” Sarah believed that part of why paddlers become so passionate about dragon boating and committed is that “it meets a lot of fears, even I had fears.” Sarah said that her fear was “being in front of people … you wouldn’t know that to know me now … but back then … it was scary.”

New to the breast cancer dragon boating environment, Heather found herself being constantly reminded about the risk of cancer recurrence. Prior to dragon boating she described how, “as you get older you think it [breast cancer] might re-occur more.” She said with dragon boating it, “brought the attention of breast cancer back into my life again, thinking of myself, and you know is this something that will happen again in the
future.” Heather described how processing her thoughts within a supportive environment helped her to confront her fears.

Many of the women spoke of having a fear of the water. Nel said, “The boat’s also helped me get over any fear that I may have had of the water.” She noted, “I certainly wouldn’t get on a boat without a life jacket but now if I was thrown off the boat ... into the water it wouldn’t bother me a bit.” Trudy was nervous yet, “I’m not a big swimmer or nothing, but I never hesitated to try it.” Trudy also spoke of team-coordinated pool time to help those in the boat who were “terrified of the water” to “feel more confident.”

To be a dragon boater meant Dee had to confront a strong phobia of drowning. Before dragon boat training Dee joined her team as a non-paddler and recalled speaking with the team organizer, “I said I will help you fundraise and so on, but I am scared to death of the water, I won’t go on the boat, because I almost drowned when I was six.” Soon however she described feeling left out of the “fun” her team was having. She decided to learn to swim, in attempting this, “the first time I only got downstairs into the pool, I didn’t go much beyond that.” She persevered, “after six practices I was feeling comfortable enough that I was doing a backstroke the length of the pool in my life jacket (voice full of emotion).” After a number of progressive steps at the pool she managed to overcome her “really, big challenge,” and paddle with the team. She now has greater ease living in a ferry-dependent community, “I don’t even get scared going over to [town name] anymore on the ferry when it is a rough day; I used to get sea sick I got so scared.”

**Emotional release.** For participants breast cancer dragon boating offered a safe environment for emotional expression. Breast cancer dragon boating allowed women an outlet for intense emotions; both those linked with cancer-specific issues and those of life in general. The women described a range of powerful emotions that were part of experiencing cancer. For instance, Dee had struggled with “anger” and Trudy with acute “grief.” Breast cancer dragon boating also connected a few participants with powerful new emotions, expanding their engagement with life. As described by participants emotional release seemed to be a significant means by which breast cancer dragon boating supported wellness and growth.
Participants spoke of how within dragon boating in general there was support for expressing emotions among team members. Contrasting her breast cancer dragon boat team to her old support group, Nel said, “The boat addresses more the emotional need whereas the support group tends to dwell more on the physical.” Dee described how, “for paddling it is physical but is not just the physical it is the emotions in combination.” Within Dee’s team crying within the group was accepted practice, especially when they faced loss of loved ones, “I’m sure Scotties Tissues is very happy with us because we go through a lot of tissue: it is cleansing when you can cry and cry with someone you feel comfortable with.”

On the team Dee became attuned to a new emotional landscape. Dee spoke of how, “the dragon boat brings out emotions in me that I’ve never really felt before, you know, a sense of pride, sadness, so many things.” For instance, Dee cried when she spoke of how at festivals “complete strangers” were cheering her on. Overall: “I get so emotionally charged on the boat.”

The carnation ceremony was particularly powerful in connecting women with emotions about their cancer experience. The following comment by Dee was typical, “you know I can’t think of anything else in my life - and I’m fifty-nine years old - that affects me the way that does.”

One reason the carnation ceremony was emotional was because it was a reminder of the reason women had become paddlers. Trudy said about finding it emotional: “Thank God I made it … along with all the others here too.” Further, Dee said, “of course the tears come again, remembering, being so thankful that we are here.” Another reason was the support shown to paddlers. Callie said, “It’s the look in you guys’ eyes … that makes it so emotional because you just realize that these people are there supporting you, no matter what.”

The power of the carnation ceremony to evoke emotions was evident by the fact that the effect did not fade over time. Trudy said, “it is still [emotional] … but it’s always so emotional,” in part because, “we have had one member that died.” Callie spoke of how, “when you throw those [carnations] you know and as many times as I’ve done it … the emotion is still there.” Likewise, Nel said, “I’ve been in a lot of them now
and it never fails to move me.” Dee was adamant that, “I think we could do it for the next dozen years and the emotion would never change.”

Dragon boating could also be emotionally taxing on participants. Regarding the number of breast cancer specific events that play out over a weekend long festival, Dee explained:

... it is hard. It is really hard, it's it's an emotional thing again because you are really up here .. you are happy and your excited but there is also a sadness ... I guess sadness being why you had to go through what you did to be able to feel that way now ... (silence).

Sarah found the breast cancer events like the carnation ceremony challenging because of the emotional nature, “I’m just shy about it because I don’t like showing any emotion and they’ve gotten me once or twice.”

**Rebuilding identity**

As the participants described in interviews, before joining dragon boating and at various points since, the women were faced with “who am I now?” Although they varied in how mindfully they engaged with identity related questions, they all had experienced a process of self-discovery. Breast cancer dragon boating was a process of personal revaluation for many of the participants.

“Breast cancer dragon boater” is a unique type of social identity for breast cancer survivors. Identification with all or parts of the paddler identity, as well as — paradoxically — rejection of parts of the paddler identity led to integration of a new sense of self, post-cancer, for my participants.

Dee spoke of how the cancer experience and the dragon boating experience “meld together.” She said, “There are so many things that incorporate into being a breast cancer survivor dragon boat paddler; we are not one and we are not the other.”

Sub-themes include: discovering pride; new realizations – lessons to learn; and better person. See Table Six.
### Table Six

**THEME: REBUILDING IDENTITY**

Some examples from subthemes

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<tr>
<td>Discovering Pride</td>
<td>“[With dragon boating, we are] always learning something.”</td>
<td>“before [dragon boating], I felt like I should hide in shame.”</td>
<td>“I have come full circle, because now I am proud ... that I am a survivor.”</td>
<td>“It gives me a sense of worth, belonging to something that is kind of an elite little group.”</td>
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<td>New Realizations – Lessons to Learn</td>
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<td>“The first time I sat on that drummer’s seat, it was, ‘My God! I can do anything.’ ”</td>
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<td>Better Person</td>
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<td>“That would be the biggest change in me through dragon boating, because I think I’m a better person for it.”</td>
<td>“[I became a] stronger individual, and [I have gained] a different emotional structure to work with.”</td>
<td>“[I have gained] new confidence.”</td>
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**Discovering pride.** For participants, becoming a dragon boater often meant gaining pride from the cancer experience. A number of participants spoke of how prior to joining the boat they felt a need to “hide away” because of their cancer experience. Nel was a poignant example of this, saying, “Before, I felt like I should hide in shame.” A source of pride was the challenging positions on the boat each woman had. For instance, when Trudy spoke of “pushing” the boat as part of the “engine room” or back of the boat (see Appendix H) her voice was full of pride.

Since joining the breast cancer dragon boating team, Dee described a slow process of releasing all the powerful, negative emotions she had around cancer. Being a dragon boater meant, “I don’t have to sit at home and hide away.” She said, “I guess I have come full circle because now I am proud of the fact that I’m a survivor.” Further, through dragon boating one of the emotions “I’ve never really felt before” was “pride.” Callie described that she had been uncertain what it meant that she had had a disease. She was challenged to regain a sense of “normal.” About being a dragon boater, Callie said, “It gives me a sense of worth, belonging to something that is kind of an elite little group.”

Callie considered her group elite because of the association with breast cancer and it was “a group of people who beat the odds.” She talked about the model of Rick Hansen and how “it just goes to show that you don’t have to be a your ‘normal’ person.”

The most striking narratives about both rebuilding identity and gaining pride come from Nel’s discussion of healing after invasive treatments. During the lengthy process of follow-up treatments and reconstruction, Nel struggled with how she thought about her body image and who she was. Concerning the time after her mastectomy, she said, “as they say you lose a piece of yourself … [text removed] … you feel that this feminine thing is gone … and how it identified you.” Then, concerning the time of chemotherapy, Nel said,

> I was losing my hair and wearing a scarf you know a lot … I was feeling … really, really ugly … and I felt everything that was feminine about me was being taken away or literally ripped off my body … I felt mutilated.

Compounding Nel’s feeling was that prior to breast cancer she had already felt her femininity had been compromised because years earlier she had had a hysterectomy related to cervical and uterine cancer. At the end of everything she said, “I just felt the
person that I was—was gone, I didn’t think my life was ever going to be the same and I
didn’t really know what to think of myself either.”

Nel told me that when she reached out to breast cancer supports she kept being
drawn to breast cancer dragon boating, whether in terms of books or meeting survivors at
breast cancer functions, because of “how empowered” they made her feel. From the start
she found herself “curious” and drawn to “the lift” she felt when seeing breast cancer
dragon boating. On becoming a dragon boater, she said,

I discovered of course my femininity was there all along and ... and right here in
my heart but I just ... I had to find it and the boat was really instrumental in
helping me with that.

She said, “now like I go around town and everyone goes oh you’re that lady that’s
always in the paper ... (laughing).” Finally, she added, “the boat is - is just changed my
identity and who I regard myself” and “I’m the dragon lady now.”

**New realizations – lessons to learn.** One of the ways cancer had a lasting impact
on participants was that they continued to deal with “lessons to be learned” or the
meaning of “new realizations.” To be a dragon boater in general was to face a new
challenge, “we’re all new to dragon boating ... you have to live and learn through
everything.” In the demanding breast cancer dragon boating environment women
continued actively to engage with deep personal issues. Trudy said by being a dragon
boater she was, “always learning something.”

Participants described the ways that being a dragon boater caused them to explore
more deeply their new realizations, originating with cancer. Both Sarah and Dee said of
cancer: “it is an awakening.” In reflecting on her life since cancer, Dee said, “cancer
makes you realize so many things that you didn’t realize before” One of the specific
issues Dee discussed was, “that’s probably my lesson .. just deal with it and get on with
life ... because we can’t, we don’t, have a say in what happens anyway.”

Many participants realized new abilities through dragon boating. Talking about
tilling, Sarah said, “I’m a good motivator – that’s when I found out.” Both Dee and Nel
described how they found out they could have athletic ability. For example, Dee said,
"I have never belonged to a team before, I have never participated in any sort of sport, let alone a physical sport and suddenly I’m dragon boating? I mean how cool is that?"

To be involved in dragon boating caused most participants to realize their capabilities at overcoming challenges. Trudy said, "... learned it before that [dragon boating] but it sort of more, that I could do anything I set my mind to." Nel’s experience was similar:

The first time I sat on that drummer’s seat ... it was like .... My god ... I can do anything ... I mean I never thought in my wildest dreams that I’d be doing something like that.

Nel went to build on her new abilities, saying, “Last year I started paddling and I discovered I’m really good at it (laughing).” Nel, who sits in the engine room or the part of the boat from which most of the propulsion is generated (see Appendix H), added, “he [the coach] wants the power you know ... I do have power.”

Dee also experienced new abilities:

I might not be able to do some things as strongly .. as I once could, because I’m, I’m not the strongest paddler on the boat believe me .. but I’m able to do it ... and there would have been a time when I was healthy there was no way I can get in a dragon boat what are you talking about, but I’m able to.

Engaging in new realizations was of particular importance throughout Callie’s interview. Callie spoke of how with cancer, “everything .... you can take for granted until .... finally one day something smacks you in the face ... that you can’t ignore.” Since her cancer diagnosis and joining the breast cancer dragon boating shortly after, she has often found herself in deep reflection, “it made me sit back” and that she had “a lot of lessons to learn.”

Callie spoke of how by being a dragon boater she has found herself amongst a breast cancer peer group which has been particularly challenging. “You know it’s not a team where you go out and you’re all giving’er because like I say ...what is 100 percent to me is not 100 percent to somebody else.” With dragon boating, she said,

I didn’t understand that that people had overcome these –and not just breast cancer – big obstacles in their life – I don’t think I gave people credit for coming through these obstacles .... but now I think I do.
As a dragon boater Nel came to a new view on her cancer:

... in some respects um breast cancer’s been a positive thing for me ... people think I’m crazy maybe but ... for me um .... because of the boat you know, like, I look at breast cancer not as totally negative.

Part of this was that, “it [dragon boating] made me realize you know that there is nothing I can’t do.”

Because of being immersed in breast cancer dragon boating culture, for the first time Heather often thought of the possibility of a cancer recurrence, and came to regard herself as “lucky” to “still be around.” She said, “It has brought home the fact to me, cause um I had breast cancer in 1991 and I am still around and that is good.” Related to this she said, “you learn ways to have fun going through all the pain and discomfort and all the memories.” She also realized she was “far more knowledgeable” about her disease than she was when she first had cancer. She noted it was a benefit that: “a lot of groups have sprung up since then, cancer support and dragon boating, things like that.”

**Better person.** In describing who they were now and how they had changed through dragon boating the phrases “stronger person” and “better person” were often used. Many of the women elaborated specific areas of their life where they felt they had improved.

Dee described herself as a “stronger individual.” By stronger she clarified, “I have a different outlook on life.” For example, Dee said,

I’ll say now oh my arm is bothering me but I won’t whine and snivel like I once did, so I guess for me the dragon boating um you work through it, you work through it and you carry on.

Dee also discussed how she is not plagued by a fear of recurrence because she has “a different emotional structure to work with.” She is now capable to “keep looking for the positive,” and “more determined.” She is also more compassionate, in that she now listens to other people as in “listening in terms of really listening.”

For Sarah the dragon boating experience has meant getting her “strength back” and gaining new “power.” Throughout her conversation she reiterated the importance for
her to be both physically and emotionally strong. Dragon boating was a key means for her to achieve these goals.

Within the dragon boating environment Callie found herself developing more “empathy” for others, as there were many women with visible health concerns. She said, “I would like to think I’ve become more patient.” Overall, “I think that would be the biggest change in me through dragon boating is I think I’m - I’m a better person for it.”

Throughout our interview, Nel described how by being a dragon boater she benefited by operating outside of her normal possibilities. From belly dancing to support groups, Nel described numerous activities she engaged in as she recovered from the trauma of cancer, but the boat is what she stuck with because of “how strong it made me feel.” Out of that feeling she came to believe, “if I can do this I can do anything.”

Although new to breast cancer dragon boating sport, Heather had noticed an increase in her “confidence.” She credited this to constantly adjusting to the activity, “this is a whole new experience for me.”

