Leisure as a Facilitator of Posttraumatic Growth in Individuals Living with Cancer

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# Abstract

Although there is a growing body of literature that shifts the focus of chronic illness and trauma research to personal growth, there is limited literature on the role that leisure has in this process (e.g., Tedeschi & Calhoun, 2004). This qualitative study explored the role of leisure in the phenomenon of posttraumatic growth (PTG) for individuals living with cancer. The findings revealed that leisure influences PTG in four domains: (a) building meaningful relationships, (b) providing experiences to develop and maintain a sense of self, (c) creating opportunities to experience positive emotions, and (d) finding purpose in life. Findings provide insight on how individuals living with cancer perceive the role that leisure has in facilitating positive change after diagnosis. These findings will better enable healthcare and leisure providers to understand the unique needs of individuals living with cancer, and help them to facilitate meaningful leisure programs to encourage PTG.

Key Words: leisure, posttraumatic growth, cancer, chronic illness

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## **Chapter One: Introduction**

The number of people living with chronic illnesses and disabilities has increased as a result of medical advancements enabling people to live their lives with improved health conditions (Lee & McCormick, 2002). In Canada, 15.7% of the population over the age of 20 is living with at least one chronic illness (Canadian Cancer Society, 2014). Among various chronic illnesses and disabilities, cancer is one of the leading causes of death in Canada; it was estimated that there would be over 191,300 new cases of cancer diagnosed, and approximately 76,600 deaths due to the disease in 2014 (Canadian Cancer Society, 2014). However, due to improvements in diagnosis, screening, and treatment approximately 63% of Canadians diagnosed with cancer are expected to survive for 5 years or more (Canadian Cancer Society, 2014). The diagnosis of cancer is not only a single traumatic event; rather, it is a chronic stressor that results in ongoing stressful experiences that presents enduring challenges and obstacles (Scrignaro, Barni, & Magrin, 2011). Chronic illnesses often require adjustments in one's lifestyle, as the illness can affect various aspects of an individual's life beyond physical health deficits. For some individuals, acknowledging their diagnosis of chronic illnesses causes psychological and social distress.

Individuals can face challenges in adjusting their lifestyles, whether it is integrating the illness into one's identity, reducing secondary symptoms through the development of healthier habits, or redefining the self through leisure and social pursuits (Lee & McCormick, 2002). People often experience psychological distress in the form of depression, anxiety, fear related to death and dying (Anar et al., 2012), and occasionally posttraumatic stress disorder (PTSD; Sawyer, Ayers, & Field, 2010). Social distress is

also common in individuals living with cancer due to the tension that results from changing social roles, as well as the incorporation of illness into identity (Shannon & Shaw, 2005). A chronic illness, such as cancer, can threaten the identity of an individual, and can, therefore, cause a disruption in their life story. The life story is comprised of past, present, and future selves, and incorporating the illness can often be challenging for the individual to divide the narrative into before and after trauma (Bury, 2001; Lee & McCormick, 2002).

Although the majority of research focuses on the deficits associated with chronic illnesses, there is a growing body of literature that shifts the focus to personal growth and thriving for individuals who experience trauma. The positive psychology movement fuels posttraumatic growth (PTG) research (Snyder & Lopez, 2002; Tedeschi & Calhoun, 2004). The phenomenon of PTG is conceptually defined as, "positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (Tedeschi & Calhoun, 2004, p. 1).

PTG literature has identified that people experience PTG in the midst of traumas including: bereavement (Calhoun & Tedeschi, 1989-1990), HIV infection (Sawyer et al., 2010), heart attacks (Laerum, Johnsen, Smith, & Larsen, 1987), sexual assault and sexual abuse (McElheran et al., 2012), traumatic brain injury (Powell, Gilson, & Collin, 2012), spinal cord injury (Chun & Lee, 2010), and cancer (Manne et al., 2004; Morris & Shakespeare-Finch, 2011; Scrignaro et al., 2011; Shannon & Shaw, 2005). When an individual experiences PTG, they will likely experience a greater appreciation for life, more meaningful relationships, a sense of gain in personal strengths, discovering of new possibilities and life paths, as well as increased spirituality or faith (Tedeschi & Calhoun,

2004). PTG literature addresses these transformations as domains for change, and there is evidence of the contribution of leisure in these areas (Tedeschi & Calhoun, 2004). After experiencing a distressing life event or trauma, individuals often express new interests, changed priorities, and occasionally new life paths (Tedeschi & Calhoun, 2004). There is a growing body of empirical evidence to suggest that leisure plays a role of coping during these novel life experiences and in rewriting the life story of individuals posttrauma (Chun & Lee, 2010; Hutchinson & Kleiber, 2005).

In the leisure field, much attention has been paid to the role that leisure has in coping with stressful life events and circumstances. The leisure literature has evolved in the past 2 decades to explore leisure experience from different perspectives including leisure stress coping, leisure and strengths and resilience, as well as leisure as a means to retain normalcy, sustain motivation, and facilitate personal transformation. Iwasaki and Mannell (2000) "proposed a new conceptualization of leisure stress coping that identifies a variety of ways in which leisure helps people cope with stress" (p. 177). Their study developed a hierarchy of leisure coping mechanisms and identified a difference between people's beliefs about coping and their coping strategies. They also stated that leisure stress coping is multifaceted suggesting that there are many dimensions of leisure that enable individuals to cope with stressful life events including Coleman and Iso-Ahola's (1993) feelings of self-determination, social support, as well as personal autonomy, tangible aid, and mood enhancement. More recently, Von Lob, Camic and Clift (2010) explored the role of singing as a recreational activity in response to adverse life events and provided empirical evidence for Iwasaki and Mannell's (2000) leisure stress coping hierarchy. Additionally, while studying incarcerated women, Figueroa (2011)

demonstrated that leisure provided opportunities for self-reflection, increased self-esteem, a sense of agency and empowerment, as well as a sense of freedom. These conceptions of increased social and personal capacities provide further support for leisure's role in coping with stressful life circumstances.

The benefits of leisure in coping with stress are transferable to coping with trauma in that leisure pursuits that are freely chosen and in one's control helps individuals to see stress as a challenge, and motivates individuals to overcome that challenge (Coleman, 1993; Iwasaki, 2003). The latter suggests that leisure helps individuals restore self-value after traumatic events. Leisure activities that are enjoyable, meaningful, and intrinsically motivated allow individuals to explore their strengths, develop their skills, and find new meaning in life after trauma (Iwasaki & Mannell, 2000). Leisure can act as a vehicle for positive self-transformation and, thus, PTG after the diagnosis of cancer. Empirical data from Chun and Lee's (2010) study on individuals with spinal cord injuries suggests that engagement in leisure activities offered companionship, opportunities for the development of meaningful relationships, and the chance for individuals to find their unique talents which contributed to the experience of PTG.

## **Purpose of the Study**

PTG literature has explored psychological growth and identified various domains that suggest a change in attitudes and beliefs (Prati & Pietrantoni, 2009; Sawyer et al., 2010; Tedeschi & Calhoun, 2004). However, there is minimal literature that addresses the behavioural changes that occur during the experience of PTG (Shakespeare-Finch, Martinek, Tedeschi, & Calhoun, 2013).

In terms of negative life events, leisure coping literature provides an in-depth exploration of the various ways that leisure acts as a coping mechanism, enabling individuals to develop a resistance to negative life events as well as acting as a buffer during trauma (Iwasaki & Mannell, 2000). Kleiber, Hutchinson, and Williams (2002) also explored the area of leisure coping and suggested that leisure is a means of adjusting to negative life events and provides an opportunity to experience a sense of control and allow self-determination. This implies that leisure has an important role in life transformation following negative life events. Therefore, further exploration of the role that leisure has in the experience of trauma is necessary to understand the phenomenon of PTG rather than examining the traditional conceptual context of leisure and stress coping (Kleiber, 2004). Moreover, no empirical study has examined leisure as a facilitator of PTG in individuals living with cancer. Traditional cancer research has focused on negative aspects of the disease and the paradigm must shift to a positive perspective, where individuals can grow and thrive in the midst of their experience. Therefore, the purpose of this thesis is to explore the role of leisure in the experience of PTG in people who have experienced cancer.

## Significance of the Study

By exploring the use of leisure in facilitating PTG, the present study will contribute to the body of literature that exists in the field of PTG and leisure, and will act as a bridge between the fields. The PTG literature has focused on the social and psychological processes of PTG, and this study seeks to incorporate human behaviour as well. This means including a person's intentional behaviour and leisure interests into the exploration of PTG. This could contribute to building the body of knowledge around

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leisure and PTG by sparking an interest in other researchers to explore the phenomenon of PTG holistically. This present study will also shed light on the use of leisure in rewriting a life story posttrauma and the meanings people associate with leisure in their lives. Furthermore, understanding how individuals who live with cancer perceive the role that leisure has in facilitating positive change will better enable healthcare and leisure service providers understand their unique needs and help them to facilitate meaningful leisure programs.

Additionally, by exploring the role of leisure in PTG, healthcare providers and leisure providers will be able to facilitate therapeutic interventions that develop social resources as well as psychological coping responses that will, in turn, facilitate experiences of PTG and enhance the well-being of individuals posttrauma through the use of meaningful leisure activities.

# Limitations

The findings of the present study are limited to the scope of this study. The participants selected to participate in this study were purposively sampled under the criteria that they showed signs of PTG. This would suggest that these individuals might perceive their experience with cancer as having some positive outcomes, as they have experienced personal growth through their experience with cancer. Therefore, the findings will not be able to be generalized to individuals who perceive their diagnosis as a strictly negative experience.

Due to the time period of data collection and the short duration of data collection, the findings only reflect the leisure behaviours of the current season, and will not be able

to explore leisure behaviours of the participants year-round, or the development and growth of PTG in individuals.

The participants in this study reside in South Western Ontario, and, therefore, the findings may not explain individuals who live in diverse parts of the world. Additionally, as this is a qualitative study, the age, gender, and stage of disease were not controlled for and, thus, may be diverse in leisure behaviours.

# **Definitions of Terms**

- Chronic Illness: Illness that involves long-term treatment and can cause withdrawal from a normal social role. Cancer is a chronic illness by definition, as there is currently no cure for cancerous diseases (Lee & McCormick, 2002).
- Leisure: Leisure has historically been understood as an activity (Kelly, 1990), as a period of time (Shivers, 1989), and as an experience (de Grazia, 1962; Neulinger, 1981, Pieper & Dru, 1964). For the purposes of this study, leisure will be defined as the experience, state of mind, and perception that individuals associate with meaningful leisure activities.
- Post-Traumatic Growth: PTG is conceptually defined as, "positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (Tedeschi & Calhoun, 2004, p. 1). This study challenges this definition of PTG to a more holistic definition that includes components of behavioural and social change.
- Trauma: Tedeschi and Calhoun have accepted the working definition of trauma as, "a set of circumstances that represent significant challenges to the adaptive resources of the individual, and that represent significant challenges to individuals' ways of

understanding the world and their place in it" (Janoff-Bulman, 1992, as cited in Tedeschi & Calhoun, 2004, p. 1). The trauma addressed in this study is the diagnosis of cancer.

# **Personal Experience**

As an individual, I am emotionally drawn to exploring the positive changes that can come with a diagnosis of cancer. Cancer has immensely affected my family, as it has been found that our family carries a gene that increases the risk of cancer up to 80%. I have found that doctors and nurses focus on the deficits and treat the symptoms, but do not address how to live well. I have also witnessed that the leisure behaviours of those who have been diagnosed with cancer change drastically, and I can see a decrease in the quality of life. I am interested to learn if the quality of life decreases as a result of the leisure engagements decreasing.

As a researcher, I am interested in shifting the focus to a positive view, where individuals with a cancer diagnosis can explore new leisure possibilities and live their lives more meaningfully and fully. My academic and professional background has focused on individuals with disabilities, and how they use leisure to cope and develop skills and self-confidence. I completed my undergraduate degree in Therapeutic Recreation with a minor in psychology, which gave me a foundation for the helping and healing field. I have worked for various organizations that cater to individuals with physical, intellectual, and developmental disabilities, as well as those who have mental health issues. I was exposed to PTG literature at the beginning of my graduate education and I was drawn to the positive focus of this phenomenon.

## **Chapter Two: Literature Review**

## **Illness Experience**

Due to medical and technological advancements, the number of deaths attributed to acute injuries and diseases have been significantly reduced; approximately 63% of Canadians diagnosed with cancer are expected to survive for 5 years or more (Canadian Cancer Society, 2014). As a result, the average lifespan of males and females has increased significantly, therefore, increasing the quantity of cases of chronic illness and disability in society (Lee & McCormick, 2002). The World Health Organization (WHO) defines quality of life as the "individuals' perception of their position in life in the context of culture and value systems in which they live" (Anar et al., 2012, p. 136). For individuals who experience chronic illness, there are many adjustments that must be made and the quality of life can be significantly affected due to treatment related aspects, social factors or intrapersonal factors associated with ill health. When a traumatic event, such as a diagnosis of a chronic or terminal illness, occurs, the life story of that individual is often disrupted. Chronic illness requires a constant adjustment, and it often includes redefining one's identity by evaluating life goals, integrating the disability into the identity, and reevaluating one's purpose in life (Lee & McCormick, 2002). This can cause great distress in an individual, and can have negative health consequences as stress often results in physiological and mental harm. The DSM-IV outlines that being diagnosed with a life-threatening illness has been recognized as an event that can precipitate posttraumatic stress disorder (PTSD) and, thus, requires proactive and precautionary measures to ensure the mental health of these individuals (Sawyer et al., 2010). Individuals with chronic illnesses cannot return to their previous physical health

status because life without disease is not always possible. Literature suggests that they can, however, recover socially and mentally within the context of their disease (Lee & McCormick, 2002).

# **Cancer Experience**

A common chronic and often terminal illness experienced by individuals is cancer. It has been estimated that 500 Canadians will be diagnosed with cancer each day during the year 2013 and 2 out of every 5 Canadians will develop cancer during their lifetime (Canadian Cancer Society, 2014. Therefore, cancer is a serious health concern for many persons, and shapes the lives of those who are diagnosed, as well as those who care for that individual (Shannon & Shaw, 2005). There are many identified types of cancer; however, in Canada, lung, breast, colorectal, and prostate cancer are the most common types of cancer and account for 52% of all new cancer cases in the country (Canadian Cancer Society, 2013). Although cancer is becoming more prominent in Canadians' health, it presents distinctive characteristics that affect the lives of individuals.

Cancer is a unique chronic illness in that it is often life-threatening and has many treatment-related challenges that may reduce quality of life (Anar et al., 2012; Charlier et al., 2012). Cancer survivors also have a potentially stressful posttreatment phase that can decrease their quality of life (Charlier et al., 2012). During posttreatment, the acknowledgment of potential reoccurrence contributes to the overall stress and trauma of the cancer experience (Morris & Shakespeare-Finch, 2011). These characteristics of cancer lead people who are diagnosed to reexamine their life priorities and roles, their significant relationships, as well as their own identity (Scrignaro et al., 2011). These

characteristics make individuals living with cancer a unique population to examine posttrauma, as there are many physical and psychosocial consequences of diagnosis.

Treatments for cancer commonly include radiation therapy, chemotherapy, and/or surgery. Radiation therapy uses high-energy radiation to damage the DNA of the cancerous cells, but can also damage normally developing cells and cause secondary symptoms (National Cancer Institute, 2012). Radiation therapy has various side effects including, but not limited to, fatigue; nausea; a development of scar tissue replacing normal tissues and potentially limiting range of motion; damage to surrounding organs such as bowels or reproductive organs resulting in diarrhea or infertility, respectively; memory loss; and an increased risk for a second type of cancer development later in life (National Cancer Institute, 2012). Radiation also increases the skin's sensitivity to sun exposure, which can dramatically influence the individual's daily activities and leisure pursuits (Shannon & Shaw, 2005).

Chemotherapy is another common treatment modality for cancer, and it uses a drug treatment to kill the rapidly reproducing cells (Anar et al., 2012). Chemotherapy has significant side effects that can affect the physical health of individuals as well as the social and psychological health. Vomiting and pain throughout the body including headaches, backaches, and limb pains are common physical symptoms of the treatment (Anar et al., 2012). A study by Anar et al. explored the effect of chemotherapy of 50 individuals with lung cancer and their quality of life after treatments. The study was holistic in that it included subscales of quality of life, which explored physical functioning, role functioning (the presence of an obstacle that presets constraints in carrying out daily work or activities), emotional functioning, cognitive functioning, and

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social functioning. The study found that receiving regular chemotherapy treatments decreased the individuals' levels of quality of life as it produced significant side effects that influenced decreased levels of physical and social functioning (side effects included: dyspnea, constipation, fatigue, nausea, insomnia, and alopecia). This study also found that there was a lack of correlation between the individuals' ages and their quality of life. suggesting that people of all ages experience similar chemotherapy-related symptoms. In contrast, another study that examined chemotherapy treatment-related variables affecting physical activity (PA) in women with breast cancer indicated that chemotherapy side effects, such as fatigue, negatively influenced physical functioning and, therefore, PA. Side effects, such as headaches, hot flashes, and nausea positively influenced engagement in PA suggesting that it did not impair physical functioning to the same degree (Charlier et al., 2012). Additionally, the literature suggests that anxiety, depression, and anorexia are common psychological issues associated with chemotherapy consumers as well (Herizchi et al., 2012). Pain is a significant issue for individuals living with cancer and it often, "leads to anxiety and emotional distress in the person, and negatively affects the functional capacity; moreover, inhibits the ability of accomplishing familial, social, and occupational roles" (Anar et al., 2012, p. 140).

The life-threatening aspect of the disease often prompts changes in attitudes and behaviours, and allows individuals time to reflect on the meaningful aspects of their lives. Some individuals experience great psychological stress and may develop PTSD, as well as a development of fear and anxiety related to dying. This influences and potentially disrupts individuals' life stories, and the way that they perceive themselves in relation to society (Charlier et al., 2012; Sawyer et al., 2010; Shannon & Shaw, 2005). Life stories

are written based on past recollections, their present self, and their future aspirations (Lee & McCormick, 2002). A life-threatening illness, such as cancer, threatens individuals' life stories, and forces them to change and adapt their story to the physical and social world around them. Literature suggests that individuals with a disability constantly "attempt to discover an alternative story to help them make sense of a life that involves an adjustment process and acceptance of limitations" (Lee & McCormick, 2002, p. 240). This suggests that a cancer diagnosis may challenge an individual's life story in the same way, as cancer confronts an individual with new limitations. Bury (2001) also argues that chronic illness can threaten a life story, as he states that "under conditions of adversity, individuals often feel a pressing need to re-examine and re-fashion their personal narratives in an attempt to maintain a sense of identity" (Bury, 2001, p. 264). Bury also suggests that the creation and rewriting of a personal narrative is a key feature "in the repair and restoring of meanings when they are threatened" (p. 264). The life story narrative of individuals with cancer is an important vehicle in understanding the cancer experience, the meanings that are associated with it, as well as the growth that it can cause (Bury, 2001).

The power of life story narratives are exhibited through a study conducted by Cayless, Forbat, Illingworth, Hubbard, and Kearney (2010) which sought to explore the experiences of 10 men identified as having prostate cancer. The researchers used qualitative research methods and in-depth interviews that continued throughout the first year after the men's diagnoses. Outcomes of prostate cancer and its treatments, such as incontinence, impotence, erectile dysfunction, pain, and rectal injury, were identified as key issues in the men's personal biographies, self-images and the way they thought others

perceived them (Cayless et al., 2010). It was concluded in this study that the diagnosis of cancer significantly influenced the men's perceptions of themselves, and both the disease and treatment formed key parts of the men's life narratives (Cayless et al., 2010).

The posttreatment phase for many individuals experiencing cancer is often described as a stressful experience. Although the treatments themselves are completed, the side effects can often linger. It has been suggested that after completing regular treatments, people feel abandoned as their regular contact with medical professionals cease and they are left on their own (Charlier et al., 2012). Although cancer is a lifethreatening illness, medical advancements have the capability of prolonging life, as "approximately two in three adults diagnosed with cancer today can be expected to survive more than five years" (Ries et al., as cited in Costanzo, Stawski, Ryff, Coe, & Almeida, 2012). Therefore, cancer has a lasting chronic impact on the life stories of those who are affected. It has been suggested in the literature that although there are many negative changes that occur in individuals after diagnosis, individuals will return to their normal mood and functioning within a year after the treatments are completed. It has also been suggested that many individuals experience profound positive changes in their lives after the cancer experience (Stanton, Bower, & Low, 2006).

# **Positive Psychology**

There has been a shift in the literature from the medical perspective of the negative aspects and deficits associated with cancer towards an outlook that is conducive to the potentially positive outcomes of living with cancer. It has been suggested that there is intention behind the traditional focus on negative emotions in psychology; negative emotions often reflect immediate dangers or threats to an individual and are often more

urgent than positive emotions that simply pass by with little conscious effort (Snyder & Lopez, 2002. The focus on negative emotions coincides with the survival aspect of human evolution and negative versus positive emotion, although it is important to note that positive and negative emotions often coexist (Morris & Shakespeare-Finch, 2011). Thus, a reduction of the adverse deficits associated with cancer does not inevitably result in an increase in subjective well-being (Carruthers & Hood, 2004). Positive psychology literature challenges the medical based deficit model to include the creation of positive capacities and experiences to promote well-being and life satisfaction (Carruthers & Hood, 2004).

Literature suggests that positive life events positively impact illness through general restorative powers as well as enable individuals to rebuild a sense of social agency, promote resilience, and foster adaptation (Davidson, Shahar, Lawless, Sells, & Tondora, 2006). It is also suggested that "in the presence of many positive events, negative events exert a small effect, or no effect, on distress" (Davidson et al., 2006, p. 152). Davidson et al. conducted a review of empirical research on positive life events and their effects on recovery from mental illness, and found that overall pleasure and positive experiences served as a respite from illness and counteract negative feelings of despair as well as provide opportunities for meaning-making of their experiences. The capacities that help people to flourish are the same as those that help people buffer their experiences of stress and chronic illness (Davidson et al., 2006). Positive life events and experiences can increase feelings of autonomy, an increased sense of purpose, self-acceptance, personal expressiveness, as well as personal growth (Carruthers & Hood, 2004).

# **Posttraumatic Growth**

The shift to focus on the positive aspects of trauma and an individual's ability to draw on positive psychology is the basis for PTG (Snyder & Lopez, 2002 Tedeschi & Calhoun, 2004). PTG is conceptually defined as the "positive psychological changes that are experienced as a result of a struggle associated with highly challenging life circumstances" (Tedeschi & Calhoun, 2004, p. 1).

The positive psychological changes that are experienced after trauma and challenging life events have been associated with flourishing, benefit finding, positive change, perceived benefits, thriving and stress-related growth, as well as PTG (Calhoun & Tedeschi, 1991; Chun & Lee, 2010; Sears, Stanton, & Danoff-Burg, 2003; and Tedeschi & Calhoun, 2004). However, PTG is distinctive because of its focus on traumatic life events. A trauma is defined by Janoff-Bulman (1992) as "a set of circumstances that represent significant challenges to the adaptive resources of the individual... and individuals' ways of understanding the world and their place in it" (as cited in Tedeschi & Calhoun, 2004, p. 1). For PTG to occur, a significant degree of threat must be experienced, suggesting that a terminal illness, such as cancer, is a prime opportunity to experience PTG (Linley & Joseph, 2004). Evidence indicates that higher amounts of PTG are experienced when the threat that is associated with the trauma is also higher (Calhoun & Tedeschi, 2006; Weiss, 2004).

Calhoun and Tedeschi (2006) argue that a "good way to judge whether an event is truly traumatic may be to consider the way it disrupts the personal narrative" (p. 9) suggesting that an event that divides the life story into a before and after structure is traumatic and thus capable of offering a foundation for PTG. As Calhoun and

Tedeschi(2006) suggest, "persons who experience [PTG] are living life in ways that, at least from their point of view, are fuller, richer and perhaps more meaningful" (p 7).

# **Domains of Posttraumatic Growth**

As seminal researchers in the field of PTG, Tedeschi and Calhoun (1996) outline five domains of PTG: personal strength, new possibilities in life, relating to others, appreciation of life, and spirituality. These five domains form the foundation for the Post-Traumatic Growth Inventory (PTGI) that was developed to measure the outcome of PTG (Tedeschi & Calhoun, 1996). The PTGI is an instrument that was developed by Tedeschi and Calhoun (1996) to assess the positive outcomes that were reported by individuals who experienced positive growth after experiencing trauma. Although the instrument is widely used by PTG researchers, there are criticisms arguing that the PTGI measures perceptions of growth rather than actual growth (Cordova et al., 2007) and that because the instrument is quantitative in nature, it does not capture the subjective experience and essence of PTG (Taubmen-Ben-Ari, 2011, p. 606). Conversely, a study conducted by Cordova et al. (2001) compared individuals with breast cancer to a group of healthy individuals and found that although both groups reported PTG, the cancer group demonstrated a pattern of greater growth overall. The researcher discussed that the individuals with cancer seemed to have an increased perception of the value of their life and relationships (Cordova et al., 2007).

The instrument has been tested and has demonstrated good internal consistency, test-retest reliability, as well as approximate normal distribution (Tedeschi & Calhoun, 1996). The PTGI is commonly used by researchers to assess PTG in individuals who have experienced a traumatic life event; however, there are some limitations to the use of

PTGI. The PTGI is quantitative in nature, limiting the ability to understand the experience of personal growth posttrauma. As Taubman-Ben-Ari (2011) stated, "merely showing that people subscribe to a set of sentences describing growth does not necessarily imply that the full essence of growth experienced following the specific event has actually been captured" (p. 606). Thus, this present study explored PTG from a qualitative rather than quantitative perspective.

Supplementary literature suggests that these domains presented in the PTGI are essential components and often highly correlated with experiences of PTG. For example, Powell et al. (2012) completed a longitudinal study on 21 individuals who experienced severe traumatic brain injury (TBI) using interviews and questionnaires to explore these domains of PTG. The study indicated that optimism (personal strength), activity levels and life events (new possibilities), social support (relating to others), present life satisfaction (appreciation of life), and personal meaning or sense of purpose (spirituality) were highly correlated with PTG in this population, although it should be noted that there were lower correlations with religious faith specifically (Powell et al., 2012). Similarly, another longitudinal study involving women with breast cancer indicated that women stated that they "developed closer relationships with others, appreciated their lives more, recognized their positive qualities and strengths and developed a better understanding of spiritual matters" (Manne et al., 2004).

The traumatic event that an individual experiences can often produce an increased sense that one's *personal strength* is being tested. This change in self-perception can alert the individual to the fragile state of their world. Moreover, it reassures them that they have experienced trauma before, and they are stronger and more resilient as a result

(Calhoun & Tedeschi, 2006). Resiliency in individuals who have experienced cancer has been demonstrated in the literature, as Costanzo et al. (2012) indicated that relative to a control group (noncancerous history group), cancer survivors exhibit less changes in positive affect and mood when stressors occurred in their daily lives.

After experiencing a traumatic event, individuals often describe the emergence of new interests, new leisure activities, and occasionally new life paths altogether. These *new possibilities* are a result of experiencing PTG, and can significantly influence the life story of the individual. While exploring the role of leisure in coping with bereavement, Janke, Nimrod, and Kleiber (2008) found that widows who increased their leisure activity repertoire and participation clearly had a more positive view on life after their loss. Supporting the emergence of new possibilities further, Sandra McGregor (2011), a scholar and cancer survivor, shared her experience of cancer and a changed career path. McGregor indicated that after her diagnosis, she pursued a new education path that led to becoming a professor and researcher in Health Studies. She argued that this career change provided the "recognition that [she was] more than [her] cancer diagnosis" (p. 205).

The third domain of PTG is *relating to others*, and this can be seen in the context of compassion and intimacy with others. Calhoun and Tedeschi (2006) indicate that increased compassion often occurs as individuals feel a greater connection with others who have suffered or experienced similar traumas, and this compassion leads to an increased sense of meaningful relationships, intimacy, and closeness. For example, a study on PTG and childhood sexual abuse found that among other social relations with caregivers, external social support was a key indicator for experiencing PTG in children and adolescents who experienced sexual abuse (McElheran et al., 2012). This study also

established that, "girls report more social support compared to boys, facilitating higher rates of growth among girls" (McElheran et al., 2012, p. 78) suggesting that social support and relations with others is a key contributor to the experience of PTG. Similarly, a study by Scrignaro et al.(2011) suggested that social support may improve psychological well-being and PTG by helping individuals to reinterpret, reinforce, and assist in making meaning out of their experiences. This study was carried out longitudinally with individuals undergoing treatment for various forms of cancer and found that specifically, social support from a caregiver that encourages autonomy, competency, and relatedness is especially significant to those who are diagnosed with a chronic illness that disrupts their life story so substantially (Scrignaro et al., 2011). Consistent with these findings, 83% of women with early stage breast cancer were found to have experienced positive benefits from living with breast cancer, and the most commonly cited benefit involved relationships with others (Sears et al., 2003).

An *appreciation of life* encompasses a change in one's sense of priorities, and an appreciation for what one presently possesses. Supporting this domain, a study by Shannon and Shaw (2005) exploring women's leisure after breast cancer identified that women's priorities changed from occupational and social role responsibilities towards self-care and meaningful leisure pursuits:

The breast cancer diagnosis was a life event that contributed to the women developing a greater appreciation of time. The recognition or awareness that 'life is short' inspired women to consider how they were spending their time and led them to make changes [in their priorities]. (Shannon & Shaw, 2005, p. 203)

The last domain outlined by Calhoun and Tedeschi (2006) is an increased sense of *spirituality*. This domain recognizes that spirituality encompasses both religious elements as well as existential elements, and, thus, can be experienced by everyone, regardless of religious status. Spirituality in relation to PTG is the ability to experience a greater sense of meaning and purpose in life, and a cancer experience commonly brings a reevaluation of life purpose (Manne et al., 2004; Powell et al., 2012; Prati & Pietrantoni, 2009; Shannon & Shaw, 2005; Tedeschi & Calhoun, 1996, 2004, 2006). Prati and Pietrantoni's extensive review of PTG literature provides support for increased spirituality, as they found that religious coping is more related to PTG than optimism or social support.

Stanton et al. (2006) address these life domains in relation to cancer, and suggest that there are other life domains that are factors in PTG. Their suggestions include the development of healthy lifestyles that incorporate more thorough screening and testing as well as developing healthy habits such as physical activity. Given the significant impact of cancer, the safe and exploratory nature of leisure is an appropriate space to develop in the aforementioned domains of PTG.

# **Meanings of Leisure**

Leisure is a key context for creating opportunities to promote recovery and healthy living and enhancing overall quality of life in healthy individuals as well as those experiencing chronic illness. The meaning of leisure, and the meanings created through leisure, have been of interest to scholars for many years, and with the changing definitions of leisure have come dynamic dimensions of leisure. Historically, leisure has been defined as a time free from obligated activities (Neumeyer & Neumeyer, 1958), as an activity (Kelly, 1990), as an experience and state of mind (de Grazia, 1962). The diverse meanings of leisure provide insight into the notion of meaning and the psychological influence of leisure on an individual.

The ancient Greek philosopher Plato was one of the first to contemplate the meaning of leisure. Plato made no distinction between work and leisure, as it was through leisure that one gained knowledge. For Plato, leisure was a part of everyday life (Guo, 2006). Aristotle further argued that leisure was a reward for hard work, and that leisure is useful to both alleviate stress and rejuvenate an individual. Aristotle supported that happiness is found in a contemplative state, and, thus, leisure has a critical role in a life of happiness (Guo, 2006). The Ancient Greek Philosophers regarded leisure as both free time and the freedom to engage in virtuous and noble activities (Sylvester, 2005).

Contemporary views of leisure are largely shaped by Plato and Aristotle and present a paradigm shift in the study of leisure. Neumeyer and Neumeyer (1958) support the Greeks in that leisure is free time separate from labour. Shivers (1989) argues that leisure is simply free time, and this free time must be disposed of. This concept of leisure is supported further by Kelly (1990) who studied leisure in the context of what activities people do in their free time, regardless of their meaning. These scholars suggest that leisure is any activity that is not work. This view supports leisure as free time and leisure as activity definitions; however, it offers a very objective view that does not take into consideration whether the activity is enjoyable or rewarding.

Henderson (1990) suggests that an activity-based definition of leisure cannot be accurate, as nearly any activity can be an obligation under certain circumstances. Using the subjective experience and state of mind as the definition of leisure allows for both the concepts of free time and activity to be considered into the meaning of leisure. Scholars

Pieper and Dru (1964) and de Grazia (1962) support the concept of leisure as a state of consciousness and mind. As suggested by Pieper and Dru, leisure provides freedom from the obligations of everyday life, but in its foundation is the state of mind that it affords. de Grazia further supports this in distinguishing leisure from free time, as leisure requires a level of engagement and a conscious state of being. Further, leisure has been defined as a perception; a self-enhancing affective state that is achieved through participation in leisure activities (Neulinger, 1981). Neulinger suggested that leisure could take on the role of whatever a person perceived it to be as a means to relax, for enjoyment, as a release or as recuperation. The various meanings of leisure and the subjective differences in the meanings associated with leisure allow researchers to gain insight into the reasons for participation, the ability of leisure to enhance well-being and quality of life, and how leisure is useful as a coping mechanism.

Traditionally, leisure has been defined in three ways: (a) as an activity, (b) as a period of time, and (c) as an experience. For the purposes of this study, leisure will be holistically and subjectively defined as the experience, state of mind and perception that individuals associate with leisure activities. This conceptual definition of leisure allows the experiences and meanings that individuals associate with enjoyable activities to be examined and understood, as "people living in different situations see different things as essential to a meaningful existence" (Shin & Rutkowski, 2003 as cited in Iwasaki, 2007 p. 235).

There is ample evidence to suggest that leisure has a vast array of benefits physically, socially, and psychologically. Iwasaki (2007) conducted a critical review of the literature surrounding the role of leisure in a high quality of life and highlighted the

major pathways that leisure contributes to quality of life. The overarching theme suggested by Iwasaki was that leisure-like activities provide a "context or space for creating meanings which then help to promote the quality of people's lives" (p. 251). The highlighted pathways include leisure's capacity to (a) increase positive emotions and well-being, (b) create positive identities and foster self-esteem, (c) create social and cultural connectedness, and (d) promote human strengths and resilience, among others (Iwasaki, 2007). Among these benefits to engagement in meaningful leisure is leisure's unique ability to help individuals cope with stress.

# **Leisure and Coping**

In the past, researchers have generally established two main methods of general stress coping: emotion-focused coping and problem-focused coping (Hutchinson, Loy, Kleiber, & Dattilo, 2003; Iwasaki, 2001). Emotion-focused coping involves mood regulation and the cognitive manipulation of the meaning of the stressor (Hutchinson et al., 2003). This form of coping has been found to be especially adaptive in situations where the stressor is unexpected and uncontrollable, such as a cancer diagnosis. Social-support seeking through friendships and religion are techniques used in emotion-focused coping (Iwasaki, 2001; Shannon & Shaw, 2005; Tedeschi & Calhoun, 2004), thus, supporting the need for support groups and group therapy for individuals living with cancer, as well as social based leisure activities. The opposite is true of problem-focused coping techniques, which involve actively dealing with the stressor through planning and the suppression of the stressors, advice seeking, and goal-setting (Hutchinson et al., 2003). Problem-focused coping is most effective in situations where the stressor is perceived as being controllable (Iwasaki, 2001), and may not be effective for coping with

the stresses of cancer diagnosis. However, literature exists that argues both forms of leisure coping are required to buffer the effects of stress in the short and long term (Hutchinson et al., 2003).

Leisure can act as a short-term relief from stress as well as a preventative measure against stress (Iwasaki, 2001). This is demonstrated by Kleiber et al. (2002) in their classification of the functions of leisure. Kleiber et al. suggest that leisure functions as a means of adjustment to negative events and as a form of self-protection. For instance, it is argued that leisure can help an individual find new meaning in life after a traumatic event, and can act as a vehicle for positive self-transformation. The latter suggests that regular participation in leisure can have a protective role in stress coping, and can help individuals build skills to become more adaptive in stressful situations (Coleman, 1993).

Another theoretical framework of leisure coping to consider is Iwasaki and Mannell's (2000) three leisure coping strategies: (a) leisure palliative coping, (b) leisure mood enhancement, and (c) leisure companionship. Leisure palliative coping has been defined as a "temporal break through leisure allowing people to feel refreshed, regroup and gain renewed energy and perspective to better handle problems" (Hutchinson et al., 2003, p. 145). Leisure mood enhancement allows individuals to regulate negative emotions and enhance positive emotions, resulting in a more positive mood and, thus, decreasing stress levels (Iwasaki & Mannell, 2000). Lastly, leisure companionships are the relationships and social ties that are developed through joint participation in leisure and can work to buffer levels of stress (Iwasaki & Mannell, 2000).

## Leisure and Coping with Chronic Illness

Everyone has a different capacity to adaptively cope with stress and it has been found that the method of coping varies according to the nature of the stress and various personal characteristics (Coleman, 1993; Tedeschi & Calhoun, 1995). Tedeschi and Calhoun (1995) suggest stress that is perceived as uncontrollable, such as chronic illnesses like cancer, elicits different patterns of coping than a potentially controllable stressor such as preparing for a life change. Visintainer, Volpicelli, and Seligman's (1982 classic study on helplessness and rats illustrates this impact. These researchers explored the relationship between experiencing helpless states in relation to great amounts of stress and the development of cancer tumors in rats. It was found that "feeling helpless produced a more rapid growth of tumors in rats while feeling 'optimistic' led to greater tumor rejection" (as cited in Groff et al., 2010, p. 42). The uncontrollable nature of trauma adds to the likelihood that the experience will have a negative impact on the individual and, thus, will likely threaten well-being (Tedeschi & Calhoun, 1995). Additionally, Lahey (1993) explored the role of leisure and chronic illness and suggested that the life-threatening aspect of chronic illness poses a challenge to one's identity, and this, in turn, allows people to find new meaning in their leisure activities. Specifically, the leisure pursuits that have contributed to the development of an identity in the past will become especially meaningful during times where that identity is challenged such as during the experience of chronic illness. Given the scope of negative aspects of cancer and the potential impact it can have on an individual's life, leisure has a significant role in supporting these individuals through assisting in coping with stress, as well as providing opportunities to experience positive personal growth.

## Leisure and Growth

Effective stress coping allows individuals to make sense of and view stressful experiences as a challenge rather than a trauma, which allows them to grow from the experience (Chun & Lee, 2010). PTG has been identified as having a greater impact on people's perceived quality of life than other coping mechanisms (Chun & Lee, 2010).

There are various factors outlined in the literature that contribute to coping and PTG including: individual coping strategies (Chun & Lee, 2010; Chun, Lee, Kim, & Heo, 2012; Scrignaro et al., 2011), personal factors such as belief systems and coping history (Hutchinson et al., 2003), social support (Brakel, Dijkstra, & Buunk, 2012; Chun et al., 2012; Scrignaro et al., 2011), and personality traits and characteristics of the individual (Chun et. al., 2012). For instance, the previously described coping mechanism, problem-focused coping is a facilitator of PTG in individuals. There is also evidence to suggest that an individual can experience personal growth while using social relationships to discuss thoughts and share feelings related to their stressful situation (Chun et al., 2012). Social relationships are one of the many benefits of leisure engagements and can be developed and maintained through positive meaningful leisure experiences. Personality traits, such as optimism, hopefulness, and extraversion, have also been documented to contribute to PTG (Chun et al., 2012) and influence leisure behaviours.

Through personal growth, a life story can be rewritten incorporating aspects that are both meaningful and beneficial to the individual. During the process of rewriting a life story, past literature suggests that there are success stories and sad tales (Lee & McCormick, 2002). Stories can be used towards creating a sense of meaning around life experiences, especially traumatic experiences such as a cancer diagnosis. Individuals can

## LEISURE AND POSTTRAUMATIC GROWTH

be hopeful and optimistic and see a positive aspect of the disease, and they would then create a success story based on this experience. An individual who writes a sad tale would view the experience from a pessimistic lens (Lee & McCormick, 2002). Identifying the type of story an individual constructs around their life helps to determine what meaning that individual draws from his/her experiences with cancer (Lee & McCormick, 2002). Leisure has a role in this process, as leisure offers the opportunity for a new identity, a focus on thriving, and new opportunities.

An individual's coping behaviours in response to stressful life events also influences the development of PTG. Therefore, only focusing on the reduction of problems, deficits, and diseases in this population is inappropriate. Instead of dwelling on the reality of the permanence of cancer and its deficits, focusing on the strengths and interests of these individuals through leisure is key to promoting a healthy and positive well-being.

## **Chapter Three: Methodology**

The purpose of this study is to explore the role that leisure plays in the experience of PTG in individuals experiencing cancer. This chapter presents the rationale for using a qualitative phenomenological methodology, the selection of research participants, procedures for interviews, the analysis of data, as well as guidelines for ethical research and reflexivity.

## **Rationale for Using a Qualitative Methodology**

This study employs a qualitative phenomenological method to explore the role of leisure in the experience of PTG for individuals living with cancer. Qualitative research seeks to understand people's perceptions and experiences (Creswell & Miller, 2000); thus, it is appropriate for the purpose of this study. The aim of this approach of inquiry is to understand the role of leisure as relevant to an individual living with cancer's meaning-making process in the experience of PTG (Guba & Lincoln, 1994). The study is guided by a phenomenological methodology where lived experiences through rich description are sought and interpreted using traditional phenomenological analysis methods.

Among a variety of approaches, the phenomenological approach was selected because it allows an in-depth understanding of individual lives and enables researchers to gain context and recognize meaning in a person's life (Atkinson et. al, 2003). It is also "extremely valuable" for PTG studies because the method can illustrate transformational processes and growth experience from an insider perspective (Pals & McAdams, 2004). Because people experience personal growth in the course of challenges in their lives, a qualitative narrative approach is appropriate to explore the role of leisure in the experience of growth.

The meaning-making process is of interest to this qualitative study because it is believed that sense-making activities shape human behaviour and action (Guba & Lincoln, 1994). Individuals living with cancer will construct different meanings around their experiences, and an understanding of truth will come from their interactions and engagement with their world (Crotty, 1998). As the research questions of the study are concerned with the meaning of a subjective experience, an interpretive approach is necessary.

# **Phenomenological Tradition**

The theoretical perspective that shapes this study is that of the phenomenology camp. This perspective grounds researcher assumptions and informs the methodology linking it to the desired outcomes of the research questions (Crotty, 1998). This method of inquiry aims to comprehend an individual's lived experience, and develop an in-depth understanding of the meaning of leisure in his/her everyday life (Genoe, 2009). Information that is based on experience can provide empirical knowledge, as returning to look at the self is a means of discovering the nature and meaning of the phenomena of PTG (Moustakas, 1994). Due to the exploratory nature of the research questions, and the focus on the meanings associated with the phenomenon of experiencing PTG with cancer, a qualitative phenomenological approach lends itself to the purpose of this study.

Researchers in the field of chronic illness and disability commonly use the phenomenological approach, as it is suggested that the symptoms and impairments of chronic illness have a profound effect on the way individuals understand their life stories and lived experience (Greenfield, 2011; Kaufman, 1988). Thus, it is important to gain a deeper understanding of the lived experiences of individuals living with cancer.

Additionally, the phenomenological method is exceptionally sensitive to the role of disability or illness on the life story, as Greenfield states that the "emphasis on meaning, subjectivity and consciousness of lived experience, is uniquely positioned to address the existential nature of illness" (p. 36). Further, the phenomenological perspective informs the methods and provides a strategy for collecting data (Crotty, 1998).

### Sampling

Due to the nature of phenomenological research methods in understanding the lived experience, this study utilized purposive criteria-based sampling and snowball methods to recruit participants to engage in open-ended, in-depth interviews. Purposeful sampling is the deliberate selection of individuals who can provide information-rich data relevant to the phenomenon of study (Liamputtong, 2009). Six to eight potential participants were recruited through the cancer support groups at the London Health Sciences Cancer Center, St. Joseph's Hospital Breast Care Clinic as well as the Wellspring London and Region Cancer Support Center in Southwestern Ontario. Specifically, support group facilitators were contacted and requested to act as gatekeepers. Approval for conducting the study from the Brock University Ethics Board was received in December 2013 and facilitators were then asked to provide information pertaining to the purpose and methodologies of the study to their cancer support group participants.

Criteria for selection required individuals who: (a) reported a level of satisfaction with their lives, (b) were capable of sharing their experiences in verbal interviews, (c) were living in Ontario, and (d) were at least 18 years old. Support group facilitators were asked to indicate whether they believed the participants met these criteria as well. The

qualitative methods literature suggests that individuals who have experienced a specific phenomenon are intensely interested in understanding its nature and meanings, and are willing to participate in a lengthy interview and potential follow-up interviews (Moustakas, 1994). The literature also suggests that women may be more open to providing in-depth accounts of their experiences with illness; however, men were not be excluded from inclusion criteria (Charlier et al., 2012; Costanzo et al., 2012; Shannon & Shaw, 2005).

The sampling process was flexible, as the qualitative methodology is emergent in nature (Hatch, 2002). The sampling process continued until the data were saturated. The point of saturation occurs when there is no longer any new data being obtained from participant interviews (Liamputtong, 2009). This concept of data saturation means that I decided to stop seeking new participants once there was repetitive data being obtained from multiple participants (Liamputtong, 2009,). For phenomenological research, at least six participants are required for the data to have sufficient depth and breadth to identify robust themes in the data analysis (Denzin & Lincoln, 1994). Therefore, I sought to interview between six to eight participants that meet the selection criteria. Six participants participated in the study. The decision that sufficient information had been achieved was documented and rationalized in my working journal as suggested by phenomenological methods.

# Participants

Three women and three men, ranging from 34-60 years old participated in this study. The forms of cancer experienced by each participant ranged, as did the time since

diagnosis. A description of each participant is included in Table 1. Participants have been given pseudonyms to protect confidentiality.

Table 1

Participant	Information
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Participant	Age	Primary Cancer	Time since	Current
		Туре	Diagnosis	Status
Lucy	44	Melanoma	8 years	Cancer – free
ЈоЈо	45	Hodgkin's	1 year	Undergoing
		Lymphoma		treatment
Jeffrey	35	Thyroid	17 years	Cancer – free
Joseph	52	Prostate	6 years	Cancer- free
Glenn	60	Non- Hodgkin's	5 years	Undergoing
		Lymphoma		treatment
Eileen	34	Breast	7 years	Undergoing
		Secondary: Liver,		treatment
		Bone, Brain		

The participants in this study have varied cancer experience, and as the Table 1 indicates, the time since initial cancer diagnosis was different for each participant. The final column indicates the current status of the participant, if they are currently receiving treatment for their cancer, or if they are living without cancer. The term "Cancer- free" is a term used to describe a cancer "survivor," an individual who has finished and is recovering from his/her cancer treatment, or is in remission (Canadian Cancer Society, 2014). A

descriptive vignette for each participant is presented in Chapter Four: Results, General Descriptions.

## **Data Collection**

Open-ended, in-depth interviews are often used in phenomenological research investigation, as they provide the participants with an environment that is conducive to mutual self-disclosure, and an opportunity to share the aspects of their life stories that they feel are important and provide a deep level of self-expression (Liamputtong, 2009; Moustakas, 1994). Interviews were conducted at locations that were convenient to the participants, and took approximately 1 to 2 hours. The interviews were semistructured with a prepared guide to assist me and maintain a conversational flow. The phenomenological interview technique involves an interactive and conversational process and utilizes a limited number of open-ended questions and prompts. This interview technique allows for greater depth and flow of conversation (Liamputtong, 2009). Introductory questions, such as, "Tell me a little bit about yourself" and "What do you do daily to increase positive mood?" were used to focus the interview on the aspects of the self that the participant feels comfortable sharing, and encouraged positive reflections. The diagnosis of cancer is not the focus of the study; therefore questions did not reflect this phenomenon unless the participants describe the experience of cancer as having an influence on their daily life activities. Moustakas suggests that questions must be carefully constructed to guide the participant in a process of reflection of the phenomena. Therefore, questions, such as "What does a typical day look like for you?" and "What role do recreational activities play in your everyday life?" were asked to seek information pertaining to the role of leisure in PTG. Convergent interviewing was be used to reflect

upon the interview and develop more appropriate questions and techniques for the next interview (Creswell, 1998). Hand-written notes were documented during the interview to focus the interview and provide context for later analysis along with the interview transcript (Creswell, 1998; Liamputtong, 2009). Given the goals and purpose for this research and the richness of information associated with data collected through personal interviews, this was the primary data collection method used for this study.

## **Data Analysis**

This study mainly employed the technique of Husserl's phenomenological reduction as articulated by Hycner (1985) and Giorgi (2009). This technique involves various stages of bracketing, whereas I committed to suspending, as much as possible, my previous knowledge, influences, and "already known" assumptions about the data set at hand and the topic in general. Of course, it is impossible to achieve a full epoche, or bracketing of one's experience of the phenomenon under study, but in this way, I can attend to the phenomenon as it presents itself through the words and stories of the informants. By engaging in this more open and holistic fashion to the phenomenon, I reduce my attention to each item individually (Finlay, 2008). Although Husserl's formation of phenomenological reduction lacks a set series of steps, Giorgi has formulated a step-based process for working with interview data from a descriptive phenomenological orientation, and this was one of the data analysis strategies for this study. The data were analyzed using both Girogi's steps as well as Van Manen's (1990) process; half of the interview data were analyzed following Girogi's process, and the second half of interviews were analyzed using the structure outlined by Van Manen. Van Manen describes data analysis as a "dynamic interplay" (p. 30) and does not describe

procedural steps for his method. With his process in mind, data were analyzed following Husserl's steps incorporating concepts from van Manen. Table 2 describes the processes utilized in each of the analysis methods which structured the data analysis of this project. Table 2

Giorgi (2009)	van Manen (1990)		
Transcription of Interview			
Gathering a Sense of Meaning			
Gestalt: The Whole Experience			
Delineating Meaning Units	Story of each Participant (Body, Space,		
	Time, Relationships)		
Specific Descriptions	Revelatory Phrases within each		
	Transcript		
General Descriptions	General Descriptions		
Patterns within each Transcript			
Comparison Across Transcripts			
Relevance to the Research Question			
Establishing Themes			

Phenomenological Analysis Methods Influenced Analysis

# Step One: Transcription of the interview. Using the technique of

phenomenological reduction (Hycner, 1985; Giorgi 2009) data were analysed by listening to the audio recording and transcribing the interview verbatim. InqScribe Software was used for this process to ensure accuracy and efficiency of the transcription process. Literal statements in the transcription as well as any nonverbal or paralinguistic communication, such as tone of voice, emphasis, and pauses, were included in the transcripts.

**Step Two: Gathering a sense of meaning**. After the interviews were transcribed verbatim, I listened to the audio recordings and read the transcripts many times to gather a sense of the meaning the participant is sharing. Bracketing techniques were used to ensure that this stage is approached with openness to whatever meanings emerge. Bracketing reduces personal presuppositions and prejudices in order for the views of the participants to be the focus (Dowling, 2007; Hycner, 1985). My presuppositions were bracketed as much as possible by recording conscious thoughts in a journal, and having open discussions with the research supervisor and thesis committee. Through bracketing, I was able to enter into the world of the participants to understand their experiences of living with cancer.

**Step Three: Gestalt, the whole experience.** The third step in the data analysis process was listening to the audio recordings for a sense of the whole experience. This is known as gestalt and involves listening and reading to understand the context of the specific thoughts and meanings (Hycner, 1985). Nonverbal and para-linguistic aspects of the interview were recorded into a working journal such as pauses in speech and laughter.

**Step Four: Delineating units of general meaning (Giorgi, 2009).** Next, units of general meaning were delineated. To do this, I engaged in rigorous review of each word, sentence, and paragraph from the interview. Significant nonverbal communication was noted in the margins at this point in the process as well. It is important to note that the research question was not considered at this phase, only meaning was significant. Literal

words were maintained to ensure that the units of general meaning were reflective of the participant's voice. All general meanings that were discovered were included, even if they were redundant. The result of this step was unique and coherent sentences that expressed the participant's meaning related to the phenomenon of living with cancer (Hycner, 1985; Girogi, 2009).

**Step Five: Relevance to the research question.** To determine meanings relevant to the research, the research question was used to address each unit of general meaning. This determined if the participant's words were relevant and responded to the research question:What is the role of leisure in the experience of PTG? Relevant meaning units were included in the next phase. All decisions made were documented to ensure transparency to the thesis committee and reader.

Repetitive statements and meaning units were deleted, leaving only textural meanings of the phenomenon of experiencing PTG (Moustakas, 1994). However, it was important to consider the nonverbal and para-linguistic aspects of the redundant statements to ensure that they were indeed repetitive. As Hycner (1985) noted, the number of times that an interviewee says something may in itself indicate a level of significance.

**Step Six: Clustering units of general meaning.** Next, units of relevant meaning were clustered together by taking the list of non-redundant units of relevant meaning and reviewing documented beliefs (Hycner, 1985; Giorgi, 2009). It was important to review biases to ensure that the findings remained true to the participant's experience of living with cancer. I looked to see if any of the units of relevant meaning cluster together naturally and whether it was a common theme of essence for the units. Select committee

members were consulted at this point as independent judges to repeat the process and compare resulting clusters (Hycner, 1985).

**Step Seven: Establishing themes.** The next step in the data analysis process was to establish themes from the clusters of meaning to determine if there were one or more fundamental themes which express the essence of the phenomenon (Hycner, 1985). A summary of each interview was then conducted to incorporate themes that have been found in the data. As a validity check, I approached the participants with the summary and themes and asked them to validate the accuracy of my understanding of their experience, and add anything they ffelt was necessary. I was then able to modify the summary and themes if necessary. Each preceding step was repeated for every interview conducted.

**Step Eight: Identifying common themes.** Finally, to identify general and unique themes for all of the interviews, I noted if there were any common themes between the interviews. Common themes were clustered into a general theme for the interviews. Themes that are unique to a single interview were important counterpoints to the general themes found. The themes were contextualised, placing them back within the overall horizons of where the themes emerged. Each horizon has a place in conscious experience, and grounds the meaning unit to the phenomenon in the lived experience (Moustakas, 1994). The world and experience of each participant was created into a composite summary for organization and clarify purposes. Each composite summary included notes on the significant individual differences between each participant's experience of PTG after being diagnosed with cancer. The end product creates a synthesis of the meanings and essence of the phenomenon of experiencing PTG while living with cancer.

# **Ethical Considerations**

Ethical considerations for working with a phenomenological method include informed consent to participate, confidentiality, and an analysis of possible risks and harms (Liamputtong, 2009). Prior to the interviews taking place, potential participants were informed of the basic purposes, methods, and potential outcomes of the study. It was ensured that the potential participants understood what was required to participate in the study, and answered any questions they had. The participants were also informed of the procedures that ensured confidentiality and respected their lived experiences. Participants were informed of their right to withdraw from the study at any time, and revoke any data previously collected without consequence. At this first meeting, an informed consent form was signed and permission to audio-record the interviews was also requested (Liamputtong, 2009; see appendix C).

Confidentiality of the participants was protected using various strategies. Firstly, all identifying information was removed from the interview notes and transcripts, and pseudonyms were assigned to each participant to ensure that data and the identity cannot be associated together. All data collected were stored in a locked drawer and electronic data were stored in a password-protected file. The information will be deleted once the study, analysis, and any following publications are complete. Only the researcher, supervisor, and committee members have access to the transcripts of the interviews as well as the notes that were taken. Ethical consideration must be given to the sampling method, as snowball techniques may compromise complete confidentiality. Participants were informed of the importance of confidentiality; however, due to the nature of support groups, this was generally understood by potential participants.

There are no inherent physical risks associated with participating in the study, although it is possible that in-depth interview discussions could trigger an emotional response. I provided a comforting and safe environment where the participants could feel supported, and this rapport was developed prior to the interview to the best of my ability. This helped to ensure that the participants felt that I was sensitive to their emotions. Additionally, I was prepared to provide contact information for support groups as well as professional counseling although this was not necessary. Although the interviews could have triggered an emotional response, it was suggested in the literature that discussing one's experience with cancer can be therapeutic if there is a focus on PTG (Shannon & Shaw, 2005).

### Reflexivity

Qualitative approaches to inquiry require a unique process of ensuring the quality of research, as quantitative methods of validity and reliability are not transferable to this method. The role of the researcher in the process of ensuring a high quality of research is extremely significant in this study. As the primary researcher, I took the role of leading the data collection process; important decisions were made as to when to continue seeking participants and when data saturation had occurred. Decisions were made throughout the collection process as well as during the analysis process. Many qualitative researchers use researcher reflexivity as a parallel means to validate these decisions and ensure a high quality of unbiased findings (Creswell & Miller, 2000 Genoe, 2009; Moustakas, 1994).

Several strategies and processes outlined by Liamputtong (2009) were used to increase the trustworthiness and quality of the enquiry and following research findings. A

careful and consistent process was used for interviewing, transcribing, and analyzing each participant's story, with each account being honestly approached with an awareness of researcher preconceived biases and assumptions. The confirmability of the data is an indication that the findings of the study are clearly linked to the raw data; that the findings are not due to researcher biases (Liamputtong, 2009). This was achieved through researcher reflexivity. Being reflexive as a researcher involves acknowledging the role that the researcher has in shaping the research and analysis. By explicitly outlining the contributions, biases, and preconceived assumptions, I was able to openly acknowledge my role and allow readers to evaluate the confirmability for themselves (Liamputtong, 2009). Reflexivity allows researchers to demonstrate self-consciousness in showing concern for participants and the way they share their lived experiences. It is argued that for leisure researchers especially, reflexive methods are significant to the research process because the meaning of leisure is subjective and is experienced in many different contexts (Dupuis, 1999). This can be applied to the current study as the subjective experience of leisure is at the center of the phenomenon of PTG.

In this study, I provided an honest statement of personal experience with cancer to the participants, and kept a research journal to maintain openness and sensitivity, and provide space for reflection. Additionally, the reflexivity of this process was strengthened by regular dialogue among the researcher, the supervisor, and thesis committee members. These discussions enabled me to reflect on any biases and be conscious of any insights or emotions involved with analyzing the data, and it also served the purpose of researcher triangulation. Member checking strategies were also employed to provide the participants with an opportunity to read the verbatim transcripts and request any alterations or

changes. This ensured that the essence and lived experience of the participants was truthful and accurate to their perceptions. Additionally, select participants were asked to review the preliminary data analysis to ensure that I interpreted their experiences genuinely (Liamputtong, 2009). Finally, the possibility for transferability was increased through the use of purposeful sampling, detailed descriptions of the participants, and the rich descriptions of the lived experience. In qualitative research, it is essential to the quality of enquiry that the above strategies are undertaken to ensure the participants' lived experiences of cancer are genuine, sensitive, and authentic. These considerations move away from separating the researcher from the data, and encouraged me to consider my role in reconstructing and understanding lived experiences.

### **Chapter Four: Results**

Each of the participants that I had the privilege to interview provided me with a unique glimpse into their experiences with cancer. Many robust and notable experiences stood out in each interview that made each participant's story beautiful, thoughtful, and unique. This chapter includes (a) general descriptions and (b) overarching themes that emerged from the data analysis. The general descriptions were created from the meaning units in each transcript and paint a picture of each individual participant. These descriptions provide the reader some insight into the role that leisure had in their experience with cancer and the facilitation of PTG. Furthermore, the overarching themes that emerged are presented with evidence to support each subtheme and the research question.

### **Descriptive Approach: General Descriptions**

Lucy. Lucy has been practicing yoga for 13 years and is now a yoga instructor. Lucy was not able to do a lot of exercise growing up because she had knee problems among other health problems. Lucy broke various bones growing up, and always had problems with her joints. Lucy always felt like she had the flu, and she was diagnosed with fibromyalgia. Lucy regularly water-walks, and does other aqua exercises, something she learned from her physiotherapist. She spends a lot of her time at the local swimming pool and has met women that also do these exercises. Lucy describes feeling grateful to be in the water, and that the water has healing properties.

Lucy started practicing yoga while she was waiting for her daughter at dance class, and felt that it was something that she could do despite her physical limitations. At first, she felt very intimidated, as she did not know anything about yoga. Although she

did not enjoy the first two classes, by the third class Lucy knew she was a "lifer." Lucy describes yoga as a gentle, forgiving practice. She loves that her teachers always seem to nurture her, and that there is a sense of love and community in her classes. Lucy feels that voga is her dharma, a duty to help others heal. She is engaged in various voga communities and takes many specialized courses to supplement her training. Lucy has been to workshops that focus on healing through various means including: Emotion yoga, Indian medicine wheel healing, Kundalini, and Qigong. She believes that it is her dharma to help heal any way that she can. She supports her yoga students 1:1 and tailors their sessions to their needs. She helps them heal naturally, and gives them a sense of support and hope in their own lives. Lucy also enjoyed taking these courses as a form of leisure. She stated that after one of her surgeries, she felt that her brain was working differently. While taking her yoga teacher's training, she was worried that she would not be smart enough or able to learn and process all the information and was concerned that she was not going to be able to pass yoga. After passing, Lucy realized that she could accomplish these milestones, and she remembers thinking that her brain felt like it was working better. Lucy feels that if she can learn something small from each course, she will be able to share it with others and that is her duty.

Lucy experienced a cancer scare, and thought she had ovarian cancer. Before her surgery, Lucy decided to take a spontaneous trip to see a friend in Newfoundland. She was scared that after the surgery, she might not be around to have the chance and she had never been there before, and there were new experiences such as getting "screeched in" that she wanted to try.

Lucy was diagnosed with melanoma during a particularly stressful time in her

life, approximately 8 years prior to participating in this study. The melanoma was on the back of her leg and was removed with another surgery. When Lucy was diagnosed with melanoma, she states that she felt very off-balance. Even in her yoga practice, she was struggling with her balance and using water-walking as a means to improve her balance, which Lucy found very interesting and linked to her cancer.

During these experiences, Lucy states that she learned to sit back and absorb everything. The potential diagnosis of ovarian cancer made her feel calm and peaceful. She realized that if she were to go tomorrow, she would feel very satisfied with her life and she believes that she has lived a wonderful life. She believes that spiritually, she felt at ease. Lucy also describes her social support network as her oxygen. Her friends developed as a result of various leisure engagements, and her friends, in turn, introduced her to new leisure experiences such as choirs and courses. Lucy believes that everyone she has met in life has taught her something, and she is grateful for those people and pays it forward in life. Lucy is now living cancer free at 44 years old.

JoJo. JoJo enjoys being active. She works as a personal support worker in a nursing home and enjoys her job because she is helping people, it is physically demanding, and she is not at a desk all day. She describes her leisure interests as anything active: being outside with her dogs, exercising and working out, and outdoor physical activities such as gardening. JoJo describes the actual environment of the outdoors as being most enjoyable; she enjoys the fresh air, the sunshine, the care-free feeling and things like watching the birds, barbequing, and getting a suntan.

Both JoJo and her husband work at the nursing home, and they often work the same shift. After work, they enjoy coming home to unwind by watching television or

having a beer or a glass of wine, and spending time with their dogs. JoJo describes herself as a homebody; she enjoys being at home and doing things around the house.

A year ago, at 44 years old, JoJo was diagnosed with Hodgkin's Lymphoma. Her sister had experienced Hodgkin's Lymphoma when she was in her 20s; therefore, JoJo felt familiar with this form of cancer, and she describes feeling somewhat prepared for this experience. JoJo describes that after being diagnosed, she felt anxious to get started with the treatment. She feels that the waiting process is the hardest part, and she does not see the need in prolonging anything. She wants to start feeling like herself again, and feeling good, and she knew that she had to start the treatment to feel that way.

The lumps in her arms restricted her ability to exercise and weight training to the full capacity that she was used to. The chemotherapy treatment affected the sensitivity in her fingers and toes, and this impacted her ability to garden, do household chores such as cleaning and painting, and caring for her dogs. JoJo also states that her sexual desires are impacted, and this affects her husband. JoJo describes feeling frustrated because she could not do these daily activities to the same degree as she could before treatment, and that it was affecting others in her life as well. Although she still continues to engage in her usual leisure activities, she cannot participate to the same degree as she did prior to her diagnosis of cancer. She knows her own body, and knows what she is capable of, and she wanted to start treatment so that she could finish treatment, so that she could start doing the things she enjoyed again. She still values being healthy and physically fit, and feels that it is best for her body, and her diagnosis of cancer has not changed this belief. She states that staying within a certain weight range helps her feel good about

herself and increases self-confidence. After taking some time off work, going back to work and being active made her feel useful and normal again.

During this experience, JoJo feels that she has become more emotional. She has experienced many negative life events during this time, and although she felt like she was strong and she did not need to talk to anybody for support, she got to the point that she needed support from a social worker. This social worker helped JoJo find exercises that helped her relax, including deep breathing exercises, muscle relaxing exercises and activities to help relieve anxiety and stress.

During treatment, JoJo also found that her memory was not good and she had a difficult time making decisions. JoJo found that her judgment changed during treatment, and she questions herself. This lack of ability to make decisions affected her at work, and she had a difficult time remembering things about residents. It also impacted her home renovations, as she felt that she was taking on too many decisions in the process and she could not process it all in her mind. JoJo describes this as "chemo fog" and although she was aware of it, she did not really understand the implications of it until she experienced it for herself. JoJo also describes that during treatment she wondered why anybody has to experience what she was experiencing. But now that her treatments are over, she does not really remember the feelings she experienced. Now that her treatments are over, she also describes that she is amazed how she can make decisions again.

JoJo's husband served as a strong support for her during this experience, and he would often go to appointments and treatment with her, despite his own physical health issues. She describes his family as very supportive as well. JoJo has a few friends that were really supportive throughout her treatment; one friend who had personal experience

with cancer was particularly helpful. Although JoJo has a support network, she states that sometimes she felt like she was burdening her friends with her problems and illness; therefore, she would rather keep to herself instead of letting it out on people. JoJo did not tell many of her friends about her cancer, but when JoJo went to visit a friend in Newfoundland, her hair was really thin and this friend asked if she was okay and she ended up telling her about her experience. JoJo felt bad about not telling her friend about her cancer. She thinks people are afraid to ask if everything is okay, and she does not want to burden them with her story.

She particularly felt this way with friends who had been affected by cancer because she did not want to bring back bad memories. JoJo also compares herself to others, and she thinks about how many other people are receiving cancer treatments, and how theirs is worse than hers. She knows that the success rate is high for her type of cancer, which is considered stage 2A and she sees others with more aggressive treatment regiments, and more severe side effects than hers. JoJo thinks that her lack of negative symptoms has helped her stay positive, and this positive attitude has helped her. She wonders if she had had something else, another form of cancer, would she have had a different experience. On the contrary, JoJo feels uncomfortable when others make comments and judgments based on her cancer, as other individuals living with cancer have insinuated that her cancer is a "good one to have" and have compared their hair loss to hers. It is a difficult experience, and she feels that comparing oneself to other cancer patients is wrong and this frustrates her. She also describes a fear of something else happening in her future related to her health, and she worries about how she will handle it if the treatment was different (including surgeries and removing body parts). JoJo

explains that when she feels really tired, she worries that something is going on with her cancer again because she always felt tired during her treatment.

JoJo writes in a personal journal that she keeps daily. Everyday JoJo writes how she is feeling, if she slept well the night before, and what medications she took. She describes this as a habit, something she learned on a trip to Haiti. Sometimes JoJo feels obligated to write things down, but sometimes she feels like she has to do it right away as she is thinking about something. It helps her remember things, and helps her to answer surveys and questions related to her healthcare to the best of her ability.

Spiritually, the cancer experience has made her more thankful to God for having life. She does not blame God; she believes there is a reason people get sick and it is not God's fault. Although she does not practice her religion in a church, she says her prayers at night and she is thankful. This experience has made her more thankful for what she has. JoJo was still receiving treatment at the time of participating in the interview.

**Jeffrey**. Jeffrey chose the chiropractic profession because it was his first experience in a profession that had principles around treating the body like it was meant to be well. Jeffrey took this principle very seriously and everything he does in life has been an application of this principle. He believes that health is a philosophical battle; you have to believe in health to be healthy, and you have to change what people believe to change what they do. This mental shift is key in a healthy lifestyle. Once he understood that his body was meant to be healthy, he asked himself what it needs to be healthy. He provides his body with good fuel and movement and it needs to be able to think about and process the outside world.

When Jeffrey was diagnosed with thyroid cancer at 18 years old, he felt that he

was not enabled. In his appointments with the oncologist, he felt like he would get beat down. He felt like he was not empowered, and they treated him poorly. He felt like the oncologists were not looking for his opinion before they ran the next tests. He also felt that he could not be a normal 18-year-old boy. He remembers feeling isolated and special, and he wanted to be able to participate in the things his friends were doing: partying, meeting girls, and being 18-year-olds.

He decided that this was not how his treatment would be, whatever the consequences. He stopped waiting in between appointments and just shutting his mind off, and he did not wait for an oncologist to tell him what to do next. He deprogrammed his beliefs that he was supposed to make everyone else happy, and started making himself happy by pursuing education in a field he enjoyed.

Jeffrey has applied a determined and positive attitude to every aspect of his life. For leisure enjoyment, Jeffrey challenges his body and his mind. He enjoys his work; he owns a fitness studio and trains hard to be physically fit and elite. His work spills over into his leisure time; he enjoys what he does and he invests all of his time into it. In the small amount of "free time" that Jeffrey has, he enjoys reading philosophical literature, scientific research articles, and playing chess to challenge his mind. He structures his day with various work and leisure activities and takes time every morning for a power hour where he spends time setting goals, evaluating his accomplishments, and planning the day. Jeffrey is now 35 and has been living cancer free for 14 years.

**Joseph.** Since his diagnosis of prostate cancer in 2008, Joseph describes his life as an enduring transformation and describes the constant changes he has experienced up until recently. He was diagnosed with prostate cancer in 2008, and had immediate

surgery to have it removed. During this time, his relationship with his wife was changing and he separated from his wife shortly after his recovery, and they divorced. In 2008, Joseph took his first physically demanding vacation where he participated in a biking trip in Tuscany. Since this first trip, Joseph has been on four more biking trips in various parts of the world, been on a kayaking and snorkeling vacation, and is preparing for a trip to Mount Kilimanjaro.

Joseph explains that he used to think that his job defined who he was; his aim of succeeding in his career was to be able to build a good life, provide for his children, and afford to do "good stuff." Since 2008, Joseph has also changed careers. More specially, Joseph lost his job in Insurance, started his own consulting company for a year, and was hired by an Insurance Brokerage in Toronto, which he left after a couple of years to move to Alberta to work at a large brokerage. He stayed in Alberta for less than a month and drove across Canada back to Mississauga. He took some time off work before accepting a position at his current organization. Joseph describes that this process has left him thinking more about himself, and about what makes him happy. He still goes to work, but he does so to be able to afford the bikes and the vacations that make him happy.

Joseph reflects on his relationships and how they have changed during this state of crisis. He describes how important his daughters are to him, and how being a father is his dream job. He realizes that since they are older, his daughters may not need him to the same extent as when they were younger but he tries his best to be supportive and stay involved in their lives. Joseph has also started dating for the first time since the 1970s and describes this as a challenging experience. He states that the consequences of prostate surgery affect those who he is being intimate with.

Joseph describes himself as a private person. He has some good friends who provide support to him, and reflects that at the time of his diagnosis he did not seek their support. He feels that he does not require ongoing support from his friends and describes how his cat was the social support that he needed during his short experience with cancer.

Joseph engages in various leisure pursuits daily, and this has become his lifestyle. He enjoys playing the piano because it challenges him; it is something personal, and it makes him feel beautiful. Joseph also enjoys the arts; he enjoys buying artwork, seeing the symphony, ballet, and orchestras. Joseph feels that his experience with cancer was overall positive; he now knows what is important to him, and what he wants to accomplish in life. He believes that he is able to deal with any stressors that may come along in his journey through life and that he has been graced with good health and he knows that being physically active and challenging himself physically will only benefit him. Joseph understands that he cannot control many things in life, but he can influence his health. Joseph is now 52 and is cancer free.

**Glenn.** Glenn owned and operated a very successful financial firm for 25 years before retiring. Glenn was diagnosed with Non-Hodgkin's Lymphoma in 2009. At the time of diagnosis, Glenn describes being in denial of the magnitude. He found a lump when he was shaving and it was not getting any smaller as time went on. The doctor referred him to an oncologist, and was diagnosed with lymphoma. Although his brother had had it when he was younger, he did not understand the severity of the diagnosis. He did not take certain rules seriously; for instance, he would not go to the hospital when he got a fever, and was not careful when working in the yard and garage as he had many cuts that became infected. Glenn describes that he just would not accept the fact that this

was life threatening; he viewed it as an inconvenience. Glenn also continued to work throughout treatment right until his second round of chemotherapy. During the second chemo, he would take a day or two off after treatment and then he would go back to work. He started taking naps in the afternoons in his office and then both his family physician and his oncologist counseled him to stop working and to retire.

During his retirement, he found it difficult to let his company be managed under someone else, and found being away from the office boring. He kept in constant contact with the staff there to know what was happening, but eventually he realized that he had to let it go. He found it difficult to be not working, and not thinking about working. He spent most of his days sleeping and puttering around his house. Although, he describes that one of his hobbies became doing the invoicing, shipping, photography and finances of his wife's jewelry business.

Glenn also loves to shop and describes himself as a shopaholic. He enjoys shopping for vehicles, decorative items such as rugs in his house, electronics, products for his pet, and groceries. In the summer, Glenn spends most of his time outdoors. He takes pride in his lawn and garden, and describes a contest amongst four of his neighbours for the best lawn, the greenest lawn, the most bug free lawn, the most weedfree lawn, and states that he has never lost as he is a lawn fanatic. He also recently purchased a puppy, and is very territorial over the dog. He thinks that she is his therapy dog, and although he has had dogs in the past, he states that this is his man dog. This dog has provided him with daily responsibilities with a work-like mentality, as he walks the dog multiple times throughout the day, and has to let her out to the bathroom many times throughout both the day and night. He is looking forward to the summer, where he can

wake up, pour a cup of coffee, and take her out for a walk in the middle of the night or whenever she needs to go to the bathroom. Glenn states that this dog is forcing him to exercise more, too, as he has lost six pounds since he got her. He thinks that his pets have been great company throughout his cancer experience and that they are therapeutic for him. He describes that engaging in these activities makes him feel better, and provide him with a sense of accomplishment. He has a sense of pride and ownership over what he has earned the right to have.

Glenn attributes his survival to his wife, who takes his condition very seriously and has experienced many side effects of being his caregiver as well. He states that he also finds his nights with his wife therapeutic; he enjoys relaxing and watching television with her, and just being with her, and finds that this relieves his stress.

During a later treatment, Glenn found that he was very fatigued all of the time. He had to contract out the yard work to professionals, and he found this depressing. He thought that the workers did a good job, but he struggled with the fact that it was not him doing it. He tried to take care of his lawn, and would cut the front lawn but would be too exhausted to finish. This made him question what was next: If he cannot do his own lawn work what would he lose control of next? He also remembers going through a phase where he did not feel motivated to do any of his daily activities, but now believes he has worked through that. He is anticipating the summer so that he can go outside and get busy on his lawn and take his dog for long walks.

**Eileen.** Eileen lives for dragon boating. She is on multiple teams and trains often, and competes in the warm months. Dragon boating is a social, mental, and physical activity for Eileen. She describes her current team as her family, and states that she has a

boat full of moms with her. Many of the people on this team are also breast cancer survivors or have been affected by cancer in some way. Eileen describes dragon boating as therapeutic, and that when the boat is on the water she does notcare about anything other than doing her best as she is very competitive with dragon boating, more so than any other sport she has been involved with. After receiving bad news, such as finding out that her cancer has spread to a new place in her body, Eileen feels that dragon boating is a tension release. She remembers that after she was diagnosed most recently, she went to practice and did not tell anyone her news. She sat in the boat, and with every stroke she said in her head "f- this. I am going to win this." and kept paddling and giving her 100%.

Eileen became involved in dragon boating after she was first diagnosed with breast cancer in 2007, when she was 27. Since then, it has metastasized to other areas of her body including her liver, bones and brain. She did not feel like she had anyone her age that she could relate to; therefore, she attempted to start a support group. This support group was not as successful as she had hoped, but it did introduce her to a woman who participated in dragon boating. At first, Eileen did not feel welcome, and she described a dynamic with the group that made her feel like the odd man out. Eileen then branched off from that boat crew and joined another that was starting in St. Catharines. Eileen is also very involved in other cancer related community groups, all of which have been related to or have derived from her belonging to the dragon boat community.

Eileen became involved in Young Adult Cancer Canada where she attended a 3day retreat for young adults with cancer in Montreal. She found that this was a fantastic experience where she could meet people her own age with cancer, and make connections with them because she was finding it hard to meet young adults. She keeps in contact

with some people she met on that trip, and uses Facebook to keep her tabs on everyone.

Wellspring is another organization that Eileen has joined, and she used to dragon boat on their team as well and she still rows as a backup on their team. She has also taken breast cancer workshops at Wellspring, and has met many women there who she feels she really connected with. She also takes healing workshops at Wellspring to better understand her body, and how her body deals with stress, and how to cope with that stress. This group has taught her imagery, meditation, and journaling techniques to help her cope with stress and negative emotions. She has met some friends in these groups who have continued to progress through the course levels with her. In the past, Eileen took belly dancing and Reiki courses through Wellspring as well as participated in the Living Ribbon Cancer run, the CIBC Run for the Cure, and The Relay for Life. In addition to being involved as a member of various community organizations, Eileen serves as a committee member on the CIBC Run for the Cure Organization, the Relay for Life, and volunteered for the Humane Society.

Eileen loves to share her story. She was featured on the front page of her local newspaper, showing her mastectomy scars in an interview about her experience with breast cancer. She was chosen as the inspirational story of the year, and the newspaper did a follow-up interview with her after the first story was published. Eileen came across an artist who does busts of women to empower and teach workshops about positive body image, and Eileen had this artist come to the school where she works and do a workshop, and Eileen did a bust of her chest after her mastectomy.

Breaking stereotypes and stigmas and going against the grain are things that Eileen enjoys doing. Throughout her chemotherapy and radiation treatments, Eileen has

not taken very much time off work. She is an early childhood educator, and although she needs to be careful of her immune system, she goes to work even after her chemotherapy treatments or if she feels fatigued. She adjusts her day, so if she is feeling tired she will play a sedentary game with the children instead of running around and playing with them. Eileen educates her students about breast cancer, and is open with them. She answers any questions they have, and she has even thrown them a wig dress up party to help them understand that she wears a wig because of her cancer. Eileen seems to share this attitude towards many aspects of her life, and is open with anyone who wants to learn about the cancer experience. Eileen is now 34 and living with cancer and ongoing treatments.

## **Themes and Consolidating Patterns**

The data analysis revealed that leisure played a vital role in several aspects of the participants' lives. From the perspective of the participants, leisure has been defined as a period of time where an activity is freely chosen and enjoyable. Leisure was not defined as a specific activity, rather an experience that was meaningful in some way. Often times, participants described an intense involvement in their activity of choice where they experienced timelessness and presence, that separated them from other aspects of life for the time being. In some instances, mundane activities became meaningful, creating experiences that for the purposes of this study are defined as leisure.

Four major themes on the role of leisure on facilitating PTG emerged: (a) fostering relationship building, (b) providing an environment to experience a sense of self, (c) providing opportunities for positive emotions, and (d) finding a sense of purpose in life. Figure 1 represents these four themes, and the following section details each of these salient themes.

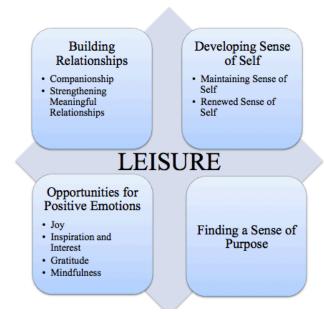


Figure 1: The role of leisure in PTG.

### **Relationship Building**

One of the distinctive themes on the role of leisure in PTG was relationship building. For some participants, leisure supported the development and deepening of relationships as it created a safe and welcoming space to experience positive events together. A number of the participants in this study reported that leisure time provided an opportunity to experience an increased sense of social support with family members, friends, and leisure companions although a few people felt a strong sense of isolation as a result of their diagnosis. The two main characteristics of relationship building facilitated by engagement in leisure activities are as follows: (a) companionship in supportive communities and (b) strengthening meaningful relationships.

### **Companionship in a Supportive Environment**

Building relationships with companions in a supportive environment was a strong subtheme in the interviews conducted in this study. Leisure provided an opportunity to

meet new people who shared the same interests (e.g., travel companions for cycling trips and vacations, companions for yoga retreats, and teammates for dragon boating teams and fundraising committees). As the data analysis progressed, building companionship emerged as a strong theme amongst participants. Notably, the participants reported their companionship not only with other participants in organized activities, but also with their own family pets. Both leisure companions and animal companions created a sense of belonging and community for the participants, and offered tangible social support.

For example, Lucy highlighted that the people she has met through yoga have become her community. Lucy compares her yoga friends to her friends from other areas of her life and suggests that her yoga friends allowed her to be more like herself and "hippy-ish" than her other social friends, thus creating a strong sense of belonging in this community; "Being with people in yoga... You're in such an open-minded environment, which I love. There's nothing too out there, and I love that! And then as you grow, you feel like okay I am in a world without judgment." Lucy states that with these people she feels she is, "in a world without judgment, and [she is] completely free to do whatever [she] want[s] with support." This yoga community provides her with support in finding her purpose, support in learning the art of yoga, and support emotionally during her cancer experience. The individuals she has met through these activities have introduced her to other people with similar interests and her circle of friendship and network of support keeps growing. Lucy has found a sense of community that she feels welcome in and that she belongs to through her enjoyable activities.

Furthermore, Joseph discussed his travel companions as a support network and community similar to Lucy's yoga community. He enjoys being around people who share

an interest in cycling, and enjoy seeing and experiencing new things. Joseph feels that it is its own social community, and having others expecting him there ensures he will participate and provides him with a sense of inclusion and kinship. His leisure companions motivate him and provide him social support and give him an opportunity to socialize with people on his own level outside of the office, where he is in a management position and interacts strictly professionally. This recreation based community supports Joseph in being himself, and being in his element of an active leisure lifestyle, while fostering a sense of community and belonging with leisure companions.

In addition to the support of leisure companions, many of the participants in this study discussed the comfort and support that animal companions provided during the cancer experience. During the interviews that were conducted within the participants' homes, family pets were present and visibly valued in the homes. Lucy did not discuss her relationship with her dog, but throughout the interview the dog was in Lucy's lap. Lucy treats her pet as a member of the family, and it is evident that she finds comfort in spending time with the dog on her lap while she watches television, reads, and relaxes.

Similarly, JoJo discussed the importance of her four dogs in her daily routine and in her life before she mentions her family or her husband. Throughout the interview, JoJo explained how her daily routine is heavily influenced by her pets' needs. Many of the activities that JoJo values involve her pets; taking them for walks, caring for them, and playing outside with them. When JoJo discussed the challenges she faced when receiving chemotherapy treatment, she emphasized how the symptoms, such as pain in her fingers and toes and her fatigue, made it difficult to care properly for her pets, but how she persisted because of her love and affection towards them. Instead of walking her dogs

daily, JoJo would often spend time with them in her backyard during cold and rainy days and take them for walks on days with nice weather. The role of leisure in the phenomenon of PTG is evident in the way JoJo describes the adaptations she has made to her leisure experience of caring for her pets and the importance and meaning this has brought to her life.

Joseph made a statement in his interview regarding his pet and the sense of social and emotional support he received from his cat. "Stripes the cat sitting on my lap all day was pretty comforting: she seemed to know I needed attention but not to be bothered, and she made me feel not alone." This is a form of emotional support that many of the participants expressed they received through their relationship with their pets. Joseph and the other participants made the distinction between a person's ability to support them and their pet's, and it is clear that they valued the support that their animal companions provided them throughout the cancer experience.

The data revealed that animal companions not only provided emotional support, but tangible support as well as they served as a means to distract the mind from negative emotions and provide opportunities for meaningful experiences. Caring for the animals also gave participants an activity with a purpose, which is a form of tangible support. This form of leisure provided participants in the study a responsibility to care for another, and this gave participants purposefulness. Glenn supports this, as he was cognizant of the role that his puppy had in his well-being in that he referred to his puppy as his "therapy dog." In the midst of many changes in Glenn's professional life, he thrived on a scheduled lifestyle and responsibilities, and caring for the dog was meaningful to him as it made him feel useful and structured. Additionally, spending time with her dogs allowed

JoJo to enjoy the outdoors and appreciate the sun and nature. These activities are all important to JoJo and through her pets, JoJo was able to find pleasure in small moments outdoors.

The findings of this study indicated that relationships with family members, friends, and leisure companions provide tangible and emotional support to the participants in the midst of their trauma, and provide means for personal growth and development and the phenomenon of PTG. Interestingly, many of the participants reflected on their experience with cancer with positivity and highlighted how the social aspect of their leisure interests played a role on building companionships in the midst of trauma.

### **Strengthening Meaningful Relationships**

Further to developing companionship, leisure played a significant role in developing and strengthening meaningful relationships with family and friends for the participants of this study. For the purposes of this study, meaningful relationships are defined as those that are marked by a sense of bonding and equal sharing amongst members. Meaningful relationships differ from companionship in that individuals share deep connections beyond acquaintanceship. For the participants in this study, leisure activities provided them a means to develop meaningful relationships with those who they cared for. Most participants described that meaningful activities during their cancer experience helped them to realize the importance of their relationships with their families and friends.

Many participants demonstrated ways in which leisure acted as a vehicle for deepening and strengthening relationships that were perceived as important. For example,

through her engagement and participation in charitable activities for raising awareness and funds for cancer, Eileen has become submerged in an active and supportive community of individuals who have experienced cancer. These individuals were Eileen's companions, but leisure helped transform these individuals into meaningful friendships. Eileen shares that, "the first support group I did, there's a group of us [and] I still talk to them... we jumped from there to dragon boating." Many of the people on her dragon boat team have had cancer, or have experienced cancer through someone very close to them. This shared experience promoted a sense of community and understanding of the challenges of living with cancer, and Eileen described that she is very close with her team. Teammates offered support to Eileen and, in return, Eileen supported them during their challenging times. Eileen relied on these people for support after difficult experiences, and although she does not always discuss her emotions at practice, she felt they really helped her cope with her negative emotions that she experienced just by being there to paddle with her. Additionally, these teammates have explored other areas of leisure interests with Eileen and as a team they have expanded their leisure repertoire, skills, and experiences. Eileen described her teammates as family, as her "boat full of momma's" suggesting that these individuals are close, meaningful friends of Eileen.

Some participants learned to prioritize relationships with others over work and previously significant activities using meaningful activity. For example, Joseph discussed the realization that his relationship with his daughters was his most important in life, and that he needed to spend meaningful time with his daughters as they grew older. Joseph explains that, "My daughters are incredibly important to me... I know that being a father is actually my dream job." Joseph continues to explain that his experience with cancer

made him think about not being able to continue his role as a father; "Before I thought it was important and now I know just how truly important it is to me." As a result of analysing his priorities, Joseph decided that developing his relationships with his daughters was important to him. He used opportunities, such as traveling, to help him connect with his daughters and make memories with them. Similar to Joseph, Glenn describes how enjoyable activities provided a means to deepen his relationship with his wife. Glenn and his wife would often spend all day working in the garden together and he shared how they would enjoy and admire each other's work in the garden, and this support was meaningful for him. JoJo also expressed how supportive her husband's family became during her experience with cancer, "It's good to know I've got that support there for sure."

Although leisure played a role in deepening meaningful relationships, some participants expressed that their relationships were negatively affected by the cancer experience. For example, JoJo disclosed that the symptoms of her cancer impacted her ability to spend meaningful time with her husband, and negatively influenced their sexual activity. Joseph also discussed the implications his prostate cancer had on his sexual activity with his wife, and how this caused stress in their relationship. Joseph states that at the time he did not realise that his cancer affected his wife in addition to himself, and believed that having life was more valuable than having a sexual relationship. Jeffrey shared that he felt isolated during his cancer experience as he was receiving radiation treatment that was dangerous to others. The participants in the study discussed how leisure provided an opportunity to develop their relationships around these challenges; JoJo discussed how sheand her husband enjoyed spending time barbequing and being

outdoors together, Joseph and his wife discovered their love of cycling and travelling, and Jeffrey used his leisure interests to create a career with his future wife.

Using leisure to strengthen relationships with close friends was evident in the interviews, as many participants discussed the tangible and social support that their close friends provided during their experiences with cancer and the activities they engaged in together. It is during the times when participants felt they were alone that the company of friends through leisure proved the most significant in true friendships. For example, Joseph describes that although he considers himself a private person and did not reach out to friends for support, close friends provided him with social support that he appreciated:

After the surgery, I was lucky to have a few good friends who constantly reached out to me...they just called and said hi, or took me out for coffee or lunch, kindly accepting the fact that I had a catheter still in me and listening to what I expect was pretty boring talk about how I spent my days sitting at home. Helped me realize that sometimes just showing up is what matters.

Joseph discussed how little moments that his friends shared with him helped strengthen their bond and provided positive daily experiences for him in the midst of his trauma. The emotional support of his friends and the tangible support that he received through their company allowed Joseph to shift his focus to the positive and examine his life priorities with a rational approach. Leisure played a role in developing these relationships through providing a social context to enjoy freely chosen activities with friends such as having coffee and talking on the phone.

Eileen also provided a vivid example of the strengthened relationship with her best friend. Eileen described that they engaged in various activities together such as

hiking and outdoor activities. JoJo and Lucy also both expressed the importance of the small actions of their close friends during their experience with cancer. JoJo expressed gratitude for her friend who lived in another province and sent her a text message before each treatment wishing her well. This made JoJo feel that she was always on her friends' mind and that she was important to her. For Lucy, her best friend was her "soul sister," and her friends are like her oxygen. She communicates with her best friend regularly and they have created a radio talk show that they host together. This radio show has developed their relationship in that they are working together as a team, and meeting new people together. Lucy and her friends get together to swim at the local pool weekly as well, and this keeps them connected. She feels that she and her girlfriends belong together because they each contribute something to the relationship that the other does not possess. Lucy describes that these women provide her with logic and advice, and Lucy contributes calmness and spirituality. At the time of the interview, one of these friends was recently diagnosed with cancer as well. Lucy described how each friend offered a form of support, and Lucy felt like she offered emotional support because she had experienced a similar situation, and reminded her friend how strong and powerful the mind is in fighting cancer, and how yoga can help the process. This balance and partnership is an important aspect of Lucy's relationship with her best friends, and leisure plays a role in facilitating this support.

In summary, the participants expressed the importance of social support from friends to their experience with cancer and described leisure as their vehicle for the development and strengthening of these key relationships with others.

#### **Developing a Sense of Self**

Developing a sense of self was another salient theme. Following the cancer diagnosis, all the participants of this study were more likely to experience the disruption in their life story and the loss of their sense of self. The cancer diagnosis threatened the participants' identities, and the treatments interfered with the social roles that the participants carried daily. Despite these challenges, leisure provided a means of both a) maintaining a preexisting sense of self and in b) creating a renewed sense of self that reflected the changing values and beliefs of each individual.

#### Maintaining a Sense of Self

For many participants in this study, the diagnosis and treatment phases of cancer brought many challenges to the emotional and cognitive concept of the self. This study found that leisure played a significant role in participants' sense of self. Although many activities were affected by the diagnosis of cancer, participants made adaptations to maintain their participation in these meaningful activities. For example, Glenn found great enjoyment and pride in caring for his lawn and garden and would spend full days working in his yard. The chemotherapy made this activity challenging, as he was easily fatigued and weak after spending time in the garden. To ensure that he could still engage in this meaningful activity and care for his lawn, he spread out his tasks over a greater amount of time, working only a few hours at a time. He also hired help to ensure that the property looked its best. At the time of the interview, he was looking forward to the warm weather when he could start fertilizing, planting, and grooming his gardens and return to his title as the best lawn in the neighbourhood.

Many participants discussed that they found a sense of self through their careers, but they also discussed how they used leisure to realize that they can still enjoy the same things in life, despite their illness. For example, when reflecting on his career, Joseph states that his diagnosis of cancer helped him realize that his career was not the source of his sense of self:

I used to think that my job really defined who I was and that the chance to grow and develop was through work... Now I think a bit differently. Work is still important to me...but I also want to enjoy what all that work gives me the chance

to do. And I know that there are some things that just matter more than my job. Like other participants, after his diagnosis Joseph put deep thought into what he wanted in life and who he wanted to be. Joseph states that "the cancer was just something that happened, it isn't really who I am. I am so much more than just a cancer survivor." Joseph uses his success in his career to allow himself more time and discretionary income to enjoy activities that he enjoyed prior to his diagnosis: cycling, travelling, and hiking.

JoJo also made adaptations to her activity behaviours; prior to her diagnosis she spent much of her free time exercising at the gym and body building. Her cancer created lumps in her arms which made lifting weights difficult and painful and when she started chemotherapy she was fatigued and sore which also impacted her exercise habits. JoJo expressed in her interview that staying in shape and exercising was still important to her during her experience with cancer, and that she still goes to the gym despite the challenges. She also uses walking her pets as exercise, and views housework as physical activity that contributes to her fitness as well. Maintaining a sense of self was important

to many of the participants, and because their leisure helped define their identity, many of them adapted their leisure behaviours to create a sense of normalcy and homeostasis.

#### **Renewed Sense of Self**

Despite the physical, emotional, and psychological challenges that the participants in this study faced throughout their cancer experiences, they maintained their sense of self using normal and enjoyable daily activities. For some participants, the ability to maintain their former identity and sense of self became difficult or insignificant and leisure presented opportunities for a creation of a modified sense of self. Leisure provided an environment for the participants of this study to create a new identity by using their interests and skills to create a niche unique to their leisure involvement.

Many participants used leisure pursuits that they were committed to define their new self. For example, Eileen became involved in dragon boat racing after she was diagnosed with cancer and competes on multiple teams. Her engagement in support groups and workshops lead her to this lifestyle, which she has adopted fully as "the crazy dragon boat lady." Eileen has created an identity and role on her dragon boat team and continues to attend practices and training sessions throughout her experience. Similarly, Joseph accomplished his first cycling vacation just 8 weeks after his prostatectomy. After this first initial trip, Joseph found himself hooked on the excitement and adrenaline of cycling through difficult trails and mountains and found a renewed sense of self through committing to the activity. He describes that he enjoys feeling healthy, and enjoys knowing that he can keep up to people who are significantly younger than he. The challenge and sense of adventure was attractive to him and helped him develop this healthy lifestyle and renewed identity. Since Joseph completed the first trip, he has

successfully completed four cycling trips that increase in difficulty, and at the time of the interview was preparing for his fifth and most difficult trip to hike up Mount Kilimanjaro and ride down. Cycling and hiking have become a key piece of Joseph's identity.

After the diagnosis of cancer, some participants in this study struggled to find ways to meaningfully fill their time. Changing career paths or creating new opportunities for careers were common amongst the participants of this study, and for some, leisure was the foundation for this newfound passion and interest. For example, Lucy took her first yoga class years after her diagnosis as a means to improve her overall health. Since then, Lucy has fully adopted the yoga lifestyle and is very involved in yoga retreats and courses and in social gatherings related to this community. Lucy has also completed her yoga teacher's training course and is now a certified yoga instructor. This leisure opportunity created a sense of self and identity for Lucy and she has made this into a career. Similarly, Jeffrey also used his cancer experience and leisure interests to shape a career in healthcare, as he is now a chiropractor and a Lifestyle Strategy specialist helping people live well through healthy lifestyles.

For Glenn, his career defined his identity and when he left his professional practice, he experienced a threat to his identity. Glenn has renewed his sense of self as he identifies with his lawn and his pride in ownership of the things that he has earned such as his lawn and garden, and his newly adopted dog. He has assumed a work-like lifestyle caring for his dog and his property, and this is both fulfilling and meaningful for Glenn. Glenn is known in his neighbourhood as the man with the best lawn, and he takes great pride in this identity. This is a renewed sense of self for Glenn, as he no longer identifies with his career but instead with his recreational interests. For Glenn and the other

participants in this study, leisure provided a safe environment where they were able to explore their skills and interests and develop these interests into a lifestyle. Their leisure lifestyles created a renewed sense of self for many participants, and contributed to the phenomenon of PTG.

#### **Positive Emotions**

In addition to using leisure as a means to define the self, engagement in enjoyable activities provided opportunities to experience positive emotions such as a) joy, b) curiosity and inspiration, c) gratitude, and d) mindfulness. These positive emotions played a role in the participants' experiences of PTG as they created opportunities for participants to be aware of their circumstance and accept the experience into their life story. This acceptance allows participants to engage in cognitive restructuring that is necessary for PTG to occur.

*Joy*. The experience of joy was a key subtheme in the findings of this study. For many of the participants, finding joy in preferred leisure activities was significant and helped buffer negative emotions that they experienced. For example, Lucy states that taking part in a choir has helped her experience "pure joy." Additionally, the practice of yoga has opened Lucy up to be more aware of positive life events and become more appreciative of these experiences. Similarly, Joseph and Jeffrey both engage in musical experiences, such as playing the piano and guitar, for joy. Joseph plays the piano because there is no pressure associated with it. Joseph thinks that he does not have enough skills to play for anyone, which means that he does it for himself only. Joseph explains,

I get to play simply because I love it ... no sense in competing, no sense in public performance; in fact, no real sense to it at all. Just sheer joy. I am as good as I

choose to believe I am, I always get to improve (and I like learning, so this is a never-ending quest), and I can spend hours just experiencing the power of music. I do it for me, and although I sometimes wish I was truly awesome at this ability,

I just enjoy the struggle and beauty of music.

Jeffrey plays the guitar, and enjoys teaching himself to play rock music. He believes that music and art are the highest expression of philosophy and this brings him great joy and pleasure in his free time. JoJo also discusses the joyfulness she experiences from participating in her preferred leisure activities: listening to the radio and being outdoors and being with her dogs. "I like music... just turning the radio on... if there's a nice song, just singing to it or dancing to it" JoJo explains. JoJo reflects on the positive emotions she experiences while listening to the sounds of nature, and feeling the sun on her skin.

Sense of curiosity and inspiration. For some participants in this study, leisure was an outlet for a sense of curiosity and an inspiration to understand and learn more about the world. The most obvious form of this curiosity was seen in Jeffrey, who spends his leisure time reading philosophy books and academic journals. He was committed to those readings because he was fascinated with how the world works, and had a deep and profound interest in knowledge. This fascination and inspiration spills into his other enjoyable activities such as playing chess. Jeffrey plays chess as a form of leisure, and enjoys the psychological challenge of the game, "I like the psychological dominance that you can have over your opponent... its just my tactics against your tactics." These activities create a sense of accomplishment and energize Jeffrey to continue seeking similar experiences in life. Lucy also has a fascination in developing knowledge and skills. The yoga teachers training course was the first course that Lucy was interested in,

and she has been constantly enrolling in educational courses in alternative healing since then. This is a positive experience for Lucy, as she is satisfying her curiosity and fascination and experiencing success. Lucy explained that when she takes courses, she notices "things working better. I'm thinking, I can do this! Where before I didn't think I would be smart enough to take these courses!" Eileen provided a similar example of experiencing a sense of curiosity and inspiration through being involved in various community based workshops. This never-ending quest of learning is paralleled in Joseph, who relates this to learning and improving his skills in playing the piano. Joseph's interest in self-improvement on the piano creates a sense of inspiration, "but that is part of the attraction: the effort to be better than I am. It also reminds me of the importance of dedication and passion in accomplishing our goals…it makes me feel that I can do anything." In sum, the findings of this study indicate that involvement in leisure activities facilitated the participants to experience positive emotions, especially a sense of curiosity and inspiration.

**Gratitude.** Participants in this study also highlighted the experience of gratitude as a positive emotion. For some participants, gratitude was expressed for still having the opportunity and ability to participate in preferred activities. For others, gratitude was evident in their reflections of their experiences with cancer, which was suggested to be connected to the social aspects of their leisure lifestyles.

Of all the participants in this study, Lucy expressed the greatest amount of gratitude in life related to leisure activities that she engages in, such as yoga and physical exercise. Lucy describes her yoga practice as being grateful for oneself and one's surroundings. In addition, Lucy emphasizes that she feels grateful for all of the people

she has met through the yoga community and in her life, and believes that each person has taught her something in life. She expresses a sense of gratitude for learning from these people, and a wish to be able to pass on the knowledge that she has gained from others to each person she meets. Eileen shares this sense of gratitude with Lucy. Eileen is appreciative of the positive experiences and the social opportunities that she has had through being involved in the dragon boat community. Similar to Lucy and Eileen, JoJo expresses gratitude and appreciation for leisure in her life as well. JoJo articulates her gratitude for being outdoors and enjoying nature. JoJo is thankful for nature-based activities, such as bird watching, and being outdoors and the peacefulness that accompanies this. JoJo also described a complicated emotion of feeling grateful for receiving her diagnosis, as she feels that her experience overall has not been as negative and challenging as others.

Some participants expressed gratitude for the small magnitude of their cancer experience in comparison to others. For example, Joseph describes experiences in his cancer journey as challenging but ultimately he is appreciative of them and grateful for their magnitude. Many times throughout the interview, Joseph eludes to the fact that he did not find his cancer experience as overly challenging compared to experiences of others. He states that he knows he is healthy, and he knows he can push himself physically and prostate cancer did not affect that:

I sometimes feel like a bit of a fraud when it comes to talking about surviving cancer: my survival took no skill whatsoever, it took no strength or courage, and it took very little time. And then I see the people who really do struggle: I see people who live with pain every day, people who fight just to walk to their desk at

work because of the polio they had as a kid. I see friends with Colitis and heart problems and bad backs and hysterectomies and mastectomies. I see the number of drugs they take every day just to function. And I just imagine the strength and courage they exhibit every minute ... and I know how incredibly easy I have it... Honestly, graduating from university was harder and took longer.

Joseph expressed his gratitude through social comparison. He is grateful that he was diagnosed with prostate cancer and states that he believes this is one of the "easiest" cancer types to deal with. Joseph has a sense of appreciation and detaches the illness from his personal self and believes that he can cycle and be physically active because of this. Gratitude was expressed by many of the participants in various ways, which were all supported by the participants' involvement in leisure. Similarly, Jeffrey expresses gratitude for his experience as he feels it makes him a more compassionate doctor and healthcare provider.

**Mindfulness.** Closely related to gratitude, the participants expressed that they appreciate the smaller things in life, and practice being present in the moment. This mindfulness was expressed by Joseph when he stated that leisure helps him be mindful; "When I am on my bike, nothing else matters and, for a few moments, I can just be me with the world." Cycling for Joseph is not something that is mindless, but he appreciates that he spends time on his bike being present, and thinking about being engaged in the ride. He values that he does not have to make any decisions while he is cycling, outside of the decisions required to ride the bike. Similarly, Lucy feels the same way about practicing yoga. She feels that her yoga practice is her time to release and calm the mind, to be fully present in the moment. This has helped her to appreciate herself and appreciate

the present moment. Specifically, Lucy discussed the importance of breathing exercises and deep breathing and how this helps reduce stress hormones in her body and allow her to be mindful and accepting of new experiences; "[Yoga is] so filled with releasing your mind and calming your mind, and the breath work that you do - it just basically transforms you" Lucy explained.

JoJo also learned that deep breathing exercises help her to reduce anxiety and worry about the future and focus on the present. JoJo uses these techniques to help her sleep and relax, and she believes that it helps her maintain a positive outlook and keeps her feeling healthy. JoJo also discusses that being outside and enjoying the birds chirping has become a valued experience for her. She describes these outdoor experiences as being carefree and calming, and she seeks opportunities for these occurrences in her leisure.

Being mindful and absorbing experiences fully has helped participants maintain a positive approach to living with cancer, and it has helped them contemplate what their goals and aspirations are in life. Lucy described her experience being present with a sense of awe and fascination, and this has helped lead her to realise her purpose in life. Mindfulness provided the participants an opportunity to accept their current circumstances openly and without judgement, and allowed them to move past their trauma and experience PTG.

#### Finding a Sense of Purpose

The final theme that was revealed through the data analysis was finding a sense of purpose in life after experiencing cancer through meaningful activities. Leisure is purposeful for participants, as they use it to experience desired emotions such as feeling social connections and belongingness, feeling a sense of accomplishment and a sense of

pride in the self, experiencing joy and happiness, and being mindful. Leisure also served as a means of realizing new life purposes in the midst of change; Lucy realized through yoga that her life purpose is to help others heal and grow through yoga practice; Joseph realized that his purpose in life not to work overtime for material objects but to excel in order to achieve happiness and deepened relationships and experiences with others. Jeffrey's purpose is to help people be healthy and influence their life philosophies.

Lucy specializes in private yoga sessions for people who have physical limitations and enjoys that people benefit from her services. She believes that this is her purpose; she is meant to pay her experiences forward and help others heal as she has. Similarly, Joseph expressed a similar purpose in paying it forward and giving back; Joseph states that his experience with cancer has helped him to mature and grow. "I have a far better sense of what I want from life, what I am willing to put up with in order to achieve it, and I am at peace with who I am and who I am not." He also shares that "having cancer meant I got a little glimpse of the thought that sometimes tomorrow really is too late. So maybe you should do the important things today." Helping others learn to help themselves through charitable organizations like Watering Can, developing meaningful relationships with his daughters, and living a long and healthy life is what Joseph has realised is his purpose in life, and this is what he has realized is important to him. Leisure plays a role in each of these purposes; he uses cycling to raise money and provide clean drinking water for developing countries. He uses adventure tourism, such as cycling, hiking, and diving, to develop his relationships with his two daughters and he uses these physical activities to ensure he is healthy and vibrant.

Jeffrey has opened a family chiropractic practice and fitness cross fit studio as a

result of his passion for health promotion and creation. He describes his leisure as his life work, and his purpose. He uses his experience with cancer and his interests to help others realise that their life is meant to be extraordinary.

The findings of this study empirically support that leisure plays a role in individual's path to find purpose in life, and, therefore, contributes to the experience of positive growth after trauma. As depicted in Figure 1, four overarching themes were found in this study to have a role in the experience of PTG for individuals living with cancer: (a) fostering relationship building, (b) providing an environment to experience a sense of self, (c) providing opportunities for positive emotions, and (d) finding a sense of purpose for the participants of this study. The contributors have experienced positive personal growth despite living with a disease that has chronic negative impacts and challenges in everyday life. The participants of this study are a sample of individuals who have used leisure meaningfully to experience PTG in the midst of cancer.

#### **Chapter Five: Discussion and Conclusions**

The purpose of this study was to explore the role that leisure had in facilitating posttraumatic growth (PTG) for individuals who have experienced cancer. A phenomenological approach guided the research process, as this methodology allows for the researcher to emerge into the lived experiences of the research participants.

To answer the research question of this study, the results from the previous chapter are explored further in this discussion. These findings explore the meaning of leisure to PTG, and are compared to previous research findings that were addressed in the literature review. The implications of the study as well as suggestions for further research and exploration into the topic of leisure and PTG are addressed in this chapter as well.

#### **Building Meaningful Relationships in Leisure Environments**

This study provided insight into the role of leisure in experiencing PTG for individuals living with cancer. Previous studies exploring the phenomenon of PTG highlight the role that leisure has in building relationships; Tedeschi and Calhoun (2006) found that individuals who experienced trauma often felt a strong sense of compassion for others who shared similar experiences, and, therefore, developed meaningful relationships with these people. Tedeschi and Calhoun (2004) further stated that as individuals share their emotions and perspectives on their experiences and others respond with support, this influences the role of the relationship on experiencing PTG. Furthermore, McElheran et al. (2012) added that females often experience higher rates of social support posttrauma, and, thus, experience higher rates of PTG. This study provided empirical evidence of the importance of meaningful relationships with friends and family members. Distinctively, female participants in this study were more likely to use

activities (e.g., yoga, dragon boating, and educational workshops) to develop relationships with others. Interestingly, both male and female participants of this study suggest that animal companions provide a significant amount of social support during traumatic experiences, which is limited in the literature surrounding PTG and illness and leisure. Carruthers and Hood (2004) state that positive relationships are associated with higher levels of mental and physical health, and this suggests that relationships have more of a role in PTG than once understood. The findings of this current study, when compared to the findings of other studies, suggest that the relationship between leisure and developing meaningful relationships has a complex role in facilitating PTG, and that the factors may interact with one another in an intricate way.

#### **Exploration of the Self using Leisure**

During the posttreatment phase, the acknowledgment of the potential manifestation of cancer contributes to the overall stress and trauma of the cancer experience (Morris & Shakespeare-Finch, 2011). As Scrignaro et al. (2011) suggest, these characteristics of cancer often lead people who are experiencing cancer to question their current life priorities and social roles, the meaning of significant relationships, as well as their own identity and life story narrative. The participants in this study provided evidence for this examination of self, and many identified ways in which they wanted to change and better their lives. This influenced the structure of their daily lives, and their leisure lifestyles. Leisure provided a spark of interest for some of the participants to create careers around their preferred leisure activities. Other participants used their leisure interests to shape their work life, so that they could accommodate their leisure interests and commitments into their regular routine because this is what they deemed as important and meaningful in their lives. Leisure also provided a structured environment where the participants could maintain work-like routines. This finding is consistent with the literature by Lahey (1993) that the life threatening and identity challenging aspect of chronic illness tends to allow people to find new meaning in their leisure activities. It was especially noteworthy to listen to the participants of this study recount their life story into "before and after" as the literature suggested that individuals often divide their narrative posttrauma (Bury, 2001; Charlier et al., 2012; Sawyer et al., 2010; Shannon & Shaw, 2005). Some participants were blatant in that they described their life priorities before they were diagnosed and they walked me through their experience to allow me to imagine what it felt like psychologically to experience a traumatic diagnosis and how this changed their priorities. Interestingly, the literature suggests that the more traumatic the experience, the more the life story narrative will be divided into separate parts (Calhoun & Tedeschi, 2006; Weiss, 2004); for some of the participants of this study, however, they do not recall their diagnosis as traumatic, and they do not attribute their own strength and persistence to surviving, rather they denote their form of cancer as "easy" yet they exhibit this narrative habit the most. This could be attributed to how these individuals have learned to cope with their illness, and could mean that the phenomenon of PTG is present and influencing their narrative perspective.

#### Leisure as a Means to Experience Positive Emotions

Prominent in the leisure research is the emphasis on how leisure can provide opportunities for individuals to experience positive emotions and create daily positive life events in the midst of trauma and negative life circumstances (Davidson et al., 2006). Contributing to this body of research, the participants in this study expressed positive

emotions as a reward for participating in enjoyable and meaningful leisure opportunities. The findings in this study are consistent with Davidson et al.'s argument that positive experiences, such as these, serve as respite from illness and counteract negative emotions. The positive psychology literature suggests that positive emotions not only enhance mental health, but have the capability of increasing immune function and physical functioning as well (Carruthers & Hood, 2004). This complex relationship between health and positive emotion could have a significant role in the experience of PTG, and leisure is a vehicle for the facilitation of this phenomenon. Davidson et al. also suggest that the positive emotions associated with leisure provide opportunities for creating meaningful experiences. Carruthers and Hood suggest that intrinsically motivated experiences such as leisure activities open individuals up to experiencing novel experiences which can lead to further positive emotions. This "upward spiral" as termed by Fredrickson and Joiner (2002; p. 172) creates a drive for participating in meaningful and enjoyable experiences (Carruthers & Hood, 2004), which can also play a role in the experience of PTG. This is related to the findings in this study as many participants recounted positive leisure experiences in their interviews, and emphasized the impact that these experiences had on their lives and their interest in pursuing the experiences further. The participants in this study associated meaning with leisure experiences beyond an enjoyable pastime (i.e., Cycling is a metaphor for life) suggesting that leisure plays a significant role in the experience of PTG.

Perhaps the most interesting aspect of positive emotion was that individuals in this study experienced gratefulness as a result of participating in preferred leisure activities. Some participants expressed that their leisure pursuits have helped them

experience gratefulness, and that it has taught them to be thankful. Other participants expressed that what they enjoy most about their leisure activities is what they are grateful for in life; taking time to experience the little things in life and appreciate them. Unique from previous studies, many of the participants in this study expressed gratefulness towards the magnitude of their experience in comparison to others. Theories on social comparison are emerging, and Buunk and Gibbons (2007) were the first to suggest that people who score high on the self-comparison scale also score high on personality traits such as self-consciousness and a strong sense of interdependency. Leisure may play a role in this phenomenon, as team based and social leisure, such as sports and group activities, is a means to directly compare skills and abilities to others in a fixed environment. One can evaluate their skills and their contribution to a team easily in a team oriented activity. Perceived health may influence this social comparison as Brakel et al. (2012) found that individuals who have a higher perception of their own health engaged in "beneficial contrasting." Those who had a higher self-perception experienced a higher quality of life due to beneficial contrasting when comparing themselves to a "comparison other" who possessed a lower perception of their health. It is worth exploring further the role of comparison to others in the experience of PTG. For many participants, reflecting on their experience with cancer was overall positive and they alluded to a comparison of their experience to others and suggested that they were lucky to have had their experience as opposed to what others have lived through. Consistent with these findings, evaluating one's own accomplishments and abilities has been found to help individuals evaluate and cope with their own lives (Schneider & Schupp, 2014) which could be applied to the study of chronic illnesses and PTG.

#### **Finding Purpose Through Leisure**

Commonly found in the PTG literature is the overarching theme of an increased sense of life purpose, and renewed meaning in life (Manne et al., 2004; Powell et al., 2012; Prati & Pietrantoni, 2009; Shannon & Shaw, 2005; Tedeschi & Calhoun, 1996, 2004, 2006). This study highlighted what the other researchers in the field found as many participants cited that after the diagnosis of cancer they questioned their priorities and found new purpose in life. This study explored the role that leisure had in this process, as it is one of the five domains cited by Tedeschi and Calhoun (1996, 2004, 2006). Powell et al. (2012) stated that having a sense of purpose and personal meaning was the largest predictor of PTG in individuals who had experienced traumatic brain injury (TBI). This finding was significant because personal meaning and a sense of purpose were not widely explored in PTG literature at the time of their study (Powell et al., 2012). This finding was supported by the participants in this study, as reevaluation of priorities and life's purpose was evident in all of the participants.

What is unique to this current study is that the participants in this study often used leisure as a means to create and fulfill their newfound purpose. For example, one participant, in particular, found that through her involvement in yoga, she found that her purpose was to use yoga to help others heal and this was common amongst the other participants as well. Another participant learned that his purpose was no longer to excel at his career, but to continue his success in order to be able to experience more leisure activities that he enjoys.

#### **Conclusions and Implications for the Future**

This study provides insight into the role of leisure in experiencing PTG for individuals living with cancer. It shifts the discussion in cancer research from a deficits approach to a means of living well and experiencing personal growth after a traumatic diagnosis of illness using leisure.

**Implications for Future Research.** This study begins to address some of the gaps in the literature connecting the role of leisure to the facilitation of PTG; however, further study into the role of leisure in chronic illness and PTG needs to be conducted to better understand this phenomenon. I would suggest that researchers in the field explore the role of leisure further using negative cases to understand the other factors that could be facilitating PTG in individuals living with cancer. This would include looking at the stage and type of cancer, as well as the time lapsed since diagnosis. The participants of this study were in various stages of their illness; some participants were cancer survivors for many years, while others were recently diagnosed. The participants in this study brought various perspectives of their illness to the interviews and it would be beneficial to understand what the influence of the stage of cancer ("survivor" versus in treatment) plays in the way an individual copes with it and attributes meaning to their leisure activities. It would also be beneficial to explore the role of leisure in facilitating PTG in other chronic illnesses that create psychological trauma upon diagnosis, as this would help practitioners learn what leisure can do for various experiences. Additionally, exploring the role of leisure in the facilitation of PTG in the midst of other traumatic experiences, such as bereavement, job loss, and natural disasters, would strengthen the literature in the field.

Extensive previous studies have focused on exploring the negative aspects of the cancer experience; however, this study contributes a positive perspective to the field. Leisure contributes a great deal to the positive aspects of living with cancer including acting as a vehicle to strengthen and develop relationships with others and the self, to experience daily positive emotions, and to increase an individual's sense of meaning and purpose in life. This study found that people living with cancer found great tangible and perceived emotional support from pets; therefore, exploring pet therapies and pet based leisure pursuits would strengthen this research as well.

Lastly, future research could focus on one of the four themes that emerged from this research such as leisure and the positive emotion of gratitude in the experience of PTG. By exploring select themes, the process of PTG will be better understood and, therefore, more practical.

Implications for Health Service Providers. This study contributes to the limited literature investigating the role of leisure in the facilitation of PTG and provides a starting point for health service providers when working with populations living with chronic illnesses to facilitate PTG. This study informs professionals of the role of leisure in the experience of PTG; leisure can be a meaningful behaviour that helps individuals experience meaningful relationships, develop a sense of self, experience positive emotions, and look inwards and reflect of existential beliefs and values. The activities that the participants in this study chose to participate in connected them to communities that they felt accepted and supported in. For some individuals, this is possible on their own accord; however, some individuals struggle with finding meaning in their leisure and this is when it would be appropriate for a professional to offer support in discovering or

adapting leisure activities to facilitate positive growth in the recovery process. These opportunities for individuals living with cancer exist through hospitals and cancer related nonprofit organizations, but those facilities should have a counselor or liaison present in the oncology units to help patients connect to community resources when needed. Information on the benefits of engaging in meaningful leisure should be made available to individuals who are diagnosed with cancer, and they should have the opportunity to complete activities and assessments to determine their leisure interests and strengths. An allied health professional could also be present on oncology units to provide leisure education towards how individuals can adapt their participation in leisure activities and explore new leisure opportunities.

Additionally, leisure serves to help individuals renew their sense of self in the midst of a loss of social and occupational roles. Persons living with cancer should have access to service providers who can help them fill their time meaningfully to help them develop a renewed sense of self. This will, in turn, help to develop leisure skills, and, thus, develop self-confidence and a sense of personal achievement which would counteract the negative side effects of living with chronic illness such as anxiety, depression, and fear. By having a trans-disciplinary team present during the cancer experience that treats patients holistically, individuals will be able to personally grow and develop, and find meaning in their lives despite their illness. In conclusion, this study sought to explore the role of leisure in the experience of PTG for individuals who were living with cancer. By using a phenomenological framework, it was found that individuals who are living with cancer use leisure as a means for social support, to create and maintain a strong sense of self, to experience positive emotions, and to experience

increased spirituality and purpose in their lives. As there are limitations to this study, further exploratory research is necessary to fully understand the complex role that leisure has in the lives of these individuals. By understanding the role that leisure has in this phenomenon, we can start to focus leisure services on the experience of PTG and personal growth in the midst of many forms of trauma, including chronic illness.

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## Appendix A

### **Information for Support Group Directors**

#### **Information for Support Group Program Directors**

Project Title: Leisure as a Facilitator of Posttraumatic Growth in Individuals Living with Cancer.

Principal Student Investigator (PI): Tabitha Vercillo, Graduate Student Department of Recreation and Leisure Studies, Faculty of Applied Health Science Brock University tv11gl@brocku.ca

Faculty Supervisor: Dr. Sanghee Chun, Associate Professor Department of Recreation and Leisure Studies, Faculty of Applied Health Science Brock University (905) 688-5550 Ext. 5225 schun@brocku.ca

### **Purpose and Rationale**

The purpose of this proposed thesis is to explore how leisure plays a role in the facilitation of posttraumatic growth (PTG) in people who have experienced cancer.

In terms of negative life events, leisure coping literature provides an in-depth exploration of the various ways that leisure acts as a coping mechanism; enabling individuals to develop a resistance to negative life events as well as acting as a buffer during trauma (Iwasaki & Mannell, 2003). Research also suggests that leisure is a means of adjusting to negative life events and provides an opportunity to experience a sense of control and allow self-determination (Kleiber, Hutchinson and Williams, 2002). This implies that leisure has an important role in life transformation following negative life events. Therefore, further exploration of the role that leisure has in the experience of trauma is necessary to understand the phenomenon of PTG rather than examining the traditional conceptual context of leisure and stress coping (Kleiber, 2004). Moreover, no empirical study has examined leisure as a facilitator of PTG in individuals living with cancer. Traditional cancer research has focused on negative aspects of the disease and the paradigm must shift to a positive perspective, where individuals can grow and thrive in the midst of their experience.

**Research Question:** What meaning does leisure have in the lives of individuals living with cancer who have experienced posttraumatic growth?

**Participant Recruitment:** Six to eight participants will be purposively selected who self identify as meeting the following selection criteria:

- 1) Have experienced cancer,
- 2) Report a level of satisfaction with their lives,
- 3) Have a capability of sharing their experiences in verbal interviews,
- 4) Are living in Ontario, and

5) Are at least 18 years old.

Facilitators of local (Southwestern Ontario; Wellspring Ontario locations, London Regional Cancer Program, St. Joseph's Healthcare Breast Care Clinic) cancer support groups will be contacted, and asked to act as gatekeepers and provide information pertaining to the study to their support group participants. If participants are interested, they will contact the principle student researcher via phone or email directly.

# **Participant Participation:**

Upon approval from the Brock University Ethics Review Board:

- Participants will be informed of the purpose, methodology and intended outcomes of the study, and will be asked to provide informed consent and permission to audio-record (See Informed Consent Form).
- Interviews will take place at a location and time that is convenient for the participants and last approximately 1-2 hours and will be audio recorded.
- Interviews will be semi-structured, and the interviewer (principle student researcher) will ask open-ended questions and use probing questions when necessary.
- Participants will be offered the opportunity to review the transcripts of the interviews as well as preliminary data analysis as a form of member-checking.

## **Possible Risks and Benefits:**

There are no physical or social risks associated with participating in this study, however there is the potential for participants to experience emotional reactions to the discussion of their everyday life. The participants may experience negative emotions towards their experience with cancer during the interview. To manage the risk of psychological harm, the focus of the interviews will be on what leisure means in the everyday life of these individuals, not on the diagnosis and experience of cancer. The diagnosis of cancer is not the focus of the study; therefore questions will not reflect this phenomenon unless the participant describes the experience of cancer as having an influence on their daily life activities. If the participant expresses emotional reactions, they will be referred to their support group facilitator for further support.

Individuals who participate in the study would have the opportunity to share their story and experience with the researcher, which may provide a sense of empowerment. Literature suggests that if the focus of the interview is on positive aspects of life or PTG, the conversation could be therapeutic in that it could be a form of social support for the participant. Additionally, individuals who participate in the study could experience a sense of purpose, as they are contributing to the research and knowledge around improving the quality of life for other individuals living with cancer.

Prior to beginning the interview, they will complete an informed consent form (See appendix A). It will be assured that the participants understand that participation in the study is on a voluntary basis and they may withdraw at any point throughout the study

without consequence. The data collected prior to withdrawal will be confidentially shredded and/or electronically deleted. The process for withdrawal without consequence will be outlined prior to the interview and written on the consent form. The purpose of the research is to understand the meaning that individuals living with cancer associate with leisure in their experience of PTG. Participants will be given the opportunity to review their interview transcript as well as provide feedback and request alterations to ensure that the interview reflects their genuine perception. Additionally, participants will provided with a summary of the preliminary data analysis as a means of member checking to ensure that the researcher has interpreted their experiences in a genuine way. Upon completion of the study, participants will be provided with a summary of the findings, and instructed on where they can access the full manuscript or any related publications.

# **Confidentiality:**

Each participant will be assigned a pseudonym that will accompany all data collected. The real identities of the participants will only be requested on the consent forms, which will be stored in a locked desk drawer in a locked office. Any written data and audio data will be stored in a locked drawer or