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## The marathon of life : an exploratory study of female cancer survivors' experiences with training for and participating in a marathon after their cancer diagnosis

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Elizabeth M. Donahue  
The Marathon of Life: An  
Exploratory Study of Female  
Cancer Survivors'  
Experiences with Training  
for and Participating in a  
Marathon After Their Cancer  
Diagnosis

## ABSTRACT

This study explored the experiences of female cancer survivors who have trained for and participated in a marathon after their cancer diagnosis. More specifically, the research focused on women's motivation for choosing to participate in a marathon, their experience with training and participating in their first post-cancer marathon, and the ways in which their marathon experience impacted their recovery process. Further, this study investigated whether women felt they had lost a sense of control during their diagnosis and treatment and if training for and participating in a marathon allowed them to regain a sense of control that had been lost.

Qualitative interviews were conducted with 6 female marathon runners, all of whom had been previously diagnosed with cancer. Interviews were based on a semi-structured interview guide, guiding the women in sharing their experiences with diagnosis, treatment, training, marathon participation, and recovery.

The results from this study indicate that participating in a marathon can positively impact the lives of women in recovery. The women in this sample chose to participate in a marathon because it represented an opportunity to reconnect with a part of their pre-cancer identity, reassure themselves about their body's capabilities, and set and reach a goal. Findings also suggest that there is a parallel between the experience of going through cancer treatment and training for and participating in a marathon. A majority of

participants also reported that, while their diagnosis and treatment left them feeling like they had lost aspects of control, their marathon experience allowed them to again feel in control of their bodies and lives. The present research has implications for the field of social work and all those who work with women in recovery from cancer, as it widens the scope of what is possible during treatment and recovery and suggests the need for further research on the positive impact of participating in a marathon after a cancer diagnosis.

THE MARATHON OF LIFE: AN EXPLORATORY STUDY OF FEMALE CANCER  
SURVIVORS' EXPERIENCES WITH TRAINING FOR AND PARTICIPATING IN A  
MARATHON AFTER THEIR CANCER DIAGNOSIS

A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work.

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2009

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## CHAPTER I

### INTRODUCTION

Whether you are a marathon runner or not, it is well known that training for and running a marathon is a rigorous and demanding experience for one's body and mind. This is also true for the experience of dealing with the diagnosis, treatment, and recovery from cancer. The American Cancer Society estimates, for the year 2008, that there will have been 1,437,180 new cases of cancer diagnosed and 565,650 deaths caused by cancer (American Cancer Society, Cancer Facts and Figures 2008). As early detection becomes more widespread and advances in treatment become more prevalent, there are a greater number of people surviving their cancer diagnosis and treatment. Given increasing survival rates, there is a need to explore the lives of cancer survivors and the experiences that can enhance and aid in recovery.

One widely researched intervention and recovery aide is exercise. Though the effects of exercise on people who are in recovery from cancer has been widely researched, there is little research on the effects of extreme exercise, such as marathon running, and its impact on the recovery process. Marathon running is no longer an experience only available to elite runners, and more and more people are taking on the challenge of training and participating in a marathon (Delmont, 2005). While having cancer can greatly impact a person's sense of confidence and control over his/her body, marathon running is a sport that requires, through training and competing, an enormous amount of trust and

confidence in one's body. As Robert Chernin Cantor shares in his book about the emotional impact of cancer, "The diagnosis of cancer more than that of any other disease can strip away our sense of control and release an assault of frightening possibilities, some known, some unknown, but all seemingly beyond our sphere of influence" (Cantor, 1978, p. 10). It is important to understand whether forms of extreme exercise, such as marathon running, can help to restore some of that lost sense of control.

The goal of this flexible method, qualitative research study is to learn about the experiences of women who have been affected by cancer and have trained for and completed a marathon after their diagnosis. More specifically, the research will focus on women's motivation for choosing to participate in a marathon, their experience of training and participating in their first post-cancer marathon, and ways in which their marathon experience impacted their recovery. Further, this study will attempt to investigate whether training for and participating in a marathon allows women in recovery to regain a sense of control over their bodies.

Knowledge about the experiences of women who have had cancer and trained for and participated in a marathon will be beneficial to the social work profession because it will provide insight into participant's experiences, while also providing information about how the experience affected their recovery process. This research will add to the existing literature on exercise and recovery, while also opening up a new body of literature on the specific impact of extreme exercise, such as marathon running, and its potential effect on female cancer survivors' sense of control over their bodies.

## CHAPTER II

### REVIEW OF THE LITERATURE

The purpose of this study was to explore the experiences of female cancer survivors who trained for and participated in a marathon. The following section will address the idea of recovery, the literature on control and its relationship to cancer, and exercise and its impact on recovery.

#### *Recovery*

In Diane Scott Dorsett's article, *The Trajectory of Cancer Recovery* (1991), she offers the following definition of recovery, "Recovery is a fundamental human process whereby change in well-being is absorbed, assimilated, and accommodated over time in the service of both survival and creativity" (p. 178). Dorsett compares her idea of recovery to the Corbin and Strauss illness trajectory, and she speaks to why a framework of recovery is more applicable to cancer than a framework of chronic illness, due to the fact that recovery is oriented towards survival, whereas an illness-based framework ends with death (p. 177). She makes a simple, yet poignant, statement when she says, "...recovery incorporates the strength of the historical self and a new, evolving complexity in order to accomplish a major health transformation" (p. 179). Recovery is a balance of finding a way to get back to the self before cancer while developing a new identity that includes the experience of having cancer. The process of recovery can touch many aspects of a person's life, including: being able to do the things that one was able to do before a cancer

diagnosis and treatment, trying new activities/ideas that are influenced by the experience of having cancer, coming to terms with physical impairments or changes in one's body and managing the effects of ongoing treatment, regaining a sense of control over one's body and life, finding a support network that is focused on recovery instead of illness, and managing the emotions and feelings that come up as a result of having had cancer (Benjamin, 1995; Cantor, 1978; Carter, Dennehy, & Schneider, 2003; Crocker et al., 2007). The process of recovery can be unique to the individual, though it can also encompass similar challenges and experiences for all cancer survivors.

### *Control*

Human beings need control. We like to be able to make decisions and feel like we have a say over what occurs in our lives. Though many people believe that there are ways to prevent cancer from occurring and millions of people are devoted to finding ways to develop new treatments and methods of prevention, there is no way to ensure that one will not get cancer. Control and the loss of control are tied to all aspects of the experience of cancer.

Harold Benjamin, founder of the Wellness Community, an organization that provides free psychological and social support to cancer patients and their families, discusses the importance of control in his book, *The Wellness Community: Guide to Fighting for Recovery from Cancer*. He suggests that negative stress in our lives is caused by the memory or anticipation of a situation that can cause harm, but over which a person has no control. If we believe that we can control a situation and that it will not cause us harm, there will be no negative stress (1995). Unfortunately, with cancer,

control is often something that people feel they are without (Cantor, 1978; Bowker, 1996).

Robert Cantor (1978) also discusses the importance of control in his book, *And a Time to Live: Toward Emotional Well-Being During the Crisis of Cancer*. He suggests that people need control in their lives so that they can believe that their words and actions have an effect on the course of their lives and that they are in control of their destinies. Without this control people experience themselves as being victims. He also suggests that cancer is associated with a loss of control because cancer is assumed to be equivalent with death, even though this assumption is not based on facts. He shares a statistic from 1974, when, "...approximately 218,000 Americans were cured of cancer while 355,000 died of it" (p. 11). Though cancer is seen today in very different ways than it was in 1978, when Cantor's book was published, it is still an experience that greatly affects people's lives and can invoke feelings of uncertainty and the inability to control one's body and life (Ulman, 2008; Courneya et al., 2007; Crocker et al., 2007). Cantor (1978) describes that feelings of control can be lost at many different points. It can occur when a person encounters hospitalization, which requires moving to a new location and trading in your unique identity for that of a patient. It can also occur when a person experiences unexpected events, such as not fully knowing about a medical procedure or feeling shocked after receiving surgery and seeing what has been done to one's body. Returning home can also result in a loss of control, due to needing to be taken care of and having the time to realize some of one's limitations. During recovery, one must decide what to share with others, which is a choice only if there are no obvious physical signs of the cancer and treatment. A person must also come to terms with not knowing whether or

not their cancer will return and for how long they might remain healthy. The loss of control can continue as a person manages the emotions and thoughts associated with cancer (Cantor, 1978).

Loss of control can also be experienced by physical limitations and feeling like one's body has committed betrayal. In Crocker, McDonough, and Sabiston's (2007) study, with breast cancer survivors who were involved with a Dragon Boat Program, many of their participants spoke about the physical effects of having cancer and how it affected their sense of control. After reviewing the participants' descriptions of their breast cancer diagnoses, the authors suggest that a cancer diagnosis causes a person to question her ability to predict and control her life and future. One participant described the frustrating experience of not being able to lift one of her arms all the way up to her shoulder; while another shared that she thought her body was giving up on her and that she wasn't in control (see p. 430).

Though control can be lost during cancer diagnosis and treatment, all authors mentioned above also spoke about the importance of regaining control after being diagnosed with cancer. Benjamin (1995) shares that maintaining and regaining control should be a high priority in a person's recovery process; however, he warns that one must take caution in attempting to regain control and not try to do more than one can handle. He also suggests that when a person is diagnosed with cancer, there is inevitably some aspect of control that must be relinquished and doing so with acceptance and composure allows the loss of control to not become a stressor (Benjamin, 1995). Benjamin goes on to explain specific actions that can be done in an effort to regain control. These include: making a list of the areas of control which have been given up, making another list of

what has been given up that can be taken back, and starting to take back control, in small ways. He suggests that assessing the things in one's life, which are either good or bad, is a method of regaining control, which can allow a person to have more control over their life than they have ever had before. It allows someone to purposefully make decisions and choose how to react to different life events, which gives a person an opportunity to critically look at the unhealthy and healthy ways they have responded to situations in the past (Benjamin, 1995).

The women in Crocker et al.'s (2007) study chose to participate in a Dragon Boat program, which, in turn, allowed many of them to regain some of the control they lost. Crocker et al. (2007), like Benjamin (1995), mention the fact that the women are making "personal decisions," which results in a feeling of being in control over one's life. The women in the Crocker et al. study (2007) show that a feeling of control can be lost during cancer diagnosis, treatment, and recovery; however, it is important, and possible, for a person to figure out ways to regain control in their life.

### *Exercise*

Exercise, and its relationship to recovery from cancer, has been widely researched and has involved a number of different types of exercise, such as walking, dragon boat racing, biking, running, group sports, and weight lifting and muscle training. (Arendzen et al., 2005; Gordon, 2008, Ulman 2008, Courneya et al., 2007; Adamsen et al., 2006; Wall, 2000; Arora et al., 2009; Crocker et al., 2007; Pinto & Maruyama, 1999). Research has shown that exercise can have an effect on mood, anxiety, and depression (Pinto & Maruyama, 1999), while also allowing for coping with stress, social support, changes in physical self-perceptions, personal control, and positive psychological growth (Crocker et

al., 2007). There have also been personal accounts of how exercise can be incorporated into post cancer identities (Ulman, 2008 & Gordon, 2008). Though, initially, many providers encouraged people to rest and remain inactive, research has proven that being active can be both physically and psychologically beneficial to a person during and after treatment for cancer (Carter, Dennehy, & Schneider, 2003).

Sarah Gordon (2008) states, “Exercise allowed me to enter the survivorship stage and see past the statistics, the words, and the forecasts” (p. 216). Gordon is the founder of a young adult cancer advocacy program called the Run-Tri program. She is also a cancer survivor who used biking and running during her cancer recovery. Douglas Ulman, who is also a survivor, is the founder of the Ulman Cancer Fund for Young Adults, President of the Lance Armstrong Foundation, and a marathon and long distance runner. He also incorporated exercise into his recovery from cancer and benefited both psychologically and physically. Three years after he was first diagnosed with cancer, he participated in a 100-mile race in the Himalayan Mountains. This experience allowed him to regain a trust in his body, which, as he states, was “...the same body that had developed cancer and survived” (p. 214). Both Gordon and Ulman found that exercise was a crucial aspect to their recovery from cancer (Gordon, 2008 & Ulman, 2008).

From the literature reviewed, the following themes emerged in relation to the psychological and physical benefits of exercise: improved mood and reduced anxiety, new identity and new opportunities, feeling of support and belonging (when done in groups), sense of control, appreciation for oneself and the opportunity to be alive, general well-being and quality of life, overcoming limitations, strengthening the body, improved



body image, and combating fatigue and weight gain. Each of these themes will be discussed in the following section.

### *Improved Mood and Reduced Anxiety*

Experiencing anxiety and depression can be common occurrences during cancer treatment and recovery. (Carter et al., 2003; Schwartz, 2004; Pinto and Maruyama, 1999) In the Crocker et al. (2007) study, mentioned earlier, twenty women were interviewed to learn about their participation in a dragon boat program for breast cancer survivors. The women, who were primarily Caucasian, had been diagnosed 3-8 years before the study and had all undergone multiple treatments for their breast cancer. Results from the study show that 14 women felt dragon boating reduced emotional stress in their lives by allowing the women to focus on something other than their cancer related stress and providing a shared sense of accomplishment and challenge. Many of the women shared that participating in the program brought “fun and laughter” (Crocker et al., 2007, p. 428) into their lives.

Arora et al. (2009), whose study focused on 408 adult survivors of aggressive Non-Hodgkin’s Lymphoma, looked at the physical activity levels of their participants, examined factors associated with level of sedentary physical activity, and explored the association between physical activity level and Health Related Quality of Life. Results showed that participants who met public health guidelines or engaged in some activity reported better mental health than sedentary participants. It was also found that the more activity that was done, the higher the mental health benefits. This was also true for depression and anxiety, specifically, with results showing that more exercise resulted in lower depression and anxiety (Arora et al., 2009).

The women in the Crocker et al. (2007) study were not compared with women who were not participating in a dragon boat program; however, both studies suggest that being committed to an exercise program and doing it consistently can bring about positive psychological changes. Maruyama and Pinto (1999) also support this finding in their review of data from the literature on exercise and its use with breast cancer patients. The authors looked at the effects of exercise on mood management, weight gain, fatigue, changes associated with menopause, body image, and sleep problems and then critiqued the studies by looking at their subjects, design, results, and limitations. In their review, the authors found that exercise can have a positive impact on mood, anxiety, and depression among cancer survivors, similar to improvements that have been reported by exercisers in other populations (p. 193). The authors conclude that further research on exercise will be important to determine whether or not exercise should become a vital part of cancer recovery.

#### *New Identity & New Opportunities*

Exercise can be used to facilitate a new identity, as that of an “athlete” or “someone who exercises,” while also allowing people to develop aspects of their post-cancer identity. Sarah Gordon, mentioned earlier, used her athletic pursuits in combination with her identity as a survivor of cancer. Gordon (2008) states, “Exercise has been a key part of my cancer survivorship. ...I was eager and excited to intertwine my passion for endurance sports with my new life lessons” (p. 215). Gordon was able to do that by becoming the founder and manager of the Run-Tri-Program, which combines health and fitness with young-adult cancer advocacy, while also tackling her own athletic

pursuits, like completing her first marathon. Gordon developed her new identity and found her career through connecting her cancer experience with her athletic endeavors.

The women in the Crocker et al. (2007) study also found that their participation in the dragon boat program provided them with a new identity and introduced them to new possibilities and opportunities. Many women, during the course of participation, began to identify themselves as athletes. The researchers also found that dragon boating provided new experiences for the participants, including opportunities for leadership and public speaking. Not only did the experience of dragon boating provide most of the women with a new identification as someone athletic, but it also introduced the women to new interests and new opportunities that they might not have discovered without the program.

Adamsen et al. (2006) also found that exercise, specifically in the form of group exercise, affected participants' identities. Their study involved 55 people with varied cancer diagnoses, all participating in a group exercise program. The program was run over the course of 6 weeks and combined multiple types of physical activity. The results, using both qualitative interviews and quantitative surveys, showed that being part of the program allowed the participants to move away from a, "sense of victimization" (Adamsen et al., 2006, p. 31), to a new identity, inspired by the group, of a person with cancer. The program was focused on the physical aspects of the participants, not their mental or emotional wellbeing; however, the experienced reality of the group gave the participants a new perspective on what it meant to be a person with cancer.

### *Feelings of support and belonging*

Exercising in groups or with a partner can affect adherence (Hacker, 2009), and it can also provide a person with a sense of support and belonging (Crocker et al., 2007; Adamsen et al., 2006; Courneya et al., 2007). Seventeen, out of twenty, of the dragon boat participants found that participation in the program expanded their social support network. They found that being around other women, in the context of physical activity, allowed them to receive support from people who had gone through similar experiences while doing so in an environment that was focused on life, not death (Crocker, 2007, p.429). The women in the Courneya et al. (2007) study, which looked at exercise and quality of life among breast cancer survivors, also found that exercising in groups or with friends can provide for feelings of support. The structure of the dragon boat program required that all participants had experienced breast cancer. The women were able to support each other but found that the environment was very different than that of a support group. Using exercise as the means for bringing the women together made the focus of the group to be that of getting on with their lives, not dwelling on their illness. The same was found in the Adamsen et al. (2006) study. The participants, who were currently undergoing chemotherapy, were able to gain support from people undergoing the same or similar experiences and use the group to collectively fight against their illness. They did this in the context of physical activity, which took the emphasis off their illness. These studies suggest that, whether in a formalized group designed primarily for people who are experiencing or have experienced cancer, or on your own, exercise done in the company of others can provide immense support, which is very important for people with cancer and for those that are in recovery (Benjamin, 1995).

### *Sense of Control*

As mentioned earlier, a sense of control over one's body, and control, in general, is a feeling that can be lost when diagnosed with cancer. Also discussed, was the importance of regaining a feeling of control. Crocker et al. (2007), Courneya et al. (2007), Wall (2000), and Ulman (2008), found that exercise, or participation in a program that required physical activity, was a method of regaining a sense of control.

Wall (2000) looked at changes in hope and power in patients with lung cancer who either did or did not participate in an exercise program. Though *power* may not always mean the same thing as *control*, there are aspects of Wall's description of *power* that relate to the other findings on *control*. Power is described as, "the capacity to knowingly participate in change," and further, "characterized by awareness, choices, freedom to act intentionally, and involvement in creating change" (2000, p. 235). Wall (2000) found there to be a steady increase in power for participants that exercised, whereas the non-exercise group identified a decrease in power over time. In her findings, Wall (2000) recognized that, due to the significance of power and hope for a person with cancer, it is important to have interventions that can allow for and encourage an active involvement in change.

Courneya et al. (2007), Crocker et al. (2007), and Ulman (2008) did not compare exercising and non-exercising groups, but all found that either their participants or themselves, in the case of Ulman (2008), noticed a change in their perception of control through the use of physical activity. Ulman (2008) has not only participated in a regular marathon and a 100-mile race, after his diagnosis of cancer, but he has also continued to

incorporate everyday exercise into his life. In his words,

Many cancer survivors describe how cancer has robbed them of a trust in their own bodies. There was a time, early in my survivorship, when I could relate to this sentiment. But my athletic endeavors over the last 10 years have proven to me that I can trust my body and achieve success through exercise. (p. 213-214)

Trusting one's body after the experience of being diagnosed with cancer and going through treatment can be incredibly challenging. Many of the women in the Crocker et al. (2007) study found that dragon boating facilitated the process of regaining control. For some, this was an activity that they were choosing to do, and, through that choice, they felt they had the ability to control their physical and psychological health. For other participants, the experience of engaging in physical activity gave them a sense of control over the quality of their lives (Crocker et al., 2007, p. 430).

Courneya et al. (2007) looked at the exercise behavior in post-diagnosis breast cancer survivors as well as the relationship between exercise behavior and reported quality of life. Their study involved 289 participants who responded to two, open ended questions, as part of a larger study. In relation to control, the results indicated that exercise was viewed as an opportunity to have a sense of normality as well as control over one's body. One participant shared the following, 'I think that exercising has been the only way that I have been able to feel normal again- like I am in charge of what is happening' (p. 1476). This sentiment is similar to that of Ulman (2008) and speaks to the impact that exercise can have on aspects of recovery, especially in relation to regaining a sense of control over one's body.

### *Appreciation*

Multiple studies indicated that participants were reminded of their renewed appreciation for life, through their participation in athletic activities and exercise. Many women in the Crocker et al. (2007) study found that facing a life threatening illness encouraged appreciation for being alive, and the fun and empowering environment of dragon boating was a reminder of how fortunate they were. One participant said, ‘So for me, it was the most amazing transformation. Suddenly I am so excited about life because I’ve got this new thing [dragon boating] in my life’ (p. 428). For many women, dragon boating was also a reminder of the positive outcomes that can be associated with having cancer. This was also true for the women in the Courneya et al. (2007) study. Results showed that many participants had gained a greater appreciation for life after experiencing cancer and prioritized maintaining a positive attitude. This caused participants to make changes in their life, which they hadn’t been able to do before cancer. One participant said, ‘I feel like my life has been enhanced by my cancer- it has given me permission to change my lifestyle and try to be more active and healthy’ (Courneya et al., 2007, p. 1478). In this way, it appears that exercise and physical activity are appropriate and beneficial to recovery, as a means to appreciate and enhance one’s health and life.

### *General Physical Well-being and Quality of Life*

It is also evident that exercise can affect a person’s general health and well being, as well as their quality of life, while recovering from cancer. The health benefits of exercise, in general, are undisputed, and the benefits of a healthy lifestyle are well known (Jeffery & Sherwood, 2000). Exercise, and its connection to quality of life, has been

heavily studied in healthy populations (Hacker, 2009), as well as with cancer survivors (Courneya et al., 2007; Adamsen et al., 2006; Arora et al., 2009; Carter, Dennehy, & Schneider, 2003; Arendzen et al., 2005; Hacker, 2009).

The Rocky Mountain Cancer Rehabilitation Institute, in Colorado, uses exercise interventions to assist people in recovery from cancer with regaining the quality of life they experienced before their diagnosis. Their research has shown that, within their 6-month intervention, all patients report improvements in their quality of life. The authors shared that they determined exercise to be vital for reducing fatigue as well as other side effects that can greatly impact all aspects of a person's life (Carter et al., 2003).

Arendzen et al. (2005) looked at the effectiveness of a multidimensional cancer rehabilitation program on cancer survivor's health related quality of life. Their research involved 81 participants, with various forms of cancer, who had their last cancer related treatment from 3 months to greater than a year prior to the start of the program. Their program involved multiple physical components, as well as psycho-education and an information component. Their results showed that their participants reported significant improvements in their health related quality of life. Their study also revealed that their intervention was possible, and equally effective, with men and women as well as various types of diagnoses, regardless of the time since completion of cancer treatment. This is an important finding, due to the fact that a majority of studies done on exercise, and its relationship to cancer, have been done with breast cancer patients and survivors (Pinto and Maruyama, 1999).

The study done by Courneya et al. (2007), mentioned earlier, found that the breast cancer survivors in their study were eager to take on a healthier lifestyle after their



diagnosis. They used exercise to become healthier, which resulted in taking better care of themselves and getting to a point of general good health and well being.

*Strengthening the Body, Combating Fatigue and Weight-Gain, Overcoming Limitations, and Improved Body Image*

When a person is diagnosed with cancer, and during ensuing treatment and recovery, fatigue, weakened physical capacity, and body image can be major concerns that exercise can help to relieve (Maruyama and Pinto, 1999). Fatigue, which is a very common side effect to treatment, is exacerbated by inactivity, stress, lack of sleep, and poor appetite (Schwartz, 2004, p. 54). According to the National Cancer Institute, 14%-96% of people with cancer experience fatigue, especially those that are in treatment (National Cancer Institute, Fatigue, Overview, 2009). Fatigue can occur for a number of reasons and the consequences can be felt physically and psychologically. (National Cancer Institute, Fatigue, Causes, 2009). Physical activity and exercise can dramatically impact feelings of fatigue and can also increase one's ability to sleep well. (Schwartz, 2004; Carter et al., 2003; Pinto & Maruyama, 1999). Anna Schwartz, who is a cancer survivor and athlete and has also been an oncology nurse and professor, says the following in her book, *Cancer Fitness*,

Those patients who exercise also tell us that the most important time to exercise is when they feel their worst. ...I have seen patients over and over go home and start to do basic exercises and return to see me a few weeks later, feeling not only a lot less fatigue but also a whole lot better about life. (p. 13)

Cancer can also negatively affect a person's physical capacity in various ways. Cancer treatment can cause declines in bone density and experiencing cancer can also impact a person's heart and lung functioning. Surgery can limit physical functioning and

cancer can leave a person feeling weak and incapable of doing everyday activities. Exercise, in various forms, can help to ameliorate these effects (Schwartz, 2004 & Carter et al., 2003).

Arendzen et al. (2005), found that their exercise program improved participant's exercise capacity as well as their muscle force. They used bicycle training, muscle force training, and sports, and found that the physical benefits that were accrued still remained at the 3-month follow-up. Another finding from this study was that most participants suffered from weakened muscle force in their lower extremities, and not in their upper extremities, at the beginning of the study. The authors suggest that this may be due to bed rest as well as a more sedentary lifestyle that is adopted after a cancer diagnosis and during treatment, which primarily affects the lower extremities. They encourage muscle exercise training that is targeted at stimulating energy in the lower extremities and suggest that this can start as early as during hospitalization, to prevent the consequences of disuse.

Body image can also be a concern for people with cancer and in recovery, due to weight changes, hair loss, and the results of surgery. Exercising can make a person feel stronger and more normal, which can have a big impact on their body image (Schwartz, 2004, p. 26). In their review, Maruyama and Pinto (1999) cite numerous studies that reveal how exercise can be used to overcome fatigue, strengthen and tone the body, and aid in weight loss. They suggest that adopting healthy behaviors, like exercise, can encourage survivors to feel more healthy, in general, and positive physical changes in one's body can provide for positive changes in body image.

## *Marathoning*

The *marathon* is named after the legend of Pheidippides, a Greek messenger, who purportedly ran from the town of Marathon to Athens, a distance of about 42 kilometers, carrying the news that the Persians had been defeated. The marathon became an Olympic event in 1896, during the first games in Athens, and achieved its current distance of 26 miles and 385 yards at the London Olympics on 1908 (Boston Athletic Association, History, 2009, para 3 & 4).

The New York City Marathon, for many years, has attracted the highest number of participants in the United States; however, in 2007, 340 marathons were held nationwide. In total, there were 403,000 recorded finishing times, up from 397,000 in 2006. Men comprised 60.5% of participants, with an average age of 40.5. Women, at 39.5%, were at an average age of 36.5 years. (Marathonguide.com, 2007, Introduction and Explanation, para 4 & 5). Participant numbers have been steadily increasing for years, and marathon participation is now widely known as an activity that is not limited to elite runners (Delmont, 2005).

Marathon training, however, is not an easy task. The participant determines training, but it is generally comprised of many months of running, multiple days a week, with a gradual increase in distance that usually tops off at 20 miles. This rigorous training, coupled with the social network that is often associated with marathon training and participation, makes the experience of running marathons a major life event that can be connected to everyday life. Marathons can help to define a person and are often associated with pushing oneself and achieving something that may have originally seemed impossible. Marathon participants are generally white and highly educated,

suggesting that a certain amount of privilege is associated with the choice to participate in a marathon (Delmont, 2005).

Charitable organizations, whose runners raise money through their marathon participation, have become increasingly popular. This is specifically true for organizations connected to cancer patients, research, and survivors. For the 2009 Boston Marathon, there are numerous organizations that will have runners supporting their cause. The Dana Farber Cancer Institute, The Leukemia and Lymphoma Society, and Children's Hospital Boston are just a few (Boston Athletic Association, Charity Program, 2009). Often, people will run in memory of a loved one or in the name of someone battling cancer. The Leukemia and Lymphoma Society's *Team in Training* program provides each of its running teams with an *Honored Teammate*. This person is someone who is currently suffering from blood cancer and can act as an inspiration to runners (Team in Training, Honored Teammate, 2009, para1).

John S. Raglan states, "The physical and psychological stress of completing a marathon is perhaps unmatched by any other Olympic sporting event" (Raglan, 2007, p.406). This stress can be witnessed just by observing a marathon from the sidelines. It is also easy to sense the triumph and sense of accomplishment that is felt at the finish line. Many runners do one marathon, and then move on to shorter races, while others come back, year after year, to challenge and push themselves to reach that triumph again (Marathonguide.com, First Marathons, 2009).

### *Present Research*

The literature that has been reviewed has guided this researcher in understanding what is known about exercise, cancer recovery, and marathon running. A diagnosis of cancer, treatment, and the recovery process that follows are profound occurrences in a person's life. Experiencing cancer can leave a person feeling completely out of control, both physically and mentally. Being able to take back that control is important during recovery. The literature has shown that exercise, in many different forms, can assist in this process. Exercise and being physically active, assist in improving physical capacities, relieving stress, creating a support network, helping to create a new identity, combating side effects of treatments, and allowing a person to appreciate their life, post cancer. Marathon running is an extreme form of exercise, requiring intense training and forcing a person to push them self, both physically and mentally. The present study will aim to learn about the experience of training for and participating in a marathon, after a cancer diagnosis, and how this experience affects a woman's recovery process. Marathon running and training, which is a time consuming and incredibly demanding mental and physical challenge, was chosen for this study because its impact on women's recovery from cancer has not been previously researched in other studies. This researcher would like to learn whether participating in such an intense endeavor impacts a person's life, in recovery from cancer, and whether or not that experience allows a woman to regain a sense of control over her body and life, which was lost during the diagnosis and treatment of her cancer. This study will aim to also learn about women's motivation for choosing to train for and participate in a marathon, their experience with training and completing

their first post-diagnosis marathon, and how their life has been impacted by cancer and their marathon experience.

## CHAPTER III

### METHODOLOGY

This qualitative research study explores female cancer survivors' experiences with training for and participating in a marathon, after their cancer diagnosis. It is an exploratory study, using a flexible research method, allowing the researcher to use a set of questions during interviews to guide the process but not limit the participant from including other information, as they saw fit. The purpose of this research was to learn about women's motivation for choosing to participate in a marathon after their cancer diagnosis, and how their training and participation related to their recovery process. Further, this study attempted to investigate whether training for and participating in a marathon allows women in recovery to regain a sense of control over their bodies that may have been lost during the process of diagnosis and treatment.

#### *Sample*

The sample for this research consisted of a non-probability sample of convenience, due to the importance of finding participants who were willing to share their stories. Sampling criteria included the following: All participants, 1.) identified as women, over the age of 18; 2.) spoke English fluently; 3.) had been diagnosed with cancer; 4.) had run a marathon, post-cancer, within 10 years of their diagnosis. The researcher did not make specific efforts to achieve age, racial, and socioeconomic diversity, due to the possible difficulty in finding participants within a short time period.

A snowball sampling technique was used, due to the researcher's hope that initial participants would be able to refer other participants that fit the inclusion criteria. Recruitment was done through an email sent out to the researcher's friends and family, contact with a local chapter of a national running organization that raises money for cancer research, and research done on organizations that work with cancer survivors. Three initial participants were found, and then further participants were referred to the study through these and subsequent participants. The researcher made repeated attempts to connect with contacts at the running group; however, this did not work out as a recruitment method. For this reason, there were unforeseen challenges in finding participants and fewer participants involved than the target goal of 8-10 participants. Seven women expressed interest in participating in the study; however, one participant cancelled her interview. The final sample for this study included 6 female marathon runners who were also cancer survivors.

#### *Data Collection*

Data was collected through the use of semi-structured interviews. Four interviews were conducted in-person, and two interviews were done by telephone. All participants read and signed an Informed Consent Form (See Appendix B) before participating in the study, which explained the purpose of the research, details of participation in the study, and confidentiality procedures. All participants were asked to fill out a Demographic Questionnaire (See Appendix C) but were given the choice of leaving questions blank, if they did not want to that information included in the research. The questionnaire consisted of 14 questions about participant age, race, ethnicity, education level, profession, household income, relationship status, type of cancer diagnosis, time since



diagnosis, treatment received, time since treatment ended, previous running experience, and marathon training experience. Confidentiality was assured by assigning participants numbers, which were used to label demographic data and transcriptions from participant interviews, as well as quoted material in the research results. A 9-question interview guide (See Appendix D) was used, to explore participant's thoughts on their experiences with marathon running and cancer. Follow-up questions were used to clarify participant's responses. Interviews lasted between 30 to 60 minutes and were audio-recorded and transcribed.

#### *Data Analysis*

Data was analyzed by reviewing transcripts and separating participant responses by interview questions. Responses for each question were then reviewed, looking for common themes that tied together participants' experiences, as well as data that did not fit within the majority of responses.

There are several limitations to this research study. First, the criteria for participation were very specific, which resulted in the small sample size. The size limited the amount of material that could be gathered, which affected the validity and generalization of the results. Another limitation was that 5 out of 6 participants identified as White or Caucasian, which did not allow for racial diversity in the sample, and all participants had a college education or higher and listed their income as \$50,000 or greater, which did not allow for diversity in education and socioeconomic status. This demographic limitation, however, is representative of the general population of marathon runners (Delmont, 2005).

## CHAPTER IV

### FINDINGS

The purpose of this study was to learn about the experiences of women who had trained for and participated in a marathon, after their cancer diagnosis. This section will address the results of why women initially starting running and then chose to participate in a marathon, what their training and actual marathon experience was like, whether or not marathon running allowed them to feel in control of their body, and if and how their marathon participation affected their recovery process. Participants' names have been substituted with numbers, in an effort to maintain confidentiality.

#### *Participant Demographics*

Participants filled out a demographic data collection form with 14 questions, and the following information was gathered. The sample for this study included 6 female participants (n=6), between the ages of 38 to 64 years. Five participants identified as White and one participant identified as Latina. Only three participants listed their ethnicity, which was Irish American, German/English, and Colombian. The three remaining participants left this answer blank. The education level of participants was a Master's degree (n=5) and a Bachelor's degree (n=1). All participants listed their income as being \$50,000 or more. Participants identified as married (n=4), single (n=1), and engaged to be married (n=1). Data about participant's cancer diagnosis, treatment, and time since diagnosis and treatment will be displayed in the following table.

Table 1: Participant Demographics on Specifics of Cancer Experience

	Type of Diagnosis	Type of Treatment	Time Since Diagnosis	Time Since Treatment Ended
Participant 1	Colorectal Cancer	Surgery, Chemotherapy, and Radiation	10 years	8 years
Participant 2	Stage IIIB Breast Cancer	2 surgeries, ACT Chemotherapy, and Radiation	3 years	2.5 years
Participant 3	Cervical Cancer	Various surgeries and radiation	8 years	1.5 years
Participant 4	Non-Hogdkin Lymphoma	Chemotherapy and Ritaxun (cancer medication)	8 years	7.5 years (1 <sup>st</sup> time) and 3.5 years (2 <sup>nd</sup> time)
Participant 5	Sarcoma of Uterus	Surgery	14 years	14years
Participant 6	Breast Cancer	Lumpectomy, Radiation, and Chemotherapy	14 years	13 years

*Why Do Women Choose to Train for and Participate in Marathons, Both Before and After a Cancer Diagnosis?*

Out of the six women interviewed for this study, five women had been runners before their diagnosis. Three women had already completed at least one marathon before

their diagnosis, two women ran their first marathon after their diagnosis, and one woman started running for the first time and participated in a marathon, after her cancer diagnosis. For this reason, the following will be discussed: how the women started running, how they decided to train for a marathon, and why they chose to participate in a marathon after their diagnosis.

For the women who had been runners, each woman came to be a runner through different paths; however, all the women thoroughly enjoyed running, and their passion for running eventually developed into a passion for marathon running. Most of the women began running as a way to stay in shape and gradually added distance to their runs, before deciding to participate in a marathon. Four of the women joined running groups, and, through their participation in their groups, began to participate in long distance running and marathons. One participant had actually been inspired to run after witnessing a marathon and then joined a running group that had been started for women between the ages of 9-99. Another participant joined a group because she was looking for something new and liked the camaraderie and support offered by the group. A third joined her group, after almost thirty years of running on her own, with the desire to train for a marathon with the support of a group. Another participant had started running, after participating in a study involving distance running and later joined a running group for the support and friendship.

The remaining participant, who had been a runner before her diagnosis, did not run with a running group. However, she is similar to the other participants in that, like the others who had been runners before their diagnosis, none of the women started running with a goal to complete a marathon. For example, participant 2 reported,

I never had the idea of running a marathon. It wasn't even in my consciousness. I had never run more than five miles before I joined this group. Participant 6 reported similar feelings when she shared the following, I never really wanted to do a marathon. I had no desire to do a marathon. I had watched Boston every year, and would go, These guys are nuts. What in the world would they want to do that for? I just never could envision doing that kind of training and running that distance.

While Participant 1 shared the following about her group running experience and her thoughts about running a marathon,

We ran outdoors, and we ran a minute and then walked two, and did that for a couple hours for a couple weeks and slowly worked up to a mile. And then I realized... that the mile races are reserved for kids. So I had to train a little bit more to run a 5K, which is 3.1 miles.... So I did that, and I had a good time. I mean, I couldn't say it was fantastic, but my goal had been reached. So you know, I felt, well, I'm all done with this, and then a week later one of my brothers called and said, "Well, why don't we run a marathon in [European city]?" And I say, "You've got the wrong number, brother. This girl doesn't do marathons. (laughter) I can barely drive 26.2. Well, of course I can, but you know I couldn't even imagine it.

Though most participants expressed strong feelings about why they would never think about participating in a marathon, eventually all the women did decide to train for a marathon, for a variety of reasons. These included: being encouraged by family members, as mentioned in Participant 1's quote above, wanting to try something new, feeling inspired after watching a marathon, feeling the pressure that is present when running with other long distance runners, and wanting to prove someone wrong, who had encouraged against it. Though each woman came to running a marathon in a different way, all of the women interviewed, who had been runners before their diagnosis, did not stop participating in marathons after their first marathon experience. For three of these women, this meant continuing to run marathons after their diagnosis and treatment. For the other two runners, this meant participating in their first, and subsequent marathons,

after their diagnosis and treatment. None of the women ceased participating in marathons after their cancer diagnosis.

All six participants had significant reasons for choosing to participate in a marathon after their cancer diagnosis, whether it was a first marathon or the 4<sup>th</sup>. For many of the women, their identity was closely tied to running. They saw themselves as runners, and participating in another marathon was a way to reconnect with that part of their identity. In reference to her identity as a runner, Participant 5 shared the following:

This is who I am. This is my identity. I think of myself as a runner. That's what I do, so why can't I do this after I was diagnosed?

This same participant also shared the following about her first marathon experience after her diagnosis:

It was the Boston 100<sup>th</sup> Marathon, and I had to do it. I absolutely had to do it. I was diagnosed in November. The Boston Marathon is in April; so I got the OK to do some running in first week of January. My doctor said, "Ok, you can run," and then I remember I went back for a check up after the marathon, in April, and the doctor said, "You did what? You did what!!"

Participant 6 reported similar feelings when she shared the following with a chiropractor,

"I'm am not ready to give up running, and I want you to get me back on the road, whatever it takes. Because it is so important to me [and] my mental health; it really helps." So, I actually got back on the roads during my chemo and have been running since.

For these women, running represented a significant aspect of their life, and getting back to it, after their diagnosis, was very important to them. This was also true for Participant 2, who shared the following,

I mean I even made treatment decisions, I think, based on sort of being a runner now. Like for example, one of my favorite places to run and to train long, especially for running marathons, is... just about thirty miles north of where I live... It's just the most beautiful peaceful place to run. And I chose my radiation treatment center...because the hospital was literally across the street from one of

the entrances to this park. And I would kind of like go for my radiation at 8 in the morning and then put on my running shoes and do like a gentle run, you know.

This Participant later added the following,

And when I found out that I would need more surgery, after my lumpectomy and everything, and that I would need chemotherapy, I began to think about what that would mean in terms of, really, honestly, would I be able to run a marathon again. I mean I had qualified for Boston in November and had thought, initially, [that] I could run it in April.... I actually asked some of the surgeons. Some of them thought I was completely crazy, and other people looked at me and said, "Well, you'll be in the middle of chemotherapy. I don't know, but there's no reason to think you couldn't do it later."

Though Participant 3 was not a runner before her diagnosis, her marathon participation also signified an opportunity to reconnect with her identity, as that of an active person.

She stated,

This is who I am. I'm determined, and I will fight until the end. And if this is what I have to do to prove it to myself, which is really strange because I know who I am, but I had to do something to prove it to myself. To say, Get your butt moving because this isn't who you are, you know, staying in bed and being tired and not being able to go out and hang out with your friends.

Another reason why women chose to participate in a marathon, after their diagnosis, was because they wanted to prove to themselves that their bodies were ok and could handle training for and running a marathon. This was also connected to fighting back against the physical and mental effects of the diagnosis and treatment. This was very significant for Participant 3, who had never run before. After experiencing severe physical and emotional side effects from her diagnosis and treatment, it was very important to feel like she could be in control of her body again. Participant 3 shared the following,

Well, I had been diagnosed, and I was just so tired all the time and felt like the only thing I could really be in control over was my own body... I'm a pretty determined person, and I have done some crazy stuff in my life. It was really about me, and forcing myself to get out of bed, because I was tired all the time. I

was like, I don't like this. This isn't who I am, and I don't want to live my life tired like this. So I said, "I am going to make sure that I do this."

Participant 1 also shared how important it was for her to get back to the place where her body was capable of completing a marathon. After pointing to a picture of herself, crossing the finish line at the Boston Marathon, Participant 1 shared the following about her feelings, soon after her diagnosis:

When my husband came to visit that day, I said that there's a picture that I need and it was this photograph of me, running. It was the marathon that I had just run a couple weeks before.... So, I had that next to my hospital bed and said, "You know, that is what I want to get back to." .... So I made a vow then, you know, that I'm going to get back to this, no matter what.

Participant 2 also felt like running in a marathon, post cancer, was an important recognition that her body was ok. She reported the following:

And I was strong enough to get out there and run. And I just felt incredibly grateful for that .... It was like, Look, I can do this. I'm getting better. It was, well, you know, that you can get over this.... I still was not in great shape, but I could get out there and run.

Another reason that two of the women reported, for wanting to participate in a marathon, post cancer, was to honor someone or to raise money for a cause. Participant 3 reported the following,

I had volunteered at a camp one summer for children who are terminally ill, after being diagnosed. And then I couldn't go and volunteer anymore because I had gotten sick again and so I thought, well, I will volunteer in the way of running a marathon for them and raising money.

Participant 2 also decided to raise money through her first post diagnosis marathon. She had been part of a cancer support organization and wanted to honor those whom she had gotten to know, both survivors as well as people who had lost their battle to cancer.



Another reason for participating in a marathon, given by the participants, was to be able to set and reach a goal. All participants, at some point during the interviews, mentioned marathon participation in connection with setting and reaching goals. Participant 4 had planned to train for a marathon, but was diagnosed with cancer and had to delay her training. She reported,

I had witnessed one marathon and I had wanted to do it... I think it was 2000 when I was present at the marathon. Then I said that I would do it in 2001, and then that's when I was diagnosed. So it became my goal, to get through that and run a marathon, in the name of God. That's what I kept telling myself.

Participant 4 later went on to report,

It became a goal. It became something that, if I'm alive, I'm going to do it. I want to be alive so that I can do it. It became something that I held on to.

Participant 2 also spoke of her marathon participation as a goal to be reached, as did

Participant 5. Participant 5 shared the following,

Just the sense of accomplishment, of achievement; you train for something and your goal is achieved.

These results indicate that there is more than one way to find running, as well as various reasons to decide to participate in a marathon, either before or after cancer. However, the findings suggest that, for marathon runners who are participating in a marathon, post-cancer, the reasons are often connected to reconnecting with one's identity, pushing oneself to reach a goal, and proving that your body is still physically capable of handling a challenge, such as a marathon.

*What is it like to train for and run a marathon after a cancer diagnosis?*

There were several interview questions that aimed to learn about the experience of training and running a marathon, post diagnosis. Again, participant's stories varied, due to the fact that some had run marathons before they had been diagnosed with cancer. For

these participants, they were able to compare their different training and marathon experiences, whereas three participants could only speak of their experience post cancer. The amount of time between the diagnosis and the marathon also appeared to impact the marathon training. This varied from 6 months to 8 years. All participants discussed the physical challenges of marathon training; however, the challenges were somewhat different, depending on the amount of time between the marathon and the end of treatment, as well as the type of treatment received. Due to the women having different types of cancer, they had different treatments and did not all experience the same physical effects and challenges, which then impacted their ability to train and run. Participant 6, who had 8 years between her diagnosis and marathon, shared that she did not consciously connect her marathon experience with her cancer experience. Participant 5, whose treatment included surgery, shared the following,

It took me a while to register that I did have cancer. . . . I only had, I shouldn't say only, but I had surgery; I didn't have chemo, and I didn't have radiation. So it wasn't that bad for me, so it wasn't that my whole life was disrupted.

Though Participant 5 shared that her treatment, "wasn't that bad," she also shared how she was emotionally impacted by her diagnosis as well as her inability to run for 8 weeks after her surgery. She shared the following,

I got really depressed because I couldn't do the things I wanted to do. I got really angry that that happened to me. I think it was actually 8 weeks that I couldn't run; about 2 months that he said I couldn't run. It was kind of a difficult time for me. I got depressed, hormonal changes were happening, hysterectomy things were happening in the body; it was hard.

Participant 1, who had gone through surgery, chemo, and radiation for Colorectal Cancer, shared that she discovered she was initially unable to make it to the end of her driveway. She stuck with it, though, and eventually built up to walking around the block and then

for longer distances. She shared the following about when she eventually made it to training for her first post-cancer marathon,

It was both very exciting and exhilarating, you know, that my body didn't let me down. It was more work. I could tell. When you have part of your colon removed, things are never back to normal. .... I call it a new normal. I just have to get used to a different body- what I can eat or how my body reacts to a long run is different now. I'm totally lactose intolerant. That means no dairy at all; so I have to take calcium in some other ways. And because I can't quite get enough, I now have osteoporosis. But, you know, so what. That's not stopping me. So I just deal with it; but it's not as easy as it was before, mainly because of the physical symptoms.

Participant 2 remained physically active throughout her treatment and shared the following about her first race and her experience with running.

I knew that pushing my body wasn't probably the best thing to do, that I needed to preserve strength. ... Whatever strength I had I needed to use to heal, as well, but I figured just a little bit of running would be as good for me. So I did what I could. But then I ran *Race for the Cure* in October, when I had just finished radiation. Actually, I think I still had another one to go, one more treatment to go, or something. And that, you know, is a short race. It's like a 5k race. But it's a race that has a huge meaning for people who run it. And I run it every year, and I felt it was very important for me to try to run it that year. I mean I could barely run, I really couldn't. I was pretty much bald still and very weak, but I did. I did, sort of run it, you know, very slowly, and I finished it. When I did that, I thought, You know, I'm very weak and tired, but I have six months now till the Boston marathon.... That's, you know, six months for my body to recover, somewhat, and I figured I could try.

For the women who had run a marathon before their diagnosis, training during or after treatment had to look different than before; however, all three women spoke of the positive aspects of training, along with the challenges. Similarly, the three women who had never run a marathon before also discussed the physical and mental benefits of training.

All 6 participants shared stories of triumph about crossing the finish line of their first post-cancer marathon, whether it was their first marathon or their fourth. The

meaning that participating in a marathon carried was different for each participant, and will be discussed later in this chapter; however, feelings of gratitude, pride, and accomplishment were felt by all the participants and will be shared here.

Participant 1:

It was just a real high. I just broke out crying. It was just, you know, I did it. It was just very personally rewarding, something that no one can take away from you. That's true of any marathoner, but I felt especially grateful that I could do it again.

Participant 2:

I never really thought, once I got through the halfway mark, I never thought that I wouldn't finish it. And then I got to the finish line; it took me like 4 hours and 37 minutes or something, and I burst into tears. I was just like, I'm done, and it was a very emotional moment.

Participant 3:

I was exhausted. It was great, and, um, everyone was there to meet me at the end. Yeah, I was great. It was like, Ok, I did this, and I can do anything. I can, you know, beat whatever comes into my body.

Participant 4:

I was elated. It was one of the best feelings I have ever had in my life. I just felt like I was on top of the world. I felt like I had conquered. It was a great great feeling. I wanted to shout to everybody. I wanted to get on top of a mountain and yell that I had survived, and I was running a marathon.

Participant 5:

It was great. I wasn't in shape. I wasn't prepared. It was a very long marathon. I had a very difficult time finishing it, but I was glad I did it, very glad I did it. Something very personal for me, just to show that I was healthy.

Participant 6:

Elation. Elation. I was so proud of myself. It's a wonderful feeling. It really is.

Though participants' narratives described the challenges that they faced, their stories of crossing their first, post-cancer finish line demonstrated the powerful feelings that were invoked by their marathon experience and the impact that it had on their lives.

Another interesting finding, connected to training, was the parallels mentioned between marathon training and cancer treatment. For some participants (n=4), the challenges of going through chemo and other treatments were similar to the challenges of training for a marathon. Participant 4 stated,

The treatment was very similar to training for a marathon, and that's how I looked at it. . . . When you train for a marathon it's about the same length of time, about 4 months, and each week it harder than the one before. And that is how chemo was. . . . So I related the training to that, but with a different outlook on how I was conquering the illness. Instead of dreading my runs, I remembered how difficult it had been. . . . My runs were great because no matter how tired I got, it was better than what I had felt. So I felt like I was so ahead of the game. When a person complained about running 18 miles, to me, it was like, "I'm just so happy that I am running 18 miles."

Participant 1 spoke more specifically about going through treatment and training when she shared the following,

Many people say that a marathon is like having cancer- well, yes and no, but mostly no. The similarities are that training for a marathon is difficult and going through treatment is difficult. It's like a marathon; you feel like giving up, you just keep going. You do a couple more steps. It's really just step-by-step, right? That's all running is, one-step after another. . . .And because I have had a lot of mantras like that, like if I was in pain, I would say, "This will pass, this will pass." And I did the same with the cancer treatment. With feelings of discomfort and nausea and no energy, this will pass. And when you say that to yourself umpteen times over again, the mind eventually moves on to something else and, yes, it did pass.

Participant 6 also shared her thoughts on the connection between marathons and cancer,

Because it's a long period of time and you have to keep focused on the goal. And with cancer it's getting to the end of the treatment, and with the marathon, it's getting to the marathon- because it's a lot of time that you are spending out there, when you kind of lose your focus.

Participant 2 shared that a friend had told her about a T-shirt he saw at a marathon. It read, “If you think running 26.2 miles is hard, try going through chemotherapy.” She shared the following about the connection between the two experiences,

While you are in the middle of cancer treatment, it feels hard. But the truth is, when you are running a marathon and struggling with each mile, that’s also really hard. There’s a parallel there, and, honestly, I wouldn’t say which one is harder.

Participants 3 and 5 did not speak about how treatment was similar to training, though they did reflect on how the two challenging experiences related to each other. Participant 3 shared the following feelings about cancer and training after her cancer experience,

Ok, If I can do this and endure the pain of this.... This is nothing. You know, I’ve gone through so much more, than what this is.... I was like, “ Are you kidding me? I’ll finish this. I won’t finish in three hours, but I’ll finish it. And, nothing is going to stop me.”

While participant 5 shared,

I have had some low points in my life and there are going to be low points in the race, like, “Ooh, I hate this. Why am I doing this?” Just like anything.

These results indicate that, for this sample, the experience of going through cancer and treatment can be very similar to the experience of training for and participating in a marathon. Both are challenges that require physical and mental determination, calling for people to push themselves beyond what they may have thought was possible.

### *How do Participant’s Marathon Experiences Connect to Their Cancer Experience and Recovery?*

For some participants, (n=4) their experience with training and participating in marathons was very closely tied to their experiences with cancer. For 2 participants, though, this connection was not something they actively thought about; however, during

interviews, they could reflect back on their experiences and see how the two could be connected. The following themes emerged in relation to running and marathons and cancer: How a sense of control can be lost during a cancer diagnosis and treatment and the impact running and marathons can have on a person's sense of control, goal setting and its impact on recovery, and the ability to feel "normal" again and sometimes even better than normal. Each topic is explored below.

### *Loss of Control*

Each participant was asked, during interviews, if they felt their cancer diagnosis and treatment left them feeling like they had lost control over their body and life. Most (n=5) participants agreed that, in some ways, their cancer diagnosis and treatment caused them to lose some form of control. Participants shared that they felt they had lost control by not knowing what was going to happen to them and feeling like they did not have control over their bodies, due to their symptoms as well as feeling like they had given their bodies over to doctors and their treatment. Only one participant shared that she experienced a loss of control due to feeling like she wasn't herself anymore. An interesting point is that this participant was the only woman who had not been a runner before and immediately after her diagnosis and treatment. Though it is based on speculation, it is possible that the other participants were able to sustain and gather strength from their identity as runners, even at times when they weren't physically capable of running. It is important to note, though, that the other participants continued to do some form of exercise either during or very shortly after their treatment.

Three participants shared their feelings in connection to not knowing how their treatment would go and not being able to have a sense of control over their diagnosis or

the outcome of treatment. Participant 1 spoke of, “Not knowing where the finish line is,” which was a appropriate metaphor for the women’s feelings of uncertainty, while

Participant 5 shared that she felt like a victim and couldn’t do anything about it.

Participant 1 also shared the following,

Cancer is like... going on a trip you don’t want, you don’t need, and you didn’t ask for. It’s a trip without a road map. You are given general guidelines. It’s like being put out on the moon in a vehicle and saying, “Let’s try this,” and you don’t know where the end is. So, you do feel out of control.

Participant 4 also shared similar feelings about the unknowns of cancer. She stated,

It’s the feeling of despair, of fighting something that you don’t see that may be taking over your entire body and you’re not even aware of it. You’re doing everything that you can and fighting it with all the tools and weapons that they give you, but you are not even sure that you are going to respond to treatment. And that was my biggest fear, because if a person doesn’t respond to treatment, then, that’s it. So there is that sense of fighting the unknown and having this thing, this invasive thing, in your body and taking over. It’s like being in a room with your eyes blindfolded and being asked to kill the enemy. You don’t know where the enemy is standing.

Four participants shared that they felt they lost control during their diagnosis and treatment because they felt like they didn’t have control over their bodies, which was manifested in various ways. Participant 3 shared that her body stopped acting the way it used to, while Participant 5 stated,

I felt my body abandoned me. I remember I started getting hot flashes, I remember [thinking], I don’t need this stuff.

Participant 1 shared the following,

You are giving up control, and you see so many physicians, oncologists, and the radiation person and the chemo person.... All of a sudden you are thrown in with people who you want to help you but you don’t want to know them....So you get this feeling of, I’m really glad you are here to help me, but I really don’t want to be here... For however long you are in treatment, your life is in someone else’s hands.



Participant 2 stated,

I never used to take medication, and I had to throw that all out the window. I took everything they gave me.

These results show that participants' cancer diagnoses and treatment caused changes in their bodies and also required the women to, not only question their survival, but also make decisions about their bodies based on medical professionals; all of which represented a significant loss of control for them in relation to how they felt and saw themselves and their life before cancer. Also important to this study was finding out if the women's experiences with training and participating in a marathon could provide them with an opportunity to regain a sense of control that was lost. While many participants discussed control in relation to their marathon experience, it was also closely tied to other ways in which their marathon participation connected to their cancer experience and recovery. For this reason, control will be discussed along with the other themes that were present in the narratives.

#### *Impact of Marathon Training and Participation on Recovery*

Participants responded to questions about the impact marathon training and participation had on their cancer experience, recovery, and sense of their bodies. The following themes emerged from participants' stories: regaining control, the impact of setting and accomplishing a goal, feeling "normal" again and, sometimes, even better than normal.

##### *Regaining control.*

When asked about whether or not participants were able to regain a sense of control over their bodies and life, participant's responses varied, with one participant

citing control as the entire reason she decided to run a marathon and another feeling like control didn't have anything to do with her marathon participation. Participant 1 shared the following:

So running the marathon and having a set schedule put me in control, once more, of my body. And that was very helpful. I wasn't just free floating anymore, not knowing where the finish line was...The marathon does give you that. So, I had a little bit of control and the rest was out of my hands, and getting that back was good.

Participant 3 also spoke of her marathon training and participation as a way to feel in control over her body again. She stated,

I needed to take control of my life again, and my body, and I wasn't going to let my body dictate any longer that I couldn't get out of bed in the morning or that I had to be in bed by 7 o'clock at night. [I] was like, No body, your going to listen to me now.

Participant 5 also shared her feelings on control when she shared the following:

I think it... gives me structure...for my day.... I like how I feel, in shape. That's a good feeling of control.

Some participants appeared uncomfortable with the idea of control and could not immediately connect their experience of marathon running with having or regaining a sense of control. However, as participants shared their stories, it seemed that they were more able to recognize the ways in which their experience did offer them feelings of control, though they may not have labeled it as such, initially.

#### *Goal setting.*

Goal setting was mentioned earlier in this section as a reason for choosing to participate in a marathon but will now be discussed in relation to its impact on recovery.

The importance of goal setting and the use of training and participating in a marathon as a way to set goals was discussed by all 6 participants. Goal setting was not only a way to

make it through the cancer treatment, as it was for participant 4, but also method of distraction and pushing oneself to achieve something. Participant 4 was very clear about how her cancer experience was tied to her marathon experience. When discussing her decision to train for a marathon she stated,

It became a goal. It became something that, if I'm alive, I'm going to do it. I want to be alive so that I can do it. It became something that I held on to.... So the two were the same; fighting the illness and being able to run the marathon was one big thing. Running the marathon was conditional to being successful with my treatment. If I was going to finish the treatment and be ok, then I was going to run a marathon. That was it. No ifs, and, or buts.

Participant 2 also felt like her cancer experience was tied to her marathon experience, and expressed this by sharing the following:

I think the pairing of running and getting through cancer is like, there's something about it. There is something about the whole idea of the marathon of life... You set up a goal to do something, and you do it with something in mind that makes you stronger and is for a good reason. I think there's a lot of ways in which running and cancer come together.

Participant 6 didn't initially see a connection; however, during the interview she recognized that there was a relationship between her marathon experience and cancer experience. She shared the following:

I didn't really think about that at the time, but, looking back now, I'm thinking, it's like, You conquer cancer, You conquer the marathon.... I have always been a person who set goals like that and I set goals with running... That was a huge mountain to conquer, both the cancer and the marathon. The marathon was actually a bigger mountain, believe it or not.

Other participants used the goal of marathon running as a way to be focused on something other than the challenging physical and mental effects of their diagnosis and treatment. Participant 1 stated,

It helped me also because I had a goal. I wanted to get back to that, and I think having a goal helps you see the light at the end of the tunnel. You have a crappy day, and you say, "Why am I still doing this? I might as well throw in the

towel.”... Having friends to say, “Don’t be self absorbed, put your energies somewhere else.” It definitely helped my recovery.

Participants 3 and 5 also used their training and marathon participation as a goal to be reached. For Participant 3 it was a way to work through her challenging symptoms. She shared,

Well, it’s a real mental and emotional thing. I really believe that your body can recover if you put your mind to it.... There was a point in time that I wasn’t going to die of cancer. I didn’t have leukemia, I didn’t have blood cancer; I mean I had cancer, but not as bad as a lot of people. I was going to die of depression. It was like, whoa, what is this? I just said, “Uh-uh, I can’t. You know, I’ve got to... put my mind to this, and I’m going to run a marathon. I’m going to.”... And I did. I have not felt better, since. During the actual training, I had a few complications, actually, but I was determined. I was like, No way. Nothing is going to take me from this earth; I am going to fight this.

These results show the impact of goal setting and the ways in which participants used the goal of running a marathon as a tool to make it through the aftermath of diagnosis and treatment, a distraction from the challenges caused by a cancer diagnosis and treatment, and a way to make meaning of their cancer experience.

*Feeling normal and better than normal.*

Another impact of marathon training and participation was the ability to feel “normal” again, and, in some cases, even better than before a cancer diagnosis. Four participants discussed how their training and marathon experience affected their sense of their bodies and their ability to see themselves as normal. Two of these participants also shared that their marathon experience allowed them to feel better than they had before they were diagnosed with cancer. The following examples describe participant’s feelings in regards to how their marathon participation impacted their sense of normalcy and

sense of their bodies. Participant 4 shared,

It gave me the sense that I could even be better than I was before. I'm not going to let this destroy me.... I was stronger. I was in better shape. I was slimmer. I was looking better than ever before.

Participant 5 stated,

I felt like I was getting back to normal. This is the way I thought of myself. I think of myself as a runner; ok, so I completed this marathon. I did this and I am going to do another one and another one. So this was fine... I was back to normal. It was real.

These results suggest that marathon training and participation can greatly impact a woman's recovery from cancer, in varying, yet equally significant ways.

## CHAPTER V

### DISCUSSION

The purpose of this research was to learn about the experiences of women who had trained for and participated in a marathon after they had been diagnosed with cancer. This study sought to explore women's motivation for choosing to participate in a marathon after their cancer diagnosis as well as the relationship between their training and participation and their recovery process. Further, this study attempted to investigate whether training for and participating in a marathon allows women, in recovery, to regain a sense of control over their bodies that may have been lost during the process of diagnosis and treatment. The role of exercise on recovery from cancer has been widely researched; however, there is a lack of research on the effects of extreme exercise, such as marathon running, which was the reason for this exploratory study. This section will compare the findings of this study to the literature on control, recovery, and exercise, while also addressing the implications for the field of social work, implications for further research, and the study's limitations

#### *Why do Women Choose to Train for and Participate in a Marathon?*

The key findings, in relation to women's motivation for choosing to participate in a marathon, were that it was closely tied to their pre-cancer identity, it allowed them to feel reassured about their body's capabilities, and it provided an opportunity to set and achieve a goal. When designing this study, it was unclear whether participants would have had previous running experience, before their post-cancer marathon. For this

sample, 5 participants had been runners, and 3 of them had already completed 1 or more marathons. This impacted the results because it separated the runners from the one participant who had not been a runner before her marathon participation. The other participants were eager to continue to identify themselves as runners, which is consistent with the findings of Gordon (2008) and Ulman (2008), both of whom were athletes before their cancer diagnosis and emphasized the importance of being able to continue to identify this way after their diagnosis and treatment. The Crocker et al. (2007) study, which looked at breast cancer survivors' experiences with a dragon boat program, was the most similar study to the present research. A big difference, though, is that participants in the Crocker et al. (2007) research could only participate in the dragon boat program if they previously had cancer, while running and marathon participation are open to anyone. While there are many similarities between the two studies, which will be discussed in this section, the Crocker et al. (2007) study focused on the program's ability to provide participants with a new identity, while this study showed that marathon participation, for people who are already runners, can assist in allowing women to continue to identify themselves as they did before their cancer diagnosis.

Another reason that was cited, for choosing to participate in marathon, was the ability to feel reassured about one's body's capabilities. Participants shared that they chose to train for a marathon because they thought it would help them to see that their bodies were ok, reminding them that they could fight back against the physical and emotional challenges of their diagnosis and treatment. This finding is supported by the research of Crocker et al. (2007) whose participants also cited, as a reason for their participation in the dragon boat program, a need for reassurance in their bodies. While

the majority of the literature reviewed did not focus on participants' motivation for participation in exercise, research done by Adamsen et al. (2006) and Maruyama and Pinto (1999) report on the negative impacts of a cancer diagnosis and treatment. Adamsen et al. (2006) reported that most of their sample, of 55 cancer patients, chose to participate in their group exercise program because of physical debilitation. Maruyama's and Pinto's (1999) comprehensive review of the literature on the relationship between exercise and the rehabilitation of breast cancer survivors highlights the negative symptoms associated with cancer, such as fatigue and depression, as well as what can be impacted by cancer, such as body image and mood. These symptoms were also described by the participants of the current study and were motivating factors in their decision to participate in their post-cancer marathon training and participation.

Another reason for participating in a marathon was because it allowed the women to set and achieve a goal. One could say that the challenges of training for a marathon are generally uncontested. Training is often spread out over a period of many months and requires long hours of running and recuperation. While the training is a huge part of the process, crossing the finish line is the ultimate goal. Unlike other interventions and exercise programs, such as the ones researched by Courneya et al. (2007); Arora et al. (2009); and Adamsen et al. (2006), dropping out or skipping training is not an option when a person wants to get to the finish line. Eileen Hacker (2008), in her article about exercise and quality of life, discusses the challenges to adherence to exercise among people with or recovering from cancer. She states, "Adherence to exercise... remains one of the most complex problems to address for clinicians and researchers interested in implementing exercise programs" (p. 35). While the criteria for this study demanded that



all participants had actually completed a marathon, the process of training and participating in a marathon sets up an opportunity for goal setting that may limit one's desire to quit or not follow through.

Lisa Wall (2000) shared that the results from her research, done with 104 lung cancer patients involved in an exercise program, "...support the notion that individuals who knowingly and actively participate in their care have a more positive outlook than those who are passive participants" (p. 240). While her research was done with people who were all actively receiving treatment for cancer, the sample from this research could be described in a similar way. By setting a goal of running a marathon, the women in this study were forcing themselves to not be passive; they were actively choosing to set themselves up for achievement, which provided them with many positive benefits that might not have been achieved had they sat back and waited for things to change or get better.

*What Were Participants' Experiences with Training for and Completing Their First Post-Cancer Marathon?*

One of the main findings, in connection with participants' experiences with training and marathon participation, was that training for and running in a marathon can be similar to the experience of going through treatment. Many of the participants mentioned the similarities between their chemotherapy and radiation treatment and their marathon training. Both experiences require one to push past pain and discomfort and continue on, even when quitting or stopping seem like a better idea. Both treatment and marathon training can take many months, and participants shared that one experience prepared them for the other. For participants who had run marathon before their

diagnosis, their experience with training set them up to deal with the challenges of treatment. For other participants, who went through treatment before ever running a marathon, their experience with treatment gave them the knowledge and strength to know that they could push through their training. For women who have gone through the experience of marathon training and running, it seems like what was gained from this experience can be very helpful in dealing with the challenges of cancer treatment. For women who are training for and participating in a marathon, after their cancer treatment, what they learned through their treatment experience can be applied when pushing through the challenges of training and marathon participation.

*How did Participants' Experiences Connect to their Cancer Experience and Recovery Process?*

Another main finding was that the participants' experiences with training and participating in marathon positively affected their recovery by allowing them to feel in control of their bodies and lives, have and reach a goal, and feel like their bodies were back to normal or even better than they had been before their diagnosis.

The findings from this study support the findings and information shared by Wall (2000); Crocker et al. (2007); Ulman (2008); Courneya et al. (2007); Cantor (1978); Bowker (1996); and Benjamin (1995), all of which support the notion that diagnosis and treatment of cancer can cause a person to feel like they have lost varying aspects of control in their life. The women in this sample, like the dragon boat participants in the study done by Crocker et al. (2007) and the women in the research done by Courneya et al. (2007), found that cancer made them feel like they were no longer in control of their bodies. Of note, though, is that this was not true for all participants in this sample. One

participant did not feel like her cancer experience caused her to lose any form of control in her life; however, exploring the reasoning behind her feelings was not within the scope of this study.

Recently, in the online version of the New York Times, there was an article written by a man who is in the process of training for a marathon, after his diagnosis and treatment of prostate cancer. Dana Jennings, the author, wrote the following:

My goal last fall was to fully recover from surgery for prostate cancer and to slog through radiation and hormone therapy. My goal this fall is to run a marathon. In the past year, my body has belonged to urologists and insurers, surgeons and oncologists, nurses and radiation therapists. It belonged to my cancer. By running again, I'm reclaiming ownership of my body. ... I've spent the past year enduring the forced march that is cancer. Now I want to do a marathon on my own terms" (Jennings, 2009).

Jennings' words reflect the feelings of most of the participants of the current study, expressing the impact that running and marathons can have on a person's sense of control and sense of their bodies, as well as the impact of goal setting. While not all participants cited marathon running as a vehicle for regaining control in their lives, the participants that did identify a relationship between control and their marathon experience reported feelings that were very similar to those reported by the women in the Crocker et al. (2007) study. These findings suggest that marathon training and participation, as well as dragon boat racing, are activities that can assist women, in recovery, in regaining control in their lives.

The impact of goal setting was discussed by all 6 participants and represents a major finding in this study. Mentioned earlier in this section was that goal setting was a reason why participants chose to participate in a marathon; however, it was also found that the ability to set and reach a goal of running a marathon had an immense impact on

participants, in a positive way. The participants shared that having a goal allowed them to push themselves to make it through their treatment, and the challenges that followed, and distract themselves from their feelings and symptoms associated with their diagnosis and treatment. These findings support the findings of Crocker et al. (2007), whose participants shared that dragon boat racing was an effective distraction from and coping mechanism for dealing with the stress and symptoms caused by their breast cancer diagnosis.

In reviewing participants' responses, it has also become clear that, for some participants, reaching their goal of finishing their first post-cancer marathon was equated with beating their cancer, or at least not succumbing to it. It represented a transition; if they could finish the marathon, then they were ok. Participants described this feeling as being able to feel normal again, while some participants shared that their marathon experience allowed them to feel even better than they had before their diagnosis. The idea of feeling normal again supports the research of Courneya et al. (2007) and Adamsen et al. (2006) and was also reported by Ulman (2008).

#### *Implications for Social Work*

This study can inform social workers who work with women who either have, or have had, cancer, in a variety of different practice settings. Marathon running is a sport in which a very small percentage of people engage. The findings from this study, though, suggest that marathon participation can positively impact women in recovery from cancer, in a variety of ways. Most people think, like most of the participants of this study initially did, that participating in a marathon is "crazy" or "impossible." While a woman should consider her physical capabilities, the participants in this research clearly show

that participation in a marathon is not unattainable. Many of the women in this study shared that they would encourage other survivors to try marathon running, suggesting that this may be a sport and experience that should be more widely suggested and introduced to survivors. It also became apparent, through participants' passion for and identification with running, that social workers and other professionals should encourage women to continue their passions, if it is possible. One participant shared that she was discouraged from running, by one of her doctors, and immediately found another doctor, who supported her passion. It is imperative for social workers, and others working with female cancer survivors, to be able to see the whole person, not just the cancer, and to encourage women to find ways to sustain their identities as they face the challenges of their diagnosis, treatment, and recovery.

Many of the women discussed how they felt they had given up control to health care professionals as well as how their diagnosis and treatment left them feeling not in control of their bodies and their lives. These findings suggest that it is important for social workers, and others, to consider ways to limit and attend to this loss of control. While it may not be marathon running for every woman, this research implies that it is necessary for women in recovery to find ways to regain a sense of control.

#### *Implications for Future Research*

This study serves as an exploratory look into the experiences of female cancer survivors who have trained for and participated in a marathon, after their cancer diagnosis. There is a need for future research, regarding various aspects of this research study. While the findings from this study suggest that women can lose a sense of control during their diagnosis and treatment, future research is needed to explore the reasons why

some people might not identify with a loss of control, such as the one participant in this research. What are the reasons why some women can remain in control, despite the challenging emotional and physical effects and the requirement to hand your body over to so many health care professionals?

There is also a need for future research with a sample that is made up of women who were not runners before their post-cancer marathon. The one participant in this study, who had not been a runner before her marathon experience, had some different reasons for choosing to participate in a marathon, and her experience also, in some ways, impacted her in different ways than it did the other women, because it was a profoundly new experience for her and not specifically connected to her pre-cancer identity.

It may also be beneficial for future research to use a sample that consists of participants who are training for a marathon with an organization or team, whose participation is limited to cancer survivors. As marathon running becomes more popular, along with cancer survivorship, there will be more opportunities for survivors to train and run with other survivors. This could have an immense impact on their experience and what they are able to take away from it.

#### *Limitations to Present Study*

There are a number of limitations to the present study. The small sample size limits the ability to generalize the findings to the larger survivor community. Five out of six participants identified as white or Caucasian, preventing the study from including a racially diverse sample. Another limitation was that the women did not all have the same type of cancer or receive the same treatments. While this showed that marathon participation is not contingent on certain treatments or types of cancer, it also limited the

study because participants had not all experienced the same types of symptoms and challenges, which impacted the ways in which their recovery was affected by their participation. Also of note, women who dropped out of training or participation in a marathon were not considered for this study; findings were limited to women who had reached their goal of running a marathon after their cancer diagnosis.

### *Conclusion*

The current study provides useful information about the experiences of female cancer survivors who have trained for and participated in a marathon, which has not been previously covered in the literature. The findings from this study can inform people working with women in treatment, as well as those in recovery, about the positive impact that training and marathon participation can have on women who have faced the numerous, taxing challenges that come with cancer diagnoses and treatment.

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Appendix A

**Human Subjects Review Committee Approval Letter**

March 1, 2009

Elizabeth Donahue

Dear Elizabeth,

Your amended materials have been reviewed. All is now in order and we are glad to give final approval to your study.

*Please note the following requirements:*

**Consent Forms:** All subjects should be given a copy of the consent form.

**Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your very interesting study. I am so impressed with anyone who runs a marathon and even more impressed with cancer survivors who take this on. It will be fascinating to discover the meaning all this had for them.

Sincerely,

Ann Hartman, D.S.W.  
Chair, Human Subjects Review Committee

CC: Jennifer Perloff, Research Advisor

## Appendix B

### **Informed Consent Form**

Dear Participant,

My name is Elizabeth Donahue and I am a student at the Smith College School for Social Work. I am currently studying to get a masters degree in social work. As part of my education, I am conducting a research project, which will conclude in a thesis. I am doing a study to learn about the experiences of women who have had cancer and, after their diagnosis, trained for and participated in a marathon. Specifically, I would like to learn about how training for and participating in a marathon can affect the recovery process and whether there is an effect on a person's sense of their body. My hope is that this research will provide you with an opportunity to share your experience and educate others who are either working with people who are in recovery or are in the recovery process themselves. The findings from this study will be used for writing my thesis and for its professional presentation. It is also possible that the findings will be used for publication.

You are being asked to participate in this study because you are a fluent, English speaker who has been diagnosed with cancer and trained for and participated in a marathon, within 10 years after your diagnosis. Your participation will include a 45-60 minute interview with me. This interview will be semi-structured, which means that I will come to the interview with questions but will allow you to provide me with any information you see fit for the study. Some demographic data will be collected, which

will allow readers to connect your experience to others who may be similar or different from you.

Though there are no anticipated risks for participation in this research, there is the potential for challenging emotions to come up while discussing your experience with cancer and recovery. Speaking about your experiences with training for and participating in a marathon may be emotional and participation will require you to identify as someone who has had cancer. If you feel you need support after participating in this research, referral sources are attached to this form. Sources include ways to reach support groups, educational information, and individual counseling.

The benefits of participation in this study include the opportunity for you to share your experience with others, which will, hopefully, not only prove to be a positive experience for you, but also give you the opportunity to provide invaluable information to women in similar situations in the future and to those that are working with women in recovery from cancer. Your experience may provide other survivors with the inspiration to see their recovery in new ways and may encourage survivors, as well as providers, to expand their views of what is possible during recovery from cancer. There will be no monetary compensation for participating in the research.

Every effort will be made to provide confidentiality to you. All names will be removed from data, and all participants will be referred to by numbers. This Informed Consent Form will be kept separate from all data, such as tapes and transcriptions. My research advisor will have access to the data after all names have been removed. Due to the extensive data being collected, anonymity cannot be ensured, though confidentiality will be provided to all participants. All narrative and quotes will be

carefully disguised using participant numbers. All written data will be stored in a secure location. Any electronic information will be stored on a flash drive that will also be stored in a secure location. All data and tapes will be kept in a secure place for three years as required by Federal regulations, and if there is a need to keep data after this time it will continue to remain in a secure location. When the data is no longer needed, it will be destroyed.

Participation in this study is strictly voluntary. You may chose to withdraw from the study during or after the interview process, and you may also let me know if you do not want to answer any of the questions I propose. If you do not let me know that you would like to withdraw from the research by April 15<sup>th</sup>, your data will be included in the study. Once you have chosen to withdraw, all data pertaining to you will be destroyed.

If at any time you have questions or would like to withdraw from the study, please contact me by phone at: (.....) or by email (for questions): (.....) Should you have any concerns about your rights or about any aspect of the study, please contact me. You may also call the Chair of the Smith College School for Social Work Human Subjects Review Committee at: 413.585.7974.

Thank you so much for your participation in this research. Please keep your copy of this form for your records.

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR**

**PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO  
PARTICIPATE IN THE STUDY.**

\_\_\_\_\_  
Participant Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher Signature

\_\_\_\_\_  
Date

## Appendix C

### **Demographic Questionnaire**

Please fill in the following information. If you do not want to share certain information, please leave it blank.

Thank you!

Age:

Race:

Ethnicity:

Education Level:

Profession:

Household Income: (please circle)

\$25,000 or less   \$25, 000-50,000   \$50,000-75,000   \$75,000-100,000   \$100,000 or more

Relationship Status:

Time since diagnosis:

Type of diagnosis:

Treatment received:

Time since treatment ended: (if applicable)

Previous running experience: (before marathon)

Training experience (individual or group, length of time)



## Appendix D

### Interview Guide

1. How did you come up with the idea to train for and run a marathon?
2. What was it like to train for and run your first marathon, post-cancer?
3. Who or what was your support?
4. Do you feel the process of training for and participating in a marathon aided in your recovery?
  - A. Do you see and feel your body differently?
  - B. Do you feel like you lost a sense of control during your cancer diagnosis and treatment? If so, do you feel like your marathon experience allowed you to regain a sense of control?
  - C. Did your marathon experience change the way you felt about your diagnosis and cancer experience?
5. How did your life change after being diagnosed with cancer?
6. Do you feel like your life, overall, has changed since your experience with training for and participating in a marathon?