**Spiritual engagement**

Participation in breast cancer dragon boating led some of the women to have deeply moving experiences that could collectively be described as “spiritual engagement.” Participant stories about breast cancer dragon boating were often marked with a vibrant sense of being alive or of a connection with deeper levels of meaning in life. When asked about the meaning of dragon boating and possible spiritual aspects, participants rarely made explicit points; instead, they often told stories that invoked how deeply moved they were by a particular experience. Part of the dynamic nature of dragon boating was, “the physical and the emotional all get tied up in there and the spiritual too,” in the words of Dee.

Dragon boating also offered the women a distinct social context imbued with meaning, not found elsewhere in their communities.

Sub-themes for spiritual engagement are: mythic identity; breast cancer rituals and myth; the boat as spiritual space; nature, and spiritual assistance. See Table Seven.
<table>
<thead>
<tr>
<th>SUBTHEME: Mythic Identity</th>
<th>N: “I’m the Dragon Lady now.”</th>
<th>D: “‘Warrior Woman’ – like the eagles, you get out there and you soar.”</th>
<th>S: “… Dragon power.”</th>
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<td>SUBTHEME: Breast Cancer rituals and myth</td>
<td>S: “It’s made by us; It’s our ritual.”</td>
<td>C: “that spiritual thing where when you throw a carnation, it’s like you’re giving an offering.”</td>
<td>H: “‘Love, Laughter, Active Life!’ That is the mantra” “We go in a circle and say that.”</td>
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<td>SUBTHEME: The boat as spiritual space</td>
<td>C: “All you hear is the paddles going in … for the first little while, it is really spiritual.”</td>
<td>N: “Your [deceased] members are still in that boat with you. Even though they’re not there, they’re there.”</td>
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<td>SUBTHEME: Nature</td>
<td>C: “The whole estuary is pretty spiritual.”</td>
<td>N: “We have eagles that fly around, and so we look at that as these people [the deceased teammates].”</td>
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<td>SUBTHEME: Spiritual Assistance</td>
<td>D: “[Because the boat has been blessed], you are drawing from something you may not understand.”</td>
<td>N: “We ask for good boating, no accidents, and that piece of yarn [from the blessing ceremony] is still tied to my life jacket – I don’t leave without it.”</td>
<td>D: “The dragon’s alive; I’m alive – they are tied together.”</td>
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Mythic identity. Being part of breast cancer dragon boating offered participants the opportunity to incorporate mythic elements of the activity into their emerging sense of self, post-trauma. From the extensive Chinese mythic traditions of dragon boating, the women drew out narratives and symbols that related to their personal recovery from cancer. Most participants used dragon stories as metaphors for their experience. The notion of mythic identity had particular importance to Sarah, Nel, and Dee.

The symbol of the dragon often relates to harnessing power and strength, and some of the women spoke of “dragon power.” Sarah said, “I see the power and strength of dragon boating … the power and the strength … and that’s the magic … the magic of it all … if you get right into the belief of the dragon.” Sarah also described how the idea of the dragon was grounding, “it’s very earthy … there’s a lot to it when it comes to … the history behind it and what it represents.” Nel summarized her experience of “empowerment” by saying, “I’m the dragon lady now.” Speaking about the eye dotting ceremony, Dee said, “The dragon’s alive, I’m alive; they are tied together.”

Although the women varied in identification with the dragon, most of the women kept symbolic representations of dragons in their home. Dee had a Chinese water-dragon suncatcher in her living room. Sarah’s kitchen featured team photos and souvenirs, including medals. Sarah showed me how her closet was full of shirts with dragon designs, as well as uniforms from her own breast cancer dragon boat team and from other teams she had traded with. Nel’s den was decorated with framed photos of key breast cancer dragon boating accomplishments and a shrine to breast cancer dragon boating, including ornate statues of classical Chinese dragons. Nel also made a point to show me her car which featured dragon decals and a festival souvenir hanging from the rearview mirror. Trudy told me she refused to believe in the symbols of dragon boating but her living room featured a number of dragon boating icons, including a metal cut-out breast cancer dragon boat “earthquake detector.”

In constructing a new identity Dee drew from local First Nations traditions as well. Her team had a First Nations elder bless them and pronounce them “warrior women” in accordance with First Nations people’s cultural traditions. With reverence, Dee told me “we are blessed warrior women.” In this context, “warrior women” was not meant in accordance with social stereotypes about breast cancer, but related to First
Nation’s beliefs from Dee’s local area. For Dee, the new identity entailed responsibilities around personal conduct and team performance. She said part of being a “warrior woman” was that “like the eagles you get out there and you soar” and this was something to which Dee aspired.

**Breast cancer rituals and myth.** Five of the participants described some of the breast cancer dragon boating rituals as being spiritual in nature, or in the case of Trudy: deep meaning. When discussing rituals, all participants placed significantly more importance on the breast cancer specific rituals and myth of their sport, rather than on ones from the history of dragon boating. The reasons involved deep existential issues.

Speaking of breast cancer dragon boating rituals (e.g., the carnation ceremony), the women expressed personal meaning and ownership. Comments included “it’s made up by us, it’s our ritual” and, “we’ve taken something and added to it.” Sarah said,

... not to be mean or sound nasty but that’s for breast cancer – that’s special ... that’s why we are where we are today ... and um... it wasn’t lung cancer and it wasn’t – not to be mean to anything else but ... um no that’s very special and ... yeah that means more.

Nel said the carnation ceremony “never fails to move me,” because “you just never forget them [lost loved ones] .... I - I couldn’t feel more spiritual at that moment.” Similar to Nel, Callie said it was, “that spiritual thing where when you throw a carnation it’s like you’re giving an offering,” and clarified “to the people that didn’t make it.”

Within individual teams, the women had the opportunity to help create new rituals to remember lost teammates. One practice was a moment of silence. Callie described how, “we are going to remember them in the boat and so we do that every now and then, we just take a minute to remember them in the boat.” Another practice was to throw a lone carnation to honour a deceased teammate. Sarah said that on the team she shares with Callie, “when a member passes ... we just came up with that ourselves ... we just take the boat out by ourselves and have a toss.” The carnation would be thrown by a team member who had been a close friend to the deceased, and in a spot chosen by the team as having special meaning.

On Heather’s team, ritualized words were part of a team created ritual to reinforce the idea of new life after cancer. She said,
Love, laughter, active life. That is the mantra, mantra. You know every time you finish paddling you get out and they do this love, laughter, active life. And we go in a circle and say that.

Sarah mythologized the founder of breast cancer dragon boating, replacing the key figure in the ancient roots of dragon boating. She discussed how she didn’t understand “the story about the fellow who drowned in the river,” referring to the ancient Chinese tale about the origins of dragon boating but she knew about “Dr. Don,” the founder of breast cancer dragon boating.

In my study when women expressed a meaningful connection to historical dragon boating ritual or myth they always related it to breast cancer. For example, Dee discussed how the dotting of the eye ceremony was spiritual because it was a metaphor of her new life post-cancer: she was now “awake” and riding the dragon of cancer that once had power over her.

**The boat as spiritual space.** The physical space within the dragon boat was often described as a distinct experience. The boat was a “safe space,” where the outside world did not infringe. Women also spoke of deep silence sometimes experienced while paddling. Further, a few participants said although team infighting was a problem on their teams, none of that fighting happened while actually on the boat.

For Nel and Callie, the physical space of the boat was described specifically as spiritual.

For Callie the act of paddling out to practice had a meditative quality:

... all you hear is the paddles going in, there’s nothing else, there’s nobody on the drum yelling, the tiller’s not yelling, you’re just paddling ... then of course the practice will start and you’re back to normal, but for the first little while it’s really spiritual.

Nel, formerly a drummer, spoke of the meaning of boat equipment to her, “it’s just a special place [the drum seat] ... you know and just like the paddles are to everybody else ... I mean my paddle’s special ... but not like the drum seat is.”

It was believed by a few of the women that the spirits of dead team members were part of the boating experience. Part of what made the boat meaningful to Nel was that, “your members are still in that boat with you ... even though they’re not there they’re
there." Speaking about lost teammates, Callie said, "they have a place on the boat ... where they used to sit on the boat that’s their seat even though someone else is in it.” Another team had plaques on the boat with the names of deceased teammates and supporters.

**Nature.** All participants expressed connections with the natural world they were involved with as paddlers. Part of West Coast dragon boating is beautiful scenery and encounters with wildlife. In addition to recreational opportunities, a number of the women discussed how they found the nature around them spiritual.

Nel described how being on the boat allowed her to experience a moving connection with nature:

> I know just sometimes being on the boat when we’re in our estuary ... um.... it’s ... you see nature and you get to see it from a .... a perspective or an angle ... that you normally don’t have a chance to do ... but um.... it just, god – it makes you feel good to be alive you know and ... it sounds corny .... sometimes you know that oh you know life is so wonderful .... It’s a gift.

She went on to describe “seeing a flock of herons”, and “the eagles too when they come down ... you know like ... you can get pretty close if we’re all quiet in the boat and the boat’s just kind of gliding along.”

Describing the same estuary as Nel, both Callie and Sarah also spoke of spiritual elements. For Callie, “I don’t know if it’s just the place we dragon boat, but the whole estuary is pretty spiritual ... when you go in there and it’s quiet and peaceful.” Within this setting her team found revered space to recognize lost teammates; Sarah said, “ours is in the middle of the estuary where all the eagles are.”

A surprising finding was that eagles were mentioned by a number of the women as having spiritual significance. As part of her routine, Sarah said she always carried an eagle token with her when she paddled. Callie and her team, which includes Nel and Sarah, saw the eagles as embodying the spirits of lost team members, she told me how “we’ve lost people and when you get in the boat you kind of feel like they’re there because we have eagles that fly around and so we look at that as these people.” Dee explained that the eagles were a reminder of the spiritual First Nation beliefs that were bestowed on her team: a reminder of goals and responsibilities.
**Spiritual assistance.** Although the majority of participants described a general sense of spiritual support or connection with something larger than they were, Nel and Dee discussed experiencing spiritual assistance.

A component of dragon boating as described by participants was blessings. When a dragon boat is first launched, either after being purchased or at a festival, the boat is blessed by a spiritual leader. For Dee, this meant, “not necessarily that God has blessed us but that the spiritual being we’ve been blessed by so that also assists us out on the water, so you are drawing from something you may not understand.” For Dee’s team, a First Nations elder blessed the boat, in part by dusting it with eagle feathers. Dee said that because of the blessing ceremony, “everything was cleansed and then sort of a new beginning.”

Dee gained a sense of protection when out paddling that overrode her intense fear of drowning. She said,

... people will say I’ve become complacent; that is not true, but I don’t become nearly as scared when the water is rough because I have this inner sense of peace; I just feel like I’m protected, I’m looked after and it might have come from Elsie blessing us, I don’t know what it is and I can’t explain it but I just feel a calmness ... I don’t feel the turmoil.

In looking out to other teams on the water she said when, “they all come back safely to shore I felt that there is a someone or something protecting them; that they are not out there on their own.”

Both Nel and Dee carried tokens from their boat blessing ceremonies that they believed helped them with their dragon boat experience. On Nel’s team a Buddhist monk blessed a piece of yarn as part of the ceremony. Along with that blessing, Nel described how the monk,

... asked for good boating (laughing) you know no accidents (laughing) and that piece of yarn is still tied to my life jacket ... I just don’t leave home without it ... that was very spiritual.

On Dee’s team, the “warrior women” blessing and prayer from a First Nations elder was reinforced with a physical reminder. Dee spoke with reverence about how each teammate was given a little paddle with a saying on it so they could take the blessing with them.
Related to the dotting of the eye customs, Dee felt like she was fully alive on a dragon boat. She said, “When they dot the eye it is an awakening of the dragon to carry you through,” and “The dragon’s alive; I’m alive; they are tied together.” Awakening the dragon also helped carry her through adversity.

Summary

In this chapter I presented the context of cancer for participants and the seven themes that became apparent from analysis of participant narratives. I have attempted to convey the sincerity and depth with which participants expressed their experiences. The findings drawn from the interviews provide a complex, nuanced picture of the experience of women breast cancer dragon boaters and the multitude of ways they have engaged wellness after cancer. It is my hope their efforts lead to application of these findings to the future benefit of cancer survivors.

In the next chapter I explore the meaning of each theme and the implications of these findings for academics and professionals who work with cancer survivors, as well as the questions that these findings raise for future research.
CHAPTER 6
Discussion

The purpose of my study was to develop a better understanding of the psychosocial experiences of women partaking in breast cancer dragon boating. The emergence of breast cancer dragon boat teams over the past ten years has led to a unique post-treatment option for survivors of cancer. The few previous studies on breast cancer dragon boating have provided preliminary evidence that psychosocial benefits and personal growth often result from breast cancer dragon boating. It would seem participation in dragon boating teams and involvement with their respective societies are becoming an integral part of cancer recovery for a growing number of women.

Unlike previous studies, my study focused on teams in small communities. Upon completing treatment, breast cancer survivors in smaller communities have had to leave behind a range of structured and unstructured supports in the urban centres where their cancer care had been cantered. To increase support for survivors from small communities, my study sought to understand the meaning and consequences of being an active paddler on a small-scale breast cancer dragon boat team.

The findings drawn from the interviews in this study provide a dynamic and multilayered picture of the role of breast cancer dragon boating in the lives of breast cancer survivors. In section one, I examine how each individual theme relates to existing theory. In section two, I discuss interconnections across themes. In section three, I highlight several of my reflections on the findings and research process. Section four explores directions for future research. Clinical implications are discussed in section five. Section six concludes this chapter, with final commentary.

Section One: Themes

The following themes reflect recurring narratives from participants’ reflections about their lives as cancer survivors who take part in dragon boating team activities. Following the presentation of these individual themes, I discuss in detail two broad aspects of all themes: meaning and psychosocial growth.
Moving past isolation – networks of like-minded support

Moving past isolation and forming networks of like-minded support was a key part of the recovery process for participants. It was one of the most important themes to emerge from the data. Trauma disrupts social relationships for the survivor, and reaching out to discover that one is not alone is a critical process for healing (Herman, 1997). With breast cancer survivors from small communities, how to cope with isolation was a main concern of survivors (Gray et al., 2004). To fully address her suffering, to move forward in healing, the survivor needs to build courage and confirmation within a safe environment (Arman & Rehnsfeldt, 2003). All of the participants in this study expressed a need to connect with other survivors who were also moving forward with their lives after cancer treatment. As revealed in interviews, it cannot be understated how important it was to all participants to be part of a group where the emphasis was placed on wellness and living life to the fullest versus an overt focus on cancer-specific concerns. Breast cancer dragon boating provided women with numerous like-minded survivor contacts as well as allies, both on the team and in the community.

The driving need to form new social connections is consistent with the concept that recovery from trauma requires an interpersonal context (Lepore et al., 1996; Herman, 1997). Being able to openly discuss trauma can help survivors to re-evaluate their understanding of the event and their subsequent life experiences. Particular to breast cancer, social support is associated with better adjustment (Helgeson et al., 2004). In order to face and reduce their suffering, breast cancer survivors need a safe and understanding environment where the full range of their suffering can be explored (Arman & Rehnsfeldt, 2003).

Interview data suggests that part of the value of dragon boating was a social environment where there are few social constraints around cancer. Social constraints are “any social condition that causes trauma survivors to feel unsupported, misunderstood, or otherwise alienated from their social network when they are seeking social support or attempting to discuss their trauma,” (Lepore & Ituarte, 1999, as cited in Cordova, Cunningham, Carlson, & Andrykowski, 2001b, para. 2). One problem faced by participants is a common one: the assumption that having “survived” cancer the survivor
is now free of medical concerns; accordingly, support from loved ones decreases (Holland & Lewis, 2001). The women in my study expressed gratitude for finding a group of women where the shared condition of breast cancer allowed for unspoken understanding and safety. Such understanding they had not found with loved ones and other non-cancer survivors. Low social constraints act as a buffer from intrusive cancer-related thoughts and the subsequent distress (Lepore, 2001).

Participant narratives reflected existing research that found the benefits of a peer support group for cancer survivors include a safe environment, mutuality, and a sense of belonging (Ussher et al., 2006). When women in my study spoke of “sisterhood” they went beyond a stereotypical term within the cancer nomenclature to expressing a unique bond or understanding with other cancer survivors, which has been demonstrated in previous research (Gray, Fitch, Davis, & Phillips, 1997). Processing trauma through social interactions has been shown to be associated with positive aspects of adjustment from breast cancer (Cordova et al., 2001a).

Participants strongly differentiated the peer support experience within breast cancer dragon boating from that of regional support groups. Typically, participants viewed participation in support groups as dwelling on cancer, which did not meet their support needs. As widely documented, cancer can often be a socially isolating experience, and peer support groups can in some cases provide an effective forum for the social support that can facilitate psychosocial well-being for survivors (Ussher et al., 2006). In regard to social inclusion, all cancer groups have the potential to convert the cancer experience from “a liability into an asset,” (Spiegel, 1993, p. 106). Nevertheless, findings based on interview data in my study are consistent with research that shows that women with breast cancer who continued with social support from organized groups, often past the end of treatment, were attending activity based groups (Thewes et al., 2004). In the case of breast cancer dragon boating, participants found not only an activity, but a team united by shared purpose, for example to attend festivals or overcome cancer. Throughout interviews it was clear that to join breast cancer dragon boating teams meant moving on from cancer “patient” and equalled admission into an exclusive group or “elite group,” as described by Callie, of active survivors. Further, the large seating capacity of the dragon boat encourages social mixing versus isolation, which was a key
reason the water craft was chosen by the sport founder (McKenzie, 1998). Dragon boating for participants was not about “rehashing” cancer issues but about being empowered and taking on new life in a public way. Overall, interactions between participants and team members allowed the group experience of dragon boating to offer mutually satisfying relationships and collective empowerment; critical elements of healthful groups for survivors of trauma according to Herman (1997).

By means of storytelling, participants in my study acted as “wounded healers” (Frank, 1997), sharing their insight and receiving that of others. Two of the ways groups function is through storytelling as a means of immediate and intimate connection and through information sharing based on personal experience (Kelly, 2000). Discussion with others has the potential to facilitate positive change after trauma and includes the possible benefits of reappraisal and integration of the cancer experience, gaining a sense of belonging and offering opportunities for altruism (Cordova, et al., 2001a). Participants in my study benefited from an intimate social network of survivors. Group participation allows women to gain a fuller picture of cancer survivorship as they move from imagining future problems and visualizing survivors of the disease to interacting with real, multidimensional people dealing with dynamic problems (Spiegel, 1993). Interview data revealed that an important group element was the sharing of personal experience among women of diverse backgrounds. Normalizing of experience resulting from group interaction was clear in participant stories.

The team environment also allowed for direct social comparisons of a downward nature. Social comparisons or comparisons with individuals viewed as part of a peer group are a known strategy for trauma survivors to reconstruct their worldview (E. Taylor, 2000). Participants in my study compared themselves with others who were less fortunate in terms of age, chronic ailments, and treatment types. Participants looked to challenged teammates as an “inspiration” to keep going and a means to frame their own cancer experience as more manageable than they had once thought. Thoitis (as cited in Rowland, 1990, p. 47) argues that one of the ways social support can assist coping is by allowing individuals to reinterpret the meaning of their trauma as less threatening. My findings also fit with S. Taylor (1983) who found that women with cancer commonly
make downward comparisons with others who are as or less fortunate than them, and that such comparisons are a vehicle to enhance self-esteem.

My findings resonate with previous research on psychosocial aspects of breast cancer dragon boating in regard to the importance of social support elements offered by the activity to paddlers. As documented, the sport offers a meaningful interpersonal connection with other breast cancer survivors and a form of peer social support (Mitchell & Nielsen, 2002; Unruh & Elvin, 2004; McNicoll & Doyle, 2003; Sabiston, et al., 2004). As with my study, the existing body of research suggests dragon boating is not a traditional support group environment, where women regularly and intentionally discuss breast cancer issues. In reality the activity is unique because, as shown in my study, breast cancer disease is rarely discussed, and support largely comes from being in a peer environment. A similar finding was reported by Sabiston et al. (2004).

Unlike previous research, my findings show the importance of community support and the diverse forms this can take. For example, participants were working alongside other community groups for fundraising and not just for the direct benefit of their team. One possible reason for my findings is that all the women in my study lived in non-urban areas where there was a greater community presence to begin with.

**Taking control**

Taking control was another important theme in my study. There is a wide body of research that documents how cancer results in numerous losses, a sense of powerlessness, and living with uncertainty (e.g., Veach et al., 2002; Thewes et al., 2004). Cancer is a traumatic and life threatening event; in disrupting one's assumptive world, cancer also alters perceptions of personal control (Tedeschi & Calhoun, 2004). Cancer involves a loss of autonomy and issues of control are common for women who have had breast cancer, even long after initial treatments (Thomas-MacLean, 2004). One element of powerlessness and cancer for the women in this study was that most of them spoke of how cancer came as a surprise. They gave many reasons why they had not thought they were at risk or had not thought about cancer at all. According to Herman (1997) helplessness is one of two core elements of psychological trauma, and likewise empowerment is a core element of recovery. As expressed by participants in my study, an
essential part of being a breast cancer dragon boater was the opportunity to gain a sense of control after the chaos of cancer. Further, breast cancer dragon boating was a means to address ongoing issues of control over one’s body and life, which are typical concerns of breast cancer survivors (Thomas-MacLean, 2005). Overall, breast cancer dragon boating helped women in my study to feel empowered or stronger.

Several elements of the women’s stories about breast cancer dragon boating correspond with means to gain mastery as described by S. Taylor (1983). Part of adjusting to trauma is to gain a sense of control or mastery over the threatening event (S. Taylor, 1983). In general, S. Taylor (1983) suggests cancer survivors can regain a sense of mastery after experiencing cancer by taking active steps that directly or indirectly control the cancer. One of the key ways survivors do this is through finding ways to believe that there is temporal discontinuity between present time and the trauma. Being a breast cancer dragon boater does accomplish this as the sense of being a capable paddler is in stark contrast to that of being an ill cancer patient. Winning race medals as a paddler, described by Sarah, Nel, and Dee, is far removed from receiving chemotherapy. Additionally, reaching out to both capitalize on and create opportunities was a powerful means for participants to assert control over their wellbeing. Breast cancer dragon boating also allowed the women to gain a sense of control through information sharing with other paddlers; S. Taylor (1983) noted that acquiring knowledge through conversation with other cancer survivors is a means to experience control. Finally, participation in breast cancer dragon boating made the women feel more capable and stronger thus having a sense of control over future recurrence.

Participants’ narratives demonstrated that control in their lives came down to making choices that put their needs first. A positive outcome of having breast cancer is that women often place a higher prioritization on themselves (Utley 1999). Findings from my study are also consistent with E. Taylor (2000), who found that breast cancer survivors who had grappled with the reality of their trauma had a healthier perspective of self, including stronger personal boundaries. By having boundaries and prioritizing self, the women in my study had a strong foundation for regaining control in a number of aspects of their life.
As revealed in interviews an element of taking control was managing stigmatization about cancer. Throughout the cancer trajectory participants were challenged by how others thought of them, and how they actually wanted to be thought of. Participants faced both the stigma of cancer as an “evil” disease or cancer equals death (Sontag, 2001), and the idea of “spunky survivorship” (Sinding & Gray, 2005, p. 148) or the idea that cancer is a self-improvement opportunity equalling a better life than before. As demonstrated in participant stories, stigmatization can create false social perceptions of the lived experience of cancer. Callie’s description captures the experience of other participants in my study: “you get this stigma when have breast cancer … people kind of look at you sideways or put you on a pedestal.” A number of the women were treated as somehow unwell or physically deficient following the end of treatment. Likewise they faced the social notion that they were “heroic” for their ability to dragon boat after experiencing cancer. The fact that women needed to deal with stigma, is a potent reminder that cancer is still unique from many other conditions because of powerful social narratives that impact survivors.

A unique finding was that the narratives of taking action against stigma and other negative forces that were common in participants’ stories fit with Wade’s (1997) concept of “resistance.” Wade proposes that resistance is any mental or behavioural act during which someone who is being oppressed or badly treated actively responds against what is happening (p. 25). Resistance is often a parallel process to oppression. Resistance can be seen at several points in the process of recovery for participants in my study, however it was most acute in their rejection of medical or/and social directives as they established personal ideals of wellness. Women with breast cancer are often subject to older paradigms of how to be a proper “breast cancer sufferer” (Amaya & Petersen, 2004), and such beliefs often place unrealistic restrictions on their life as a survivor (Harris & Niesen-Vertommen, 2000). Herman (1997) observes that providers within the medical model as well as well-meaning individuals in general often fail to recognize the value of empowerment for survivors of trauma. It is crucial to realize that for survivors of illness, “as the body becomes contested territory, autonomy of self becomes tied to keeping control of the body” (Charmaz, 1999, p. 370). The very act of becoming a breast cancer dragon boat paddler can be seen as resistance; for many women in my study it meant
rejecting the concept of cancer equaling the end of active living. Resistance was clearly a key element for participants in healing from cancer, whether by choosing to learn paddling in spite of medical advice not to use an arm or something more subtle such as leaving a support group that no longer served their needs.

My finding that my participants were able to regain a sense of control through dragon boating is supported by the prominence of control issues in previous psychosocial breast cancer dragon boating studies. My findings reinforce and elaborate the findings of the previous studies. Dragon boating offers women a way to regain control of their lives and challenge cancer (Mitchell & Nielsen, 2002; Unruh & Elvin, 2004). For participants in Parry’s (2007) study breast cancer dragon boating meant being back in the “driver’s seat” or taking some control. Upon completion of their first breast cancer dragon boating season, women in Mitchell et al.’s (2007) study reported feeling they had regained some control of their life, including health. The feeling of “strength” and other outcomes of sense of control as reported by my participants support the mentioned findings. However, my finding of resisting negative forces through being a dragon boater was unique to my study and highlighted how breast cancer dragon boating offers women numerous and novel means for regaining control.

Journey into adventure

“Journey into adventure” reflects the renewed sense of purpose and new life focus which are common narratives for trauma survivors. In describing their experiences survivors of cancer commonly report that there has been a shift in their sense of the world and that there is no continuity between the cancer event and life before (S. Taylor, 1983). Not only have concepts surrounding health been altered, but often the meaning of life itself (IOM, 2005). Cancer survivors tend to have an enhanced appreciation of life and gratitude for still being alive (IOM, 2005). It is my experience that after the initial cancer experience, it is not uncommon for survivors to become engaged in ongoing struggles to achieve a sense of wholeness and life purpose. There is often a longing to refine new notions of balance and wellness post-disease.

Breast cancer dragon boating was part of various “quests” or large-scale life goals for participants in this study. The cancer diagnosis was a turning point that set into
motion a cascade of new directions and possibilities for the women. Participants in my study had long moved past being overwhelmed by the chaos of their cancer experience. Instead many stories became quest narratives (Frank, 1997), as evidence of this participants spoke openly of their suffering, acceptance of cancer, and seeking ways to use the disease experience for personal betterment (Frank, 1997). Mitchell et al. (2007) found in their study with breast cancer dragon boaters that women coming into dragon boating had substantial expectations about how participation in the activity might assist healing and general life issues. My findings parallel the “dragon quest” described by Mitchell et al. (2007) in that participants in my study were seeking a means to meet diverse needs after cancer treatment. Breast cancer dragon boating was a process by which each of my diverse participants could realize new goals derived from the cancer experience, such as finding breast cancer allies; becoming emotionally stronger or improving physical fitness. Further, participating in breast cancer dragon boating was a public way to “prove” new outcomes, such as wellness.

Part of the revitalized sense of life participants described, was the love of being a paddler. If cancer survivors actively engage a search for meaning a positive outcome can be enjoying life with new passion (Nelson 1996). Most participants spoke emotionally of dragon boating as a passion, whether they had discovered a love of paddling or drumming or whether they enjoyed secondary aspects of the sport, such as travel. This expands on the finding of Mitchell and Nielson (2002) that, women in their study framed breast cancer dragon boating as a new pursuit in life that was exciting and intense. Involvement in enjoyable and meaningful leisure activities is also known to improve health (Henderson & Ainsworth, as cited in Parry, 2008, p. 231). As revealed in interviews, for many women in my study a benefit of breast cancer dragon boating was that it was an engaging experience that helped them fully embrace life.

In my study, renewed purpose was strongly linked with the need to engage in community based advocacy. All of the women expressed a deep need to assist other survivors and achieved this through functions open to them via breast cancer dragon boating and allied community volunteer roles. Women who do engage in advocacy have grown from their cancer experience; they have learned from their suffering and now wish to reflect that growth (E. Taylor, 2000). Altruism is one of the positive social effects that
survivors of cancer may experience (IOM, 2005). A driving desire to “give back” and finding a way to do so is often part of long-term cancer survivorship (Holland, & Lewis, 2001). Trauma cannot be undone but a way to transcend trauma is for survivors to engage in a “survivor mission” or social action that addresses socio-political dimensions of their experience (Herman, 1997). One of the key elements that initially drew women in my study to dragon boating was a means to help other women with breast cancer. Advocacy, in particular breast cancer awareness, is a critical part of the mandate of breast cancer dragon boat sport as established by sport founder Dr. McKenzie (A Breast In a Boat Team Manual, 2004).

Activist positions concerning cancer first emerged in the Sixties (Amaya & Petersen, 2004) and the possibility of being a breast cancer dragon boater is part of the evolution of such attitudes. No longer are women, by default, isolated “victims of disease”. They are often active members of survivor communities, breast cancer dragon boating being a specialized form of one. In my study, dragon boating offered women the following reversal described by Frank (1997), “as wounded people they may be cared for, but as storytellers they care for others” (p. xii). The position of breast cancer dragon boater has the potential to offer women what Wade (1997) calls a de facto form of resistance, where they can address trauma against themselves and others through establishing new ways to live with respect following trauma. Breast cancer dragon boating offered the women in this study a structured, creative, and public way to reach others. The women were not simply advocates; often they were community role models whose participation in their sport alone inspired others to take action.

It struck me that most of the women in my study fitted with Frank’s (1997) notion of the female cancer survivor “hero” as bodhisattva. Frank reworked the notion of hero in the cancer journey to more accurately reflect the experiences of women survivors. The notion of the bodhisattva is that of a compassionate and enlightened being reaching out to share her experience. She is not a hero of force, but one of possibilities, offering a path for others to consider options for their own struggles and recovery. In our interviews together, participants freely shared the nuances of their experience, good and bad, and they spoke of doing the same for other cancer survivors. I could see the genuine
compassion and willingness to be there for other survivors and that such empathy was rooted in the women’s own personal encounter with cancer.

The advocacy efforts of four of the participants were concrete examples of how growth or change from trauma is an ongoing process. Sarah, Nel, Callie, and Heather described ever-evolving volunteer efforts. For example, Nel and Callie helped found a new all-cancer team in their area because of a continuing need to be engaged in cancer advocacy. Through their experience of cancer, dragon boating participants had gained new strengths, strengths that they continued to build on and refine. In Sarah, Nel, Callie, and Heather’s volunteer activities I could see how dragon boating was just one step in their journey with cancer, often leading to many new directions and choices.

The reciprocal nature of advocacy was a key part in Dee’s process of healing and becoming stronger as a cancer survivor. Helping others can aid survivors of trauma in feeling both cared for and recognized (Herman, 1997). Dee spoke of how the intense anger she harboured about her cancer experience, gradually dissipated after assisting a teammate to cope with her problems.

In naming this theme I acknowledge that the words “journey,” “adventure,” and “quest” have become contested words in cancer narratives. Nevertheless, participants themselves used these specific words in describing experience. Notably, Sarah, Nel, and Dee used such language throughout the interviews and in common speech. In recent years the idea that serious illness can be a “journey of discovery” has become common in our society (Gray et al., 2001). Often in cancer narratives stereotyped words are used in ways that occlude nuances of the lived experience of survivors, particularly the unpleasant aspects of the disease. Death and suffering are not part of the new image of cancer in Western society (Sinding & Gray, 2005). As consistent with existing literature on the stereotypical nature of the word “journey,” participants struggled to qualify the word or dismissed it in favour of something else. Yet, like other stereotypes around cancer, participants in my study used established language in personalized ways so as to capture their experiences. This was one of many examples in my study of the tensions between lived experience and social discourses on cancer.
Affirmative outlook

The participants in my study varied greatly in terms of both personality and life philosophy, but what resonated among all their stories was an evolving outlook that was ever more attuned to their needs and being assertive in satisfying those needs. One of the ways individuals can find meaning in life is by the attitude they take toward their suffering and unchangeable circumstances, including cancer (Frankl, 2006). A positive outcome of having breast cancer is that women tend to become more assertive (E. Taylor, 2000). My finding of a new affirmative outlook elaborates that of Mitchell and Nielsen (2002) who noted that the breast cancer dragon boaters in their study had an “increased focus on the self” combined with a “changed overall perspective,” (Embracing Life section, para. 1).

It is important to note that the “affirmative outlook” adopted by participants is in some ways related with efforts to establish a sense of control. In discussing efforts of breast cancer survivors to gain a sense of mastery or control S. Taylor (1983), noted that many such efforts were mental ones. A very common manifestation of such a mental effort was the idea that a positive attitude would prevent a cancer recurrence (S. Taylor, 1983). Positive attitude and other mental strategies were apparent in the narratives of women in my study. For example, as described by participants the positive thinking that was encouraged during team activities, was a way for participants to gain a sense of control over cancer: if they thought positively they believed they were less prone to undesirable cancer outcomes. Despite such overlaps with the theme of taking control, developing an assertive, self-oriented outlook was primarily about attitude not actions taken.

An integral part of the recovery process for women in my study was forming the ability to be selective in regard to what one stressed or fusssed about. Cancer has been found to impact quality of life by fostering in survivors “a determination to enjoy life without letting little things upset them” (Foley et al., 2006, p. 251). Letting go of stress is a companion process to taking control of their wellbeing; many of the women discussed how they eventually learned how to “let go” of things beyond their control. Part of posttraumatic growth is a shift in what one considers to be a “big deal;” thus, things one might have once considered troubling are now considered insignificant (Tedeschi &
Calhoun, 2004). My finding of “letting go” supports the understanding that relinquishing control is often a part of the experience of cancer survivors (Foley et al., 2006).

A number of participants also embodied the breast cancer dragon boating principle of “never give up.” The catchphrase had taken on deep meaning for several of the women and was now part of a broad philosophy for daily life. Participant experience in my study reflected the finding that a constituent of never giving in was accepting the challenge to go on living (Jensen et al., 2000). Participants were determined to “keep trying” and find a way through trials. Most of the participants successfully balanced determination with personal boundaries.

The paradox of “letting go” and “never giving up” being embodied as outlooks in the same participant speaks to the commonality of paradox in posttraumatic growth. By nature posttraumatic growth is paradoxical as that the growth is rooted in loss (Tedeschi & Calhoun, 2004). Within areas of growth such as altered outlook on life, the paradox is evident in the nuanced expressions of mindful recovery.

A surprising finding was that participants in my study had developed not only a willingness to take chances, but a level of comfort with such actions. In speaking of human potential philosopher John O’Donohue (2004) asserts that risk is tied to growth. In taking risks one is not stagnant, but rather, one is challenging circumstances. Part of the process of cancer survivorship is the ability of survivors to act in the face of great risk, and this contributes to the social perception of survivor as “hero,” (Charmaz, 1999). Women in my study were seasoned dragon boaters, with the exception of Heather, and all were a few years beyond their cancer diagnosis. By this point in their cancer trajectory, calculated risk taking had become part of their normal routine to the point that they reflected on a number of past fears and anxieties, which now seemed unthreatening. They had shifted into new levels of confidence in dealing with uncertainty.

The need to frame events in a hopeful way and find the humour in situations, as demonstrated by my participants, is a known part of managing the trauma experience. Finding the positive is a coping strategy for women who had experienced breast cancer (E. Taylor, 2000). Developing a positive attitude is part of the active struggle to overcome death and other threats associated with cancer (Jensen et al., 2000). In relating their experiences with cancer and dragon boating, participants noted small “blessings”
and positives that had emerged. Throughout the interviews with all the women, jokes were made about personal experience and laughter was common as they reflected on challenging moments. Coping through the use of humour has been associated with decreasing levels of distress in women with breast cancer (Carver et al., 1993). During interviews, it often seemed humour helped women to become at ease with painful or awkward memories.

Reflecting on the importance women placed on a positive frame of mind I was reminded of what Holland and Lewis (2001) refer to as “the tyranny of positive thinking,” (p. 14). Naturally, the cancer experience is punctuated by fears and uncertainty. Nevertheless, mainstream belief in the necessity of cancer survivors having a positive attitude, particularly in order for them to survive cancer, may invalidate survivor experiences. Part of the social expectation of “spunky survivorship” (Sinding & Gray, 2005), which is often imposed on breast cancer dragon boaters, is that women will frame their cancer experience heroically and maintain an upbeat approach to life. Women with breast cancer are often under significant social pressure to conform to stereotypes of successful recovery that occlude the often painful reality of their cancer experience (Breast Cancer Action, 2007). Perhaps being in a concentrated breast cancer culture such as dragon boating increased the social pressure. I initially wondered if participants were providing overly positive renderings of their stories and feelings. Nevertheless, I came to realize that, like their metaphor use, the women had often personalized social expectations around cancer. In particular, the positive reframing the women did often reflected the new meaning they had found and their deeper engagement with life.

**Confronting painful experience**

As revealed in interviews, a unique aspect of breast cancer dragon boating was the opportunity to express and engage painful experiences, such as grief or loss, fears, and intense emotions. Mitchell and Nielson (2002) presented limited evidence that breast cancer dragon boating offered women in their study a means to face their cancer and to potentially deal with ramifications of the disease experience. Participants in my study spoke of diverse ways breast cancer dragon boating had allowed them to face cancer, and
participants also described relief at facing general life issues, such as phobias that had restricted them for years.

Within the breast cancer dragon environment, participants had the chance to honour difficult aspects of lived experience, especially through breast cancer related rituals. Part of achieving trauma recovery is engagement in mourning and acknowledging painful memories or losses that are often invisible (Herman, 1997). Notably, the carnation ceremony made visible both the reality of survival for participants and the death of loved ones. Included among the many functions of group rituals are: to gain a sense of connection with others; to honour cycles of life and death; and to provide comfort and peace regarding difficult life events (Kelly, 2000). The carnation ceremony stood out for all the participants as a poignant means to connect with feelings of grief and loss about cancer - both their own personal losses, and the loss of people they cared about. A function of social rituals is to serve as gateways to beginning and endings (Bolen, 1996). The carnation ceremony, candlelight vigils and other breast cancer rituals mentioned by participants were outside of the hectic pace of racing and were times of reflection and acknowledgment. If disease, such as cancer, is viewed as a disruption in life’s harmony (Achterberg, Dossey, & Kolkmeier, 1994) then the communal ritual of the carnation ceremony is a means to restore balance and bring closure. Further, Tedeschi and Calhoun (2004) assert that posttraumatic growth needs to be actively maintained. The emotions invoked by the carnation ceremony and other breast cancer specific events had the potential to aid growth for participants by means of active engagement with grief. Overall, acknowledgment of personal losses within dragon boating assisted the women in my study to help restore harmony and balance after trauma.

It is important to note that unlike participants in Unruh and Elvin’s (2004) study, women in my study were able to take an active role in honouring and grieving teammates lost to cancer. Participants in Unruh and Elvin’s study were troubled by cancer recurrences and deaths of teammates, and noted their own lack of “skills” to cope and lack of team “rituals” to honour fallen teammates. In comparison, participants in my study were saddened by the loss of teammates, but they all seemed to be able to incorporate such losses into their experience and move on. Participants described how as part of their teams they had means available to them to honour lost teammates and loss
generally; this was a large reason for managing grief. For example, Sarah, Callie, and Nel’s team had a private team ritual for deceased teammates. Heather, Dee, and Trudy’s team had team circles to cry together, and to cheer each other up; as well they had plaques on the boat honouring teammates.

Unruh and Elvin (2004) speculated that the team in their study may have unwittingly suppressed troubling aspects of the cancer experience because of the focus on reframing the cancer experience in a positive light. This was not the case in my study where death was a visible part of the experience. There was not only a supportive dragon boating environment, but, also participants had individual means within their specific team environment to address the upheaval of cancer related illness and death of teammates.

Throughout interviews, participants touched on how facing deeply held fears often lead to a significant shift in the adaptive process of both cancer and dragon boating. Confronting personal fears can be a powerful turning point or moment of transformation for breast cancer survivors (E. Taylor, 2000). A cancer fear for participants in my study was that of recurrence, which is consistent with research findings that fear of recurrence is widespread in breast cancer survivors (Wade, Nehmy, & Kozcwara, 2005). A review of existing research suggested that 60 to 99 percent of women with breast cancer fear recurrence (Johnson Vickberg, 2001). A general fear many of the participants had to confront in order to even participate was a fear of water/drowning. Philosopher John O’Donohue (2004) speculates that to realize the transformative value of our personal demons or issues, one needs to “lay aside your fear and take the risk of loss and change that every inner encounter offers” (p. 100). Breast cancer dragon boating was a context where participants knew fears would be tested, and when women found themselves in direct confrontation of those fears they slowly made meaningful inroads towards personal growth.

Within participant stories was the transformative process of emotional release. Like the parallel process of awakening after cancer, the open expression of emotions by participants within dragon boating was a form of psychosocial release that alleviated suffering. Emotional expression is known to mediate many of the negative psychosocial aspects of breast cancer (Classen & Butler, 2001). Developing outlets for emotional
expression is one form of active coping, a coping style that tends to be effective when dealing with illness (Stanton et al., 2007). Emotions were an integral part of the breast cancer dragon boating experience for participants, a finding that is consistent with that of Mitchell and Nielsen’s (2002) study on breast cancer dragon boating.

**Rebuilding identity**

Trauma commonly results in a fundamental shift in the sense of self or identity and psychosocial healing from breast cancer, because traumatic elements of disease experience involve a negotiation between former ideas around self and new realities. Trauma involves suffering which, “poses existential problems of identity and continuity of self” (Charmaz, 1999, p. 3). Breast cancer, like other diseases, challenges sufferers to accommodate the disease into ideas of self. A common challenge can be the shift from being a cancer “patient,” a fairly passive subject position, to that of a survivor (Parry, 2007), who is re-entering her life. Following trauma, survivors are faced with becoming who they want to be. If fully engaged this process is a lengthy one of recognizing the elements of oneself that are most valued and integrating these elements into a new sense of self (Herman, 1997). Overall, breast cancer may start an intense process of self-discovery.

As part of self-discovery as a dragon boater, rebuilding identity was a significant issue for women in my study. They all had distinct notions on what it meant to be a breast cancer dragon boater and breast cancer survivor, versus the ways they perceived themselves during earlier times in or before the cancer trajectory. This finding is consistent with the fact that cancer survivors often describe life as different than before cancer (Brennan, 2001). Like women in Parry’s (2007) study, participation in breast cancer dragon boating for most women in my study eased their transition into life after ending cancer treatment. As part of survivorship it is common for women who have had breast cancer to experience new learning leading to increased self-knowledge (E. Taylor, 2000). In my study participant stories were ones of small steps towards redefined identity, and the multiple adjustments made along the way. In terms of social labels, most of the women engaged in a gradual progression from being an active cancer patient to a
perceived-to-be-well loved one back at home to a support group member in a local community group to being a dragon boater.

All but one of the women in my study evoked Herman’s final stage of trauma recovery (1997), which involves integration of valued parts of self into a new notion of identity. Women in this stage of recovery require daring and imagination to reconceptualize new ways of being. Fortunately, women in this stage tend be “adventurous” while at the same time their life is starting to settle. The fact that some women in my study were several years post-cancer and were continuing to refine identity when they recently entered breast cancer dragon boating coincides with the finding that identity reconstruction is a prolonged process which can require many years as it involves hard work on the self (Jordens, Little, Paul, & Sayers, 2001). The novelty of the breast cancer dragon boating role greatly assisted women in my study in their formation of a new self.

Herman’s (1997) theory helps to explain how Trudy was unable to fully embrace being a breast cancer dragon boater. Trudy was struggling with several recent crises that left her immobilized regarding creative output. In the language of Reeve’s (2001) energy management model she did not have enough energy free to engage in healing, as most of her energy was consumed by grieving. Moving into active reconstruction of identity is costly for both the effort it requires and the risks. According to Herman (1997), to move out of a “victim” identity (e.g., a passive patient identity), is to take a large chance and to risk disappointment. Trudy had the desire to take chances and had made some steps in finding herself since the cancer diagnosis, but was too vulnerable to deeply engage in such difficult work.

The public aspect of being a dragon boater offers a strong foundation for rebuilding self because it allows women a sense of connection with something much larger than themselves (Herman, 1997). The “breast cancer dragon boater” identity is a public one signalling visibility within the local community. When the participants in my study entered into breast cancer dragon boating, their experiences of suffering became visible to fellow paddlers and to the public, if only at the superficial level of admitting to having breast cancer. As documented in my study, “breast cancer dragon boater” has become a celebrated social identity, which in some ways is an archetype of full recovery
from cancer. In mainstream culture breast cancer survivors are often viewed as symbols of hope (King, 2004), and participants in my study embraced the public dragon boater identity as a means to prove a sense of aliveness and wellness after the cancer diagnosis. Claiming the boater identity in this way can be seen as resistance against notions of cancer equalling illness. A benefit of “spunky survivorship,” which my data shows to be part of “breast cancer dragon boater” identity, is that it challenges ideas of the survivor as unwell and associated with death (Sinding, & Gray, 2005).

A part of the public aspect of breast cancer dragon boating that impacted participants was the perception of the paddler as hero, whether participants embraced this role identity or not. Breast cancer dragon boating is a unique example of suffering offering an opportunity “to play out the myth of hero who emerges victorious against all odds” (Charmaz, 1999, p. 368). By being “the hero” a survivor validates their chronic condition by raising the moral status of their suffering (Charmaz, 1999) to that of a deserving illness survivor who has overcome great adversity. The prevalence of “paddler as hero” concept in modern society was evident in that whether participants in my study identified as hero or not they all at some point defined their identity against this standard. Interestingly, participant experiences were validated through dragon boating at the same time they were losing support in private circles.

Related to identity and pride, Mitchell et al. (2007) noted that because “dragon boat races occur in a public forum [it] also builds a sense of accomplishment and pride” (p. 135). The public identity available to participants was important in my study, yet my understanding of their stories was that pride was often associated with personal achievement and overcoming obstacles. S. Taylor (1983) found that trauma is often associated with a drop in self-regard; likewise, as part of adjustment, many people seek ways for achieving self-enhancement. For participants in my study joining a breast cancer dragon boat team can be seen as an effort to gain pride from a previously painful and sometimes humiliating experience. The public aspect of dragon boating added to and/or confirmed their new sense of pride.

The theory that the more severe the trauma, the greater the need to adjust identity or concepts of self (Tedeschi & Calhoun, 2004) was supported in my study. The participant who had several bouts of cancer and invasive surgeries spoke of more identity
related issues than did the other participants. After undergoing both chemotherapy and a severe mastectomy surgery involving removal of part of her chest wall, Nel struggled significantly with her sense of womanhood. Nel had believed that with the loss of her hair and breast she was no longer a woman. Impaired body image is a known psychosocial problem faced by breast cancer survivors (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998). Additionally, surgeries leading to visible changes in appearance, including mastectomies, result in increased stigmatization (Holland & Lewis, 2001). For Nel, a sense of femininity had been a key part of her self. Following cancer she was in despair about how to reclaim the sense of femininity. The more that fundamental parts of one’s assumptive world are challenged, including assumptions about one’s identity, the greater the sense of crisis one will experience (Janoff-Bulman, 1992, as cited in Tedeschi & Calhoun, 2004, p. 5). Not only was Nel’s identity challenged by the degree of physical trauma, but also that of emotional trauma. By participation in breast cancer dragon boating she found a new means to “be a powerful woman.” By engaging in this experience, she eventually became her community’s “dragon lady.” As consistent with Brennan (2001), by revaluating her identity Nel discovered a level of personal control and affirmed her sense of self.

Although the exact ways that participants grew as a result of participation in breast cancer dragon boating were highly individual, it was common for the women to speak of becoming a “better” or “stronger” person. For each participant in my study the meaning of “better” or “stronger” varied greatly, including physical strength, emotional resiliency, and being more empathetic. A sense of improved personal strength is a domain of posttraumatic growth (Tedeschi & Calhoun, 2004). One aspect of this is that survivors often report an amplification of pre-existing inner strengths because of the cancer experience (Foley et al, 2006). The sense of strength women obtained from dragon boating was often built on a fledgling sense of personal power after surviving breast cancer.

**Spiritual engagement**

As illustrated in participant narratives, part of what makes breast cancer dragon boating subculture and sport unique is the overt spiritual elements. As discussed in the
first chapter of this thesis, a defining element of spirituality is “connectedness and being in relationship with the inanimate and animate; in the larger universe” (Canadian Society for Spirituality and Social Work, 2007, Principles section, bullet 2, pt. 2). The social context of breast cancer dragon boating is layered with levels of meaning, that participants could engage with according to their needs and comfort level with spiritual issues. Breast cancer dragon boating is an uncommon modern community where spirituality is a recognizable and vibrant part of the structure.

Within the trauma literature and psychosocial oncology practice there is growing recognition that part of the multifaceted nature of adjustment to trauma, such as cancer, is altered spirituality. The process of suffering can be a pathway to spirituality (Chiu, 2000). E. Taylor (2000) noted that a benefit breast cancer survivors attributed to their disease experience was an intensified awareness of spiritual qualities of life, including new meaning to life. As part of their online emotional support program, Cancer Care (2006) encourages “strengthening the spirit,” where cancer survivors connect with personal spirituality and its healing aspects. Overall, there is an increasing recognition of psychospiritual elements of trauma.

In their interviews, participants provided rich descriptions of spiritual aspects of breast cancer dragon boating subculture. Basic dragon boating is an ancient Chinese sport, saturated with meaning, often in the form of ritual or symbols. Within participant stories were descriptions of how the typical dragon boating festival is opened by Taoist priests who first bless the five elements in an ornate ritual of acknowledging unseen forces and then awaken the slumbering dragon spirits in each boat by dotting the eyes with paint. On the foundation of these Chinese traditions breast cancer dragon boating has added the modern mythic or heroic elements of breast cancer social discourses. Participants in my study not only developed new personal power through dragon boating, but had a mythic social context in which to enact those new strengths in. The mythic and spiritual elements of the dragon boating experience offered participants further horizons for psychosocial wellness.

The symbols of breast cancer dragon boating offered participants a mode of personal grounding. There is potential within breast cancer dragon boating for women to find great meaning in their life, thus escaping the sense of a deep inner void or
"existential vacuum," as described by Frankl (2006). From such broad-scale symbols as the dragon and the "warrior paddler," women had the option to formulate an identity grounded in myths that were also flexible enough to reflect deep personal truths. The metaphors within breast cancer dragon boating are another form of symbols utilized by the women. Teucher (2003) argues that metaphor is a "fundamental human response to crisis," (Cancer Narratives and Metaphors section, para. 3) and that metaphors are existentially important in times of crisis as they are a means to explain a reality that is beyond words. Consistent with Teucher (2003), women in my study used symbolic language to communicate the suffering they experienced from cancer and subsequent efforts of healing, which were often emotionally taxing. A dimension of this for Sarah was the use of metaphor to discuss frightening aspects of her cancer treatments. Overall, for my participants the symbols of dragon boating were powerful tools for the expression of deep personal beliefs in the face of cancer.

In the section “Confronting painful experience,” I discussed rituals in relation to their function of honouring loss. Rituals were also important to some participants in terms of spiritual engagement. Ritual is a distinctive facet of the breast cancer dragon boating experience, and there has been academic interest in understanding the meaning of those rituals to paddlers. Regarding her study (Unruh & Elvin, 2004), Unruh has noted that she had reason to wonder about rituals and symbols, including possible connections with spirituality but data wasn’t clear on meaning for participants (A. Unruh, personal communication, April 1, 2006). In my study, one of the spiritual elements of rituals described by participants was spiritual assistance; for example, there was Dee’s description of how after her team’s boat had been blessed, she was now a "warrior woman."

A surprise finding in my study was the degree of ownership women had in regard to rituals specific to breast cancer dragon boaters, notably the carnation ceremony. Typically, they had less regard for the traditional rituals of dragon boating, because traditional rituals were perceived as not directly relating to the cancer experience.

Part of the connection for participants may be that the carnation ceremony and allied breast cancer rituals are forms of “self-generated ritual,” or rituals created by groups of individuals based on their needs rather than being rooted in culture or history.
(Achterberg et al., 1994). In other words, the breast cancer rituals discussed by participants were created in response to the needs and beliefs of breast cancer survivors. Ideally for existential healing, rituals are external expressions of private experience (Bolen, 1998). The carnation ceremony does not come from a distant cultural tradition, but instead generated within the current social climate to reflect modern needs of breast cancer survivors. The power of non-traditional ritual derives from, “their potential for symbolic meaning and their capacity to touch emotions, to invoke the sacred,” (Bolen, 1998, p. 158). For participants in this study, breast-cancer specific rituals were deeply revered in part for connecting participants to existential issues of their cancer experience. One example is that such rituals provide a reminder of mortality - their own mortality and that of loved ones.

In addition to speaking of the carnation ceremony, some women spoke of the power of ritualistic words such as team mottos or chants. Like ritual events, the ritual words appear to be potent reminders to the women of where they have been, how far they have come, and the importance of continued growth. For example, “dragon power” was typically used in direct contrast to past feelings of vulnerability around cancer. Bolen (1998) in discussing the value attributed to ritual words noted, “They are affirmations of what we believe and want to be so. They draw upon memory and past meaning, and have power in themselves to move us emotionally and spiritually” (p. 175). As an example of the meaning of such words to participants, Dee presented me with a team bracelet featuring her team’s motto as a token of good will and connection.

In addition to the mythic elements of breast cancer dragon boating which increase participants’ spiritual engagement, there were the peaceful, reflective elements of paddling. A means to become more spiritually attuned is to retreat to natural settings or other spaces one finds spiritual (Cancer Care, 2006). With the “otherness” of the physical boat space and the natural settings in which women paddled there was opportunity for operating outside of the regular pace of one’s life, on a more meditative plane. An example is Callie’s moving description of her experience in the boat as her team would paddle out to their practice area, including the recollection that all she would hear “is the paddles going in.”
Surprisingly most participants expressed meaningful connections with not only the beauty of the West Coast paddling experience, but the eagles that are such a living presence in those places. This demonstrated to me the diversity and range of deep connections that women were experiencing through dragon boating.

To summarize, breast cancer dragon boating involved deepened connections with life and personal meaning. In the words of Dee, one aspect of boating was “drawing on something you may not understand.”

Section Two: Connections Across Themes

In the previous section I discussed particular issues relevant to distinct themes. In this section I elaborate themes by presenting significant interconnections among them: search for meaning and psychosocial growth. I highlight the way dimensions of themes interact to contribute to participant’s general experience and adjustment to cancer.

An increasingly extensive body of research shows “the experience of ... living with breast cancer (is) a path from decisive tragedy to a new orientation” (Arman & Rehnsfeldt, 2003, p. 516). The path, however, is not a linear one. Recovery from trauma is often tumultuous and survivors are faced with complex choices. Breast cancer survivors tend to view their cancer experience as a challenge that has helped them to develop new insight into their life (Jensen et al., 2000). Breast cancer dragon boating was chosen as a “path” for participants in my study and out of participation in boating came refined psychosocial adjustment.

Findings from my study punctuate the notion that survivorship is a “dynamic, life-long process” (Pelussi, 1997, p. 24). Trauma recovery is never complete; the impact resonates throughout the survivor’s lifecycle (Herman, 1997). For instance, breast cancer survivors often experience a degree of uncertainty long after their treatments have concluded (Thomas-MacLean, 2004), and face the possibility of several late medical effects (IOM, 2005). Even for women who have confronted their issues, the struggle with suffering has no end (Arman & Rehnsfeldt, 2003).

The findings of my study and of the other psychosocial research studies on breast cancer dragon boating collectively describe the new freedoms and opportunities available
to paddlers and the corresponding sense of aliveness. Breast cancer dragon boating offers active survivorship, where women can find novel ways to cope with the ramifications of cancer, and improve well-being. In discussing the original intentions of breast cancer dragon boating, sport founder Dr. Don McKenzie emphasized how the sport helped to challenge the presumption of restricted wellness and activity for cancer survivors (McKenzie, 1998). Women of different ages, cancer trajectories, years of survivorship, and life circumstances have all reported enhanced wellness from breast cancer dragon boating participation (e.g., Mitchell & Nielsen, 2002; Parry, 2007).

In numerous ways breast cancer dragon boating allowed women in my study to move past losses after cancer, toward healing. The energy management model (Reeves, 2001) suggests that people have a finite amount of psychosocial energy and when one is grieving a large portion of that energy is consumed by the loss experience. Slowly individuals shift from basic survival after trauma to the ability for life enhancement. There is always a part of their energy reserve impacted by trauma, but upon healing it is no longer restrictive. Life enhancement is not a “given,” and involves a committed struggle with personal issues. With breast cancer dragon boating, the participants in my study found a supportive context to address their losses from cancer openly, and to create possibilities for change.

According to Herman (1997), in order to engage in healing the survivor of trauma “must be the author and arbiter of her own recovery” (p. 133). From the time of initial diagnosis cancer survivors are constantly faced with decisions as to next steps (IOM, 2005). If trauma survivors are able to face the tragedy of their experience, they can move from “why?” and “why me?” questions to action-oriented questions such as, “Where do I go from here?” (E. Taylor, 2000). For my participants, to join a breast cancer dragon boat team was part of a larger effort to find new directions and to convert the darkness or traumatic elements of the cancer experience into one of light or wellness, a process described by E. Taylor (2000) in relation to breast cancer survivors. Choosing to participate in dragon boating was a survivor directed effort, and participation in team activities provided further opportunity for meaningful recovery choices. In my study it was clear that participants involved with dragon boating were able to take an active role in two broad processes: “a search for meaning” and “psychosocial growth” from cancer.
Meaning

Meaning can be roughly conceptualized as “a sense of coherence” (Yalom, 1980). Cassel (as cited in Fife & Taylor, 1995) noted, “personal meaning is a fundamental dimension of personhood, and there can be no understanding of human illness or suffering without taking it into account,” (p. 1). In my study it was clear that to be a breast cancer dragon boater was to exist in a complex matrix of meaning. Participants could draw from a diversity of elements within dragon boating culture to construct new meanings as breast cancer survivors. My findings are consistent with the belief of Fife and Taylor (1995) that: “meanings evolve throughout the illness trajectory as circumstances change and are unique to each individual” (p. 1).

a) Worthwhile project. My study supported the idea that trauma, for some individuals, can become a reason to take on a cause-specific project related to that trauma, which in turn can eventually cause individuals to have a different meaning to their trauma histories. Thompson and Janigian (1988) reported that there was “anecdotal evidence that, for some individuals, a traumatic experience becomes an occasion for a worthwhile project” (p. 271) (e.g., a woman founded Mothers Against Drunk Drivers because of the loss of her child). Five of the six women in my study played a part in forming the breast cancer dragon boat teams in their local areas. Those five participants spoke of how their role in the forming of those teams caused them to view their cancer differently, and to take on new challenges in their life after cancer treatment. For the one participant who joined breast cancer dragon boating as a paddler, it was an extension of the breast cancer activities she had been part of for several years, a way to keep challenging her ideas of her cancer experience. The importance of such projects is that, “for the individuals involved, the potential good works of these organizations may give a different meaning to the events that gave rise to them” (Thompson & Janigian, 1988, p. 271). Overall, for the women in my study breast cancer dragon boating experience was a way to create new meanings around their breast cancer experience.

b) Reframing. As I saw with my dragon boating participants, a cancer diagnosis has the potential to alter the meaning of life (IOM, 2005). Highly negative events can adversely impact a person’s life scheme or the cognitive representation of one’s life that
provides order and purpose (Thompson, & Janigian, 1988). Once a life scheme has been disrupted, the world is often seen as less orderly and more threatening.

As documented in existing psychosocial cancer research the search for meaning is a key element of cancer survivorship (E. Taylor, 1995). The search for meaning can be defined as:

an effort to understand the event: why it happened and what impact it has had ... [and] attempts to answer the question (s), What Is the significance of the event? [and] What caused the event to happen? [and] What does my life mean now?" (S. Taylor, 1983, p. 1161).

Cancer may prompt survivors to find meaning through reworking priorities and reconfiguring life as to be more satisfying (S. Taylor, 1983). All of the participants in my study discussed ways that breast cancer dragon boating allowed them to frame the cancer experience and subsequent life experiences in a more positive light than before. The search for meaning that results in positive attributions is adaptive, and can be viewed as a functional coping strategy (E. Taylor, 2000).

c) Structure. On a pragmatic level, breast cancer dragon boating offered participants in my study a level of structure, which is a counter-balance to the uncertainties that come with cancer. Structure is offered at the level of team organization: being a team member means conforming to certain standards of conduct. More importantly, within dragon boating there are numerous models of meaningful life for cancer survivors. Part of the search for meaning is the effort to integrate the disorder of the illness experience into an orderly new model of life, which, if successful, has the benefit of empowering the survivor (E. Taylor, 1995). Participants in my study were surrounded by women who were all engaged in efforts to establish meaning from the cancer experience. From their peer group participants women in my study had powerful examples of how they too could find deep personal significance in the cancer experience.

d) Myths. The mythic fabric of breast cancer dragon boating also helped to provide participants in this study with a sense of meaning post-cancer. Breast cancer dragon boating exists in a modern culture where many of the master narratives or myths that once provided individuals with direction in times of crisis have been lost (Glavin, 2007). Contrary to modern perception, myths by definition are not stories of falsehood. Myths are meaning-making narratives that document essences of human experience, deep
universal truths (Harpur, 2004). Embedded within myths are clues about dealing with
“problematic human predicament” (Armstrong, 2006, p. 6); there is not so much a sense
of how to do something but how to deal with it. Because of this coping element Campbell
boating weaves modern mythic narratives of breast cancer survivorship and ancient
Chinese existential traditions, such as the dragon awakening from slumber, into a guiding
tale of successful life as a cancer survivor, which is dynamic enough that it can be
interpreted by individual paddlers in ways that suit their personal needs. It provides
“horizons” (Campbell, 2004) for cancer survivors to see beyond their current situation to
further possibilities.

e) Metaphors. With cancer survivorship metaphors are often used in the struggle
for meaning (Teucher, 2003). Participants in my study often used metaphors when
attempting to express the depth of their experience. This is consistent with McNicoll and
Doyle (2003)”s finding of extensive metaphor usage by members of pioneer team Abreast
in a Boat. Cancer is a difficult experience to express in words, but survivors such as my
participants are compelled to discuss it. Metaphors can be a critical expressive tool, they
can “function as vivid, embodied gestures that mediate between lived experience and
familiar everyday life” (Teucher, 2003, Cancer Narratives and Metaphors section, para. 3). Additionally, affirming cancer metaphors may serve as powerful counter-metaphors
for the many negative things cancer can represent in our society, such as death (Sontag,
2001), or disability. Participants in my study used uplifting breast cancer dragon boating
metaphors in this way; cancer was often associated with new life and enhanced personal
strength.

When discussing cancer metaphors and meaning it is important to note the
potential danger of generalized metaphors. Frank (1997) gives examples of how
metaphor usage can be powerful for healing trauma, but notes that the generalization of
metaphors and the imposition of one’s metaphors on others may interfere with the
personal work of self-stories or creating stories about one’s experiences. In my study the
participants existed within breast cancer dragon boating networks saturated with icons
and language about “spunky survivorship” (Sinding & Gray, 2005). Sinding and Gray
(2005) discuss “spunky survivorship” as being the new standard of social roles for breast
cancer. They propose that the “spunky survivorship” role may impose unrealistic expectations on women survivors. Inherent in the metaphor use by participants in my study was the paradoxical presence of both stereotype and deep personal meaning. Interestingly, women in my study did not accept stereotyped metaphors readily and often personalized aspects of breast cancer dragon boating culture that they related to. By doing so they tended to feel empowered not oppressed. My finding is consistent with the idea that “women need to take on those who commodify a disease, but at the same time, recognize what breast cancer survivors have made use of in these spaces women have worked to create” (Milden, 2005, p. 98). Participants in my study often found great meaning in the metaphors inherent in breast cancer dragon boating culture.

Psychosocial Growth

Breast cancer dragon boating is a challenging experience that - like cancer - consists of ongoing adverse conditions and transitions that test participants. The aftermath of cancer involves “a long process of adaptation to multiple threats and novel experiences” (Brennan, 2001, p. 3). The first year following a breast cancer diagnosis is marked by “intense personal and interpersonal challenges” that include complex decision making (Stanton et al., 2002, p. 93). Generally the cancer experience involves a series of transitions as individuals adapt to the demands of their condition (e.g., Veach et al., 2002). Such transitions involve learning new approaches to life (E. Taylor, 2000). Breast cancer dragon boating membership was one of the decisions made by participants, and became part of efforts to engage new life after active treatment. Breast cancer dragon boating was also a parallel process of adaptation, in that it combined learning a new sport with immersion into a well-developed culture. With both dragon boating sport and cancer as chronic illness there is the risk of spiralling consequences, yet there is also the potential of psychosocial growth through active struggles with powerlessness and uncertainty.

Regarding trauma, especially breast cancer, there is a large body of academic literature on adjustment and allied concepts, such as psychosocial transition (Parkes, 1971, as cited in Cordova et al., 2001a, p. 176) and posttraumatic growth (Tedeschi & Calhoun, 2004). There are a number of models and theories that elaborate on how
survivors of trauma tend not to experience abnormal levels of psychosocial distress and in contrast often experience meaningful personal change. Although the narratives of women in my study were multi-layered and not easily simplified, it can be said that in a broad sense their stories were ones of profound personal change and successful recovery from the trauma of cancer.

**a) Turning points.** Breast cancer dragon boating involvement resulted in a significant change for my participants in the trajectory of their cancer recovery. Turning points are common features of breast cancer narratives (Arman & Rehnsfeldt, 2003), where survivors experience something that causes them to shift perspective and engage the transforming process of personal change. For Sarah, she found dragon boating “really shocks,” shifting her life from a journey to an adventure. E. Taylor (2000) found that turning points require a conscious decision to face the personal tragedy and to ease into a new passage of life. Just as cancer had been a turning point, so was breast cancer dragon boating. Participants often differentiated their life before and after dragon boating. The breast cancer dragon boating experience involved a refinement of recovery efforts, whether a participant progressed from being emotionally charged by the “fallout” of cancer to being psychosocially comfortable, such as happened for Dee, or whether she went from being well-adjusted to thriving, as did Callie.

**b) Active engagement.** In my study participants engaged in a range of activities such as facing fears, devising solutions for dilemmas and making mindful choices that all opened doorways to personal growth. In the words of Nel, “the boat is all about choosing to find your life again.” A feature of successful recovery or adaptive survivorship is the use of active coping styles (Stanton et al., 2002), and such coping was an integral part of participant stories. In general, survivors of trauma can react to stressors by choosing either approach or avoidance. Active engagement with stressors has been associated with decreased distress in cancer survivors (e.g. Stanton et al., 2007). To restore wholeness after trauma a survivor needs to “voluntarily enter the struggle of suffering” (Arman & Rehnsfeldt, 2003, p. 522). In her model of growth demonstrated by breast cancer survivors E. Taylor (2000) talks of the need to: encounter darkness or to face the trauma, convert light or find possibilities, and reflect light or extend out to help others. The survivor of trauma is actively engaged in processes of transforming her tragedy.
c) **Fit with basic principles of posttraumatic growth (PTG).** Findings of my study resonate with basic tenets of the posttraumatic growth model of Tedeschi and Calhoun (2004). Significantly, all the participants spoke of how growth after trauma is an ongoing process, one of choices and revaluation. For instance, they all spoke of steps they took that became the building blocks of further development, whether the outcome was successful or not. Their stories were also characterized by paradoxes, such as raw anger at having had cancer but at the same time also a deep appreciation for the experience.

In regard to the domains of posttraumatic growth there were a number of ways the findings were consistent. First, all but one of the participants had a greater appreciation for life because of both the cancer and breast cancer dragon boating experience. All the participants had shifted their approach to life. Some women spoke of their good fortune throughout the cancer experience. Second, the participants did have improved social relationships. They spoke of deeper connections with others, and of gaining enhanced empathy. One participant, Callie, marvelled at her new compassion for people of limited or lesser ability. Third, all of the participants spoke of new strength which started with having cancer and blossomed once they were dragon boaters. Finally, connected with new strength the women recognized a number of new possibilities in their lives. The role of breast cancer dragon boater opened up many doors and satisfied a desire for new paths that came out of the cancer experience.

**d) Disagreement with PTG.** Participants in my study did not experience the posttraumatic growth domain of spiritual development as postulated by Tedeschi and Calhoun (2004). Participants through breast cancer dragon boating sport did not purposively engage with existential issues nor did they experience enhanced religiosiy. Participants in my study found themselves experiencing a more abstract engagement with spiritual issues and a sense of connectedness to something greater than themselves. Participant struggles with trauma and corresponding enhanced engagement with life, including spiritual aspects, correspond with the experience of *becoming suffering* (Arman & Rehnsfeldt, 2003). The ontological model of health and suffering (Arman & Rehnsfeldt, 2003) elaborates a nuanced struggle with suffering that is existential in nature: the individual has suffering, for example from trauma; which may be followed by
being suffering, where values are altered and a new openness for life emerges. By means of encounters with the consequences of trauma, survivors can reach a state of bearable suffering in which they may enjoy a new level of wholeness. Issues of spirituality are discussed further under the spiritual engagement theme.

The issue with spirituality and posttraumatic growth speaks to a larger issue regarding the Tedeschi and Calhoun (2004) model and my findings: that the complex issues faced by my participants do not fit as well with models of growth that are linear in some way. Models such as those proposed by Arman and Rehnsfeldt, 2003, described above, and E. Taylor (2000) involve spiralling, interconnected processes that defy a linear conceptualization of moving from tragedy to growth. Participants in my study described experiences that were highly convoluted because there were multiple layers of experience. Reflection on those experiences eventually led to growth. Just as spirituality was not confined to a narrow window of spiritual experience for participants, neither was their other experiences of growth.

e) Community. A key element of participant narratives that is not elaborated by the posttraumatic growth model is community. Support groups and allied groups often foster a strong sense of community, which counteracts the isolation individuals with cancer often experience (Ussher et al., 2006). To belong within a group or community is supportive for trauma recovery (Herman, 1997). At the core of participant experience in my study was the creation and maintenance of community: notably, the building of connections with other wellness-focused survivors and the creation of organized social ties. My findings suggest an expansion of the posttraumatic growth model beyond individual variables to the collective elements of community.

Breast cancer dragon boating exists within the larger social context of an “age of extinctions” (Glavin, 2007), which includes communities in a state of flux and often collapse. Regarding modern mainstream culture it has been speculated that “our hunger to belong may gradually assist us in awakening new and unexpected possibilities of community and friendship” (O’Donohue, 2002, p. xxv). Breast cancer dragon boating can be seen a poignant example of an emerging community of breast cancer survivors, and a community primarily driven by survivors, who by default know their needs the best. In my study, all participants but one were involved in the creation of the teams they now
paddle with, and all the women in my study were compelled by a need to end their feelings of isolation after cancer treatment. In stark contrast to the trend that “society is losing the art of fostering community” (O’Donohue, 2002, p. xxiv), participants in my study were building community, both within the breast cancer subculture of dragon boating and within their local communities through volunteerism.

To understand the scope of community supporting initiatives and breast cancer dragon boating, it is important to consider the multitude of communities with which dragon boating actively intersects. At a societal level breast cancer dragon boating is a part of the larger cancer survivor movement and corresponding breast cancer subculture that has emerged in the last twenty years in North America. At the intersection of these two movements, with its “heroes,” “fighting spirit,” and “war cries,” breast cancer dragon boating culture can be viewed as the epitome of the concept of battle metaphors and cancer as discussed by Sontag (2001). Women involved with breast cancer dragon boating are part of a “global sisterhood” of not only other paddlers, but breast cancer survivors in general. On a regional level, breast cancer dragon boat societies are often a public part of their local communities: at public workshops, community celebration days, and perhaps, if the community is large enough, water craft festivals. The importance of community in the breast cancer dragon boating experience for survivors is being increasingly recognized (Mitchell et al., 2007; Parry, 2007).

Dragon boating was a powerful “alternative vision” for community (Ife, 2002), for participants in my study and that allure is part of the activity’s current appeal. It was true for women in this study that, “for most people attachments to particular communities of belonging and activism run deep; they are our sites of hope in a difficult world,” (Joseph, 2002, p. ix). From the first team created to the teams my participants are on, breast cancer dragon boating has often been and continues to be a powerful source of hope for paddlers. For my participants to join a dragon boat team as survivors was an act of hope, and it was an active step forward as breast cancer survivors. Being on a dragon boat inspires hope because teams often focus on affirming goals, e.g., paddling well to demonstrate cancer has no control over them. Further, the teams in this study like the vast majority of teams in Canada were grassroots efforts and were started by survivors as
a way to rally against cancer. Out of such mobilization emerged a strong culture that provides the “capacity to aspire” (Epidural, 2004), both for the women within that culture and for the women who look to it for guidance. Overall, participants in my study as breast cancer dragon boaters were deeply enmeshed within communities that provided various types and levels of support which helped them to recover from cancer.

f) **Summary to psychosocial growth.** To summarize the section on growth, participants spoke of engaging in transformative processes that lead to survivorship which was characterized primarily by growth, not by distress.

### Section Three: Reflections

A resonating pulse throughout the composition of this thesis document has been the concept of process. Process is not static, but flowing like air currents. And like air currents process is throughout all aspects of this thesis and the products of its research. Through their story sharing, I have witnessed the process of recovery faced by each participant. There has also been my personal process from naïve student researcher to engaged researcher in the field. My professional maturation is eclipsed by the sharpening acuity of my perspectives on trauma, in regard to my own experiences and those of others in my life. The arduous process of writing is an introspective one, ironically furthering my own healing from trauma and deepening my compassion for other trauma survivors.

The following are a few, select issues that have come to mind since the formulation of my research question.

**On endurance**

The experiences of both breast cancer recovery and writing a thesis do not follow a linear time schedule, and they require a balanced mix of patience and perseverance. At the beginning of my thesis process a good friend of mine who has a doctoral degree said, “Remember a thesis is not a sprint; it is a steeple race.” He was trying to warn me of the long haul and the pacing that was required. However, I could not have fathomed the depth of endurance that would be required of me and came to realize that there was no way to have known without the actual experience. Pushing forward with the thesis, I kept
hearing Sarah’s words in my head, “you’re not going to stop now; are you crazy?” She was speaking of ongoing recovery from cancer, but her words applied to my circumstances completely. It struck me that breast cancer survivorship in many ways was a similar experience to working through the thesis process. Each participant in my study spoke of events strung out over years, which as a whole equalled a tale of dealing with what life brings you, while mustering as much grace as possible.

There is irony in breast cancer survivors’ engagement in dragon boating. Dragon boating like cancer is a challenging and ongoing process. Although breast cancer dragon boating is a sprint discipline, within each race is the lengthy struggle of propulsion. The boat is driven by the strokes of individual paddlers, and each stroke needs to be in time with those of other paddlers in order for the boat to glide smoothly forward. Paddlers need not only to keep time with others, but to be able to dig the paddle deep when there is a need for greater speed. Each stroke can be a trial, especially if a paddler is a breast cancer survivor who has had surgeries impacting range of motion in their upper body. In this way breast cancer dragon boating sport parallels the cancer experience: it requires mindful commitment over time for ideal outcomes.

On “becoming”

Just as it was possible over time to note themes or patterns among pieces of data collected in my study, both my development of this thesis and participant engagement in dragon boating were processes of becoming. “Becoming” as conceptualized within an ontological health model is a counter process to the fragmentation of self that is common with trauma. Becoming is about integration and the personal decision to face one’s challenges and enfold them into a new life (Arman & Rehnsfeldt, 2003). Becoming is deeply existential by nature, a process of enhanced connection with self and the meaning of life. To quote Canadian songwriter Issa, formerly known as Jane Siberry, “rather than my steps taking me farther, they took me deeper” (personal communication, February 12, 2008).

Throughout the analysis of data, I was aware of a comment by Janice Morse with regard to women who breast cancer dragon boat. She said, “Remember it [dragon boating] is only a small part of their life” (personal communication, June 27, 2006).
Although I kept that comment in mind, I could see that even with Callie, who was a self-reliant individual, breast cancer dragon boating experience was not contained; it seemed pervasive in the lives of my participants. Being a dragon boater changed the way they interacted with daily life, whether they had more compassion for others, like Callie, or they had someone to call when in crisis, such as Trudy. Notably, with Sarah, Nel, and Dee breast cancer dragon boating became a significant part of their overall identity, regardless of whether they were in a team-related setting or not. Participants repeatedly qualified the notion of breast cancer dragon boating as “sport” or “just boating” - all participants thought it was a much greater experience than that. Breast cancer dragon boating was a process of becoming that was not limited to being a paddler. There were ripples throughout their lives and often individual changes at a deep level of self. Fittingly, here was another paradox: I strove to keep myself from romanticizing the psychosocial benefits of dragon boating, yet sometimes my documentation seemed “sweeping” or overly sentimental simply because that was how the experience was projected by participants.

The stories of becoming that were told by participants were something I worked to uphold in the thesis process. As I worked with data and constructed themes I endeavoured to retain “the spark” (Ely et al., 2001) that was so inherent in participant stories. Notably, when participants spoke of their sense of aliveness, it was with deep reverence. Beyond methodological standards of qualitative research I tried to show participant narratives the respect I would show a neighbour or friend - the attitude that “you are most welcome here.” Only one participant in my study was caught half emerged in transformation like the figures in Michelangelo’s prisoners of stone. Part of my process as a researcher was to not inadvertently “trap” participants’ experiences by misrepresenting their stories in the process of creating an interpretative form.

With regard to my personal discovery, the thesis process has led me to enter into new dimensions of relationship with my Mother, who originally inspired my research topic. In some ways my research process has been a continuation of her own quest, begun more than a decade ago, to raise awareness of two issues: the struggles of long term breast cancer survivors, and the number of women still dying from the disease. Now, as I finish writing my thesis with the new knowledge that my Mother herself will die of
metastasized breast cancer, I see my thesis as a lullaby to her years of advocacy as a breast cancer dragon boater. It is a lullaby with an edge of anger, as I now share her distress both at the long reach of cancer and the social avoidance of the dark side of "spunky survivorship," (Sinding & Gray, 2005). The stories of my participants reveal a common spirit that is shared by my Mother: finding your own unique way to triumph over cancer. My refusal to stop writing my thesis, despite my Mother’s illness, and her refusal to stop living are part of the sisterhood of breast cancer dragon boating.

In conversation with breast cancer dragon boat founder Dr. Don McKenzie, prior to the start of my research, he asserted that my interactions with the participants of my research would deeply inform my future professional interactions with cancer survivors. The processes of qualitative research tend to also become processes of professional growth, in large part due to the reflective focus of the work and immersion in the field (Ely et al., 2001). Near the end of my thesis I undertook a counselling practicum at BC Cancer Agency in Victoria. I found that my research experiences with participants eased the steep learning curve of the practicum and gave me a level of confidence earlier rather than later. Most important, I carry the emotional resonance of the stories told by my participants with me and they provide a compass for my actions with all trauma survivors I deal with. “Dr. Don” was astute in his assessment, and I do feel I have matured in the area of professional growth.

Related to “Dr. Don,” one of the founders of breast cancer dragon boating, I want to note how breast cancer dragon boating has progressed from an isolated sport available to a few survivors to becoming a social movement. Five of the participants in my study were part of community efforts to create breast cancer dragon boating societies in non-urban areas on the West Coast of BC. Their actions were fuelled by a sense of isolation in those communities and by the social invisibility of local survivors, as discussed by both Callie and Nel. Both teams involved in my study used the format of creating non-urban breast cancer dragon boating teams devised by my Mother and two friends to form the first non-urban team in BC. My Mother in turn had had advice from both Dr. Don McKenzie and Susan Harris. In BC there are now dozens of teams in operation and they form a network of support that extends to non-paddlers in their perspective communities.
Prior to beginning my research I had been aware of many of these teams, but did not understand the community impacts of these teams.

On insiders and outsiders

Paradox has been a thread throughout the thesis process and my role as both an insider and outsider to breast cancer dragon boating is another example of this. I was an insider as a former paddler and coach as well as the daughter of a team founder. I was an outsider as I no longer bustled along with dragon boating circles. Instead I have had time to stand aside and turn a critical eye on my experience. I was an outsider, also, for not having had breast cancer myself. Nevertheless, I was considered a type of survivor by some for being my Mom’s daughter and caregiver. Significantly I was an outsider because I was not a resident of participants’ home communities. At the same time, I was an insider for being an “Island girl” with extensive backpacking history in the communities of participants. Overall, “perception is crucial to understanding” (O’Donohue, 2004, p. 154). My status as insider/outsider was not lost on me nor was its potential influence on the thesis process.

Participants knew there was some common ground we shared and connection with them was aided by the insider status attributed to me as both a dragon boat paddler, dragon boat coach, and the daughter of a breast cancer dragon boat founder. Participants often punctuated the meaning of their experiences by saying “you know what it is like” or “your mother would know.” My status also meant I had to be very careful to have participants clarify what they meant by certain statements, and not assume solidarity on an issue. That insider status in general allowed for better rapport and an easier flow of conversation, without long introductions or preamble.

However, a surprise for me was how I came to feel as an insider because of the shared elements between my own story as a multiple trauma survivor and the stories of participants. I was startled by how often the emotional turbulence and the steps taken by participants were very similar to my own experiences. It is one thing to have an academic knowledge of trauma issues, and quite another to find a cluster of shared experiences with a survivor of a different type of trauma than oneself. My realization led me to read the groundbreaking work of Judith Herman (1997) on types of trauma and recovery, in an
effort to better understand. In the writing of my thesis document I challenged myself to critically examine the parallels I had discovered in an attempt to ensure I was not imposing my experience on participant stories.

My sense of understanding for participants was further enhanced by my own breast cancer scare, which occurred mid-way through the thesis process. Although having previously survived a number of non-cancer related health ailments and medical procedures, I was disturbed by the possible implications of a lump I found on my right breast. I spent three weeks in the limbo of not knowing whether it was cancer, and the fear I felt during that waiting period was far more intense than I could have anticipated. That fear changed how I came to look at participant experiences, and I gained greater comprehension of the anxieties they had expressed, and the relief of favourable outcomes.

**Section Four: Limitations and Directions for Future Research**

There are limitations inherent in the design and conduct of my study that need to be acknowledged. A method limitation was that as a novice interviewer I did not have the refined sense of how and when to use probes that would have drawn out deeper layers of meaning. I did use a semistructured interview schedule to balance against this (Morse, 1994), yet with increased experience and supervision my interview skills would become more intuitive. Sample size was also limited by the scope of this study which was a graduate studies thesis. Although interpretative descriptive design is intended for smaller studies, ideally my sample size would have been larger according to general principles of the method (Thorne, et al., 2004).

An outstanding question from my research is: how do the women who choose breast cancer dragon boating differ from those who do not? As pointed out in Sinding and Gray (2005) breast cancer dragon boaters are a unique set of women. Throughout my research I wondered at the assertiveness participants showed and their continued striving for greater wellness, even the one participant who was somewhat overwhelmed by the emotional fallout of her life experiences. With breast cancer disease there is as equal potential to be psychosocially “stuck” as to be transformed (Arman & Rehnsfeldt, 2003).
Frankl (2006) suggests there are two patterns of response to trauma: those who cannot envision hope, so give in; and those who are determined to live and mobilize inner strengths. Were the participants in my study engaged in a greater hope or vision in comparison with non-paddlers? Understanding of how and why breast cancer survivors choose dragon boating as a wellness resource would better illuminate survivor experiences. A study design which incorporates a control group and compares survivor paddlers with non-paddler survivors may be a means to satisfy this question.

Researchers also need to consider how different types of cancer support groups meet the needs of survivors (Samarel et al., 1998). Breast cancer dragon boating is not a traditional cancer support group; however, it is one of the few structured groups available to women in smaller communities. How groups meet needs of survivors falls under the larger neglected field of “what do cancer support groups actually provide that other supportive relationships do not?” (Ussher et al., 2006, p. 2566). Such understanding would inform creation of psychosocial supports of survivors. My study has provided insight, but is only a starting point.

A final question is: what is the role of breast cancer dragon boating in supporting the families of paddlers? I was fortunate to interview participants in their own homes, and I became aware of the family structures their lives were embedded in. At the end of my interview with Dee, her husband emerged from outside and asked how the interview was going. Then he came over to the table where we sat and placed his hand on his wife’s shoulder. With a warm smile he looked down at Dee and said, “Dragon boating was the best thing for her.” From the relief in his voice, I was tempted to ask him if breast cancer dragon boating had been good for him as well. Several participants also spoke of the ways their partners were part of breast cancer dragon boating culture; there was room for family participation within the structure of breast cancer dragon boating. To truly understand breast cancer dragon boating experience, clarification of the following is needed: what is the impact on immediate family; what are their thoughts on participation, both regarding their own psychosocial concerns and that of loved ones.

For future research, multiple data collection strategies could be utilized to provide a more comprehensive picture. Such strategies, which are also consistent with an interpretative descriptive method, could include photographic representations. In my
research I was aware of the value in noting the material culture of breast cancer dragon boating. I knew the level of meaning that might be present even in objects one might perceive as mundane, for example: pink wrist tape. Sandelowski (2002) argues that increased attention to artefacts or physical objects needs to be included within future qualitative health research studies. This need is particularly relevant to understanding psychosocial issues and breast cancer dragon boating. The collective objects that represent the trauma and recovery experienced by paddlers are key in shaping both the boating subculture and survivor experience within it.

Section Five: Clinical Implications

My study confirms the need for professionals to both acknowledge and support the dynamic, ongoing nature of survivorship. The concept of cancer survivorship within Canada is rapidly evolving, with increasing recognition amongst medical systems and regional communities that cancer is a chronic disease. Participant stories were complex mosaics of the suffering and healing that accompany recovery from breast cancer. Breast cancer dragon boating gave women permission to express their suffering openly, which needs to be a goal of professionals working with breast cancer survivors (Arman & Rehnsfeldt, 2003).

My findings support the need for professional guidelines to address wellness concerns of long-term survivors. Cancer survivorship involves lingering uncertainty and questions about care long after completion of treatments (Arman & Rehnsfeldt, 2003). Breast cancer survivors are left with emotion laden memories of treatment and strong feelings about their illness (Thomas-MacLean, 2004). With long-term cancer survivorship increasingly common, individuals are faced with questions about next steps (IOM, 2005). Breast cancer dragon boating was a key next step for women in my study and a safe venue to raise concerns; there are few other options in their small communities. There are currently no standardized survivorship guidelines for cancer survivorship care in Canada and survivors face reduced and fragmented professional support upon completion of active treatment, especially in smaller communities. This is unfortunate because the survivorship phase of cancer provides numerous opportunities to
improve the quality of life of patients (IOM, 2005). One simple starting point for health professionals to assist survivor needs is to find out what matters to the patient (Folkman & Greer, 2000) or to honour the questions of survivors.

Participant accounts highlight the importance of professionals honoring the need of cancer patients to take an active role in their treatment options. As noted by S. Taylor (1983) "many people prefer to contribute actively to their treatment," (p. 1161). Part of this is both acknowledging the pre-existing abilities that patients have (Wade, 1997, p. 24), and validating their experiences (Herman, 1997). Often the “resistance” shown by cancer survivors to restrictive directives is a healthy response to preserve self (Wade, 1997), and honoring such resistance honors the survivors’ capabilities. Generally, there is a need for cooperative relationships with trauma survivors in order to encourage their efforts to restore a level of control in their lives (Herman, 1997).

I stress that professionals must address the isolation along with other issues faced by many patients, especially those in small communities, to better support breast cancer survivors. Breast cancer dragon boating offered women in my study a communal atmosphere where they enjoyed the understanding of like-minded peers. The healing gained by breast cancer survivors has often resulted because their lingering questions about care and illness were addressed (Thomas-MacLean, 2004). In times of need people tend to turn to social networks for support rather than to professionals (S. Taylor, 1983); nevertheless, many women in my study expressed being misunderstood by many, including professionals. This is consistent with the finding that breast cancer survivors report the failure of health care providers to take their concerns seriously (Foley et al., 2006). Professionals are part of the network of support for survivors, and the need for greater understanding of both long-term survivor needs and rural or small community issues was evident in my study.

Section Six: Conclusion – Closing Statement

It is ironic that breast cancer dragon boating for participants in my study was linked with enhanced recovery from cancer. Historically, in ancient China dragon boat festivals were associated with the ability to produce the life giving rain that would
guarantee a good harvest (Barker, 1996). Such rain was crucial for avoiding community starvation, and ensuring the well-being of all community members. During those ancient festivals, the boats were raced from the north, the region of death, to the south, the realm of life. Participants in my study were living proof that adversity is a potential catalyst for growth, and if cancer survivors respond with resilience and adaptability they can not only live well with cancer but transcend or move beyond their experiences (Magee & Scalzo, 2006). Breast cancer dragon boating was viewed as central in the lives of all but two of my participants. All my participants discussed how the experience of breast cancer dragon boating was nourishing and assisted their return to life after the end of active cancer treatment.

With survivors of breast cancer, as well as individuals facing other serious health concerns, “helping requires ongoing negotiation and work. We must learn to listen and adapt to the changing needs of the ill people we care about,” (Gray et al., 2001, p. 247). Breast cancer dragon boating is but one response to such needs, and the concept of “breast cancer dragon boating” calls out for other creative means to address survivor needs.
References


Appendix A: Certificate of Approval

The University of British Columbia
Office of Research Services and Administration
Behavioural Research Ethics Board

Certificate of Approval

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR</th>
<th>DEPARTMENT</th>
<th>NUMBER</th>
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<tbody>
<tr>
<td>Cadell, S.</td>
<td>Social Work &amp; Family Studies</td>
<td>B05-1078</td>
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INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT

UBC Campus ,

CO-INVESTIGATORS:

Shermak, Sheryl, Social Work & Family Studies

SPONSORING AGENCIES

TITLE:

The Experiences of Women Breast Cancer Dragon Boaters

APPROVAL DATE

JAN 10 2006

TERM (YEARS)

1

DOCUMENTS INCLUDED IN THIS APPROVAL:

Nov. 4, 2005, Advertisement / Consent form / Nov. 16, 2005, Questionnaires

CERTIFICATION

The application for ethical review of the above-named project has been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approved on behalf of the Behavioural Research Ethics Board

by one of the following:

Dr. Peter Suedfeld, Chair,

Dr. Susan Rowley, Associate Chair

Dr. Jim Rupert, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.
Appendix B: Participant Recruitment Notice

THE UNIVERSITY OF BRITISH COLUMBIA

School of Social Work and Family Studies
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
Tel: (604) 822-2255 Fax: (604) 822-8656
www.swfs.ubc.ca

Are you a breast cancer dragon boater?

I am a Master’s student in the School of Social Work and Family Studies at the University of British Columbia. For my Master’s thesis I am studying the meaning of dragon boating for breast cancer paddlers. The title of my project is: “The Experiences of Women Breast Cancer Dragon Boaters.”

Specifically, I am interested in:
• The ways in which breast cancer dragon boaters derive meaning from their participation in dragon boating
• The ways in which dragon boating may lead to personal transformation.

You are eligible to participate in the study if:
• You are female;
• You are over the age of 18;
• You are a breast cancer dragon boater;
• You speak fluent English; and
• You are willing to participate in one interview (maximum total 2 hour commitment)

This study is being supervised by Dr. Susan Cadell, Assistant Professor in UBC’s School of Social Work (phone 604-822-5302).

Interested? Please Contact:

Sheryl Shermak, Co-Investigator
Phone: 250-886-4691
E-mail: pacloon@island.net
Appendix C: Participant Consent Form

**THE UNIVERSITY OF BRITISH COLUMBIA**

Consent Form

The Experiences of Women Breast Cancer Dragon Boaters

Principal Investigator: Dr. Susan Cadell, Faculty of Social Work 604-822-5302
Co-Investigator: Sheryl Shermak, Faculty of Social Work, University of British Columbia, MSW candidate 250-886-4691 pacloongisland.net

This research is being conducted as a requirement for a course assignment of Social Work 554. This research may later be used as part of a Master’s thesis, a public document. You will be informed regarding the use and access to the information provided. All identifying information will be removed from information collected during interviews.

**Purpose:**
The purpose of this study is to gain a deeper understanding of the psychosocial benefits of breast cancer dragon boating. Specifically we will explore the positive and negative experiences of breast cancer survivors participating in breast cancer dragon boat teams.

**Study Procedures:**
You will be asked to participate in one or two interviews, lasting no more than two hours each. You will be asked to share your experiences of being a breast cancer dragon boater and about the meaning of dragon boating in your life. Total time commitment will not exceed four hours.

**Confidentiality:**
Your identity will be kept strictly confidential. Any identifying information will be removed from interview transcripts, and documents will be stored in a locked filing cabinet. Only the investigators named above have access to identifying information. Any
documents related to the study stored on computer will be password protected. Participants will not be identified by name or identifying details in any reports of the completed study.

**Risks:**
The research will be dealing with a sensitive topic. While no risks are anticipated, I, Sheryl Shermak, will attempt to alleviate any potential risks to you by ensuring that you are aware of your right to stop the interview at any point if you become distressed or are unable to continue. Further I will provide information on counselling resources.

**Remuneration/Compensation:**
There will be no remuneration or compensation for participation in this study.

**Contact for Information about the study:**
If you have any questions or desire further information with respect to this study, you may contact Dr. Susan Cadell at 604-822-5302.

**Contact for concerns about the rights of research participants:**
If you have any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

**Consent:**
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without consequence.

Your signature indicates that you have received a copy of this document, and that consent to participate in this study.

Participant Signature ___________________________ Date ____________

Printed Name of the Participant.
Appendix D: Interview Guide

Please tell me about your experience of becoming a breast cancer dragon boat paddler.
What did you expect to get out of breast cancer dragon boating? How have you been changed by the experience of being a breast cancer dragon boat paddler?
What does it mean to your life to be a breast cancer paddler?
What have you learned from becoming a breast cancer dragon boat paddler?
Is there anything about yourself that helped or hindered the process?
What aspects of dragon boating have profound meaning for you, if any?
What have been your experiences with the structured rituals of dragon boating? (for example: “dotting of the eye” or the “carnation/flower ceremony”).
Does spirituality help you in anyway? (If yes, “Could you tell me more?”)
For you personally, does dragon boating differ from other sources of cancer related support? (If yes, “In what ways?”)
How has your outlook on your cancer experience changed since you started breast cancer dragon boating?
Appendix E: List of Seven Themes

Moving Past Isolation – Networks of Like-Minded Support

Taking Control

Journey into Adventure

Affirmative Outlook

Confronting Painful Experience

Rebuilding Identity

Spiritual Engagement
Appendix F: List of Subthemes Which Support Each Theme

Moving Past Isolation – Networks of Like-minded Support
- Contained “Support System”
- Understanding
- Team – The whole is greater than the parts
- Support from the public

Taking Control
- Reaching out
- Putting herself first
- Resisting

Journey into Adventure
- Quest
- Renewed life
- Love of paddling
- Social advocacy – giving back

Affirmative Outlook
- Letting go
- Never giving up
- Try anything
- Hopeful reframing

Confronting Painful Experience
- Honouring loss
- Facing fears
- Emotional release

Rebuilding Identity
- Discovering pride
- New realizations – lessons to learn
- Better person

Spiritual Engagement
- Mythic identity
- Breast cancer rituals and myth
- The boat as spiritual space
- Nature
- Spiritual assistance
Appendix G: Sharing the Wisdom

Women sharing their wisdom: Unedited excerpts from personal communication.
Note: All participants answered this question via email after their interviews, meaning they had time to reflect on issues brought up in the interview. The one exception to this was Trudy, whom I asked at the end of our interview together.

Q: Supposing it's today and you meet someone whose situation has been very similar to yours. And now they were thinking about joining breast cancer dragon boating. What would you say to them?

Sarah
Let's see. Want to get your health back? Start thinking of the future again! I guarantee you will laugh! You’ll make some very special friends... You'll love it...even if you hate water. It can turn your journey into one fabulous adventure at the same time! You might say we are all in the same boat. We are all as one when we paddle! It is one of the most exciting ways of getting back one's own health, power, energy and of course spirit back.

Callie
So in answer to your question, as I sit today, it would be: Join, by all means, but try it out first. I love the sport. I like my team mates, but sometimes the infighting can be very hurtful and you see people that you like arguing and leaving the team over what? I read the first lines of this survey how we are all like the strokes of the dragon boat paddle, working in unison to cross the finish line proud of how we played. That finish line for me is life. Its meant to be travelled with your friends and family, its meant to be travelled with achievements, but achievements that are reached without hurting someone else along the way. What I do say to those contemplating joining our team is "c'mon along for the best ride of your life" but at the moment, I would say it cautiously until we can reach some peace on our boat, like the peace in our beautiful estuary.

Nel
I would tell them all of the above that I just wrote for you but mostly I would tell them that it would be one of the best gifts that they could give to themselves. I would tell them that it will change their lives for the better and it will bring them the peace and calmness to their lives that they have likely have not felt since having had cancer. It will give them strength where they never knew it existed before and it will enable them to meet a whole new group of friends who all share in their experience. Then, I would not just tell them about it. I would make sure they were right there beside me the next time that our boat pushed away from the shore. I love the glow in their smiles as they are about to embark on the best ride of their lives. They would feel the heartbeat of the dragon as 20 of us all paddled as one. They would hear the drum beat, the splash of the water, the laughter, and the heavy breathing of everyone around them, as we all made our way through the water. After that experience, they would know for themselves why they needed to join us. Once you step onto that boat, you never want to step off. Paddles up!
Heather
If someone asked me about joining a breast cancer dragon boat team. I would say: "You go Girl". The exercise will help you greatly, only, go at your own pace. Pull up if necessary. You will meet inspiring woman who have overcome many challenges. I would leave it up to the individual after that to decide whether this was something for her or not. I am presently in the gym on the rowing machine trying to row 500 metres in 2 minutes......that is a stretch (in every sense of the word). Group dynamics. I am not sure how much your paper touched on this. Administration is required in any organization and I think that is where a lot of the cliquey-ness comes in. It is normal in any organization. I think the first step is one steps into the boat and is made to feel like an owner of the boat with all the responsibilities that come with it. 22 people all on the same page and making executive decisions together....perhaps that is another stretch.

Dee
What a wonderful idea. Dragon boating will open up a whole new positive chapter in your life. You will join a wonderful group of ladies that are like a second family. We laugh together and we cry together. Nobody understands what you have gone through like your group of "sisters will. Dragon boating is a sport that requires you to get into shape. It is physical but not to the point that you wouldn't be able to do it. No one has ever been turned away from our team. We welcome everyone with open arms. You will have a cheering section right from the "drummer to the steersperson" encouraging you and assisting you where they can. I can pick you up Tuesday night and introduce you to the girls. Come on. What do you say. Give it a try. You have nothing to lose and so much to gain.
I am sorry to be a little wordy but I would like to encourage everyone to try the sport.

Trudy
Oh yeah, oh yeah definitely, oh yeah it is great in the boat, get them “well I’m not a water person,” or “I can’t swim” so? (laughing) doesn’t matter, (laughing) I’m not very good (laughing) get in the boat and try it.
Appendix H: Typical Dragon Boat

*Dragon boat – breast cancer team*

Source: Alan Thurston, used with permission.

*Dragon boat – positions*

Drummer

Engine Room

Steersperson/Tiller

Source: Alan Thurston, used with permission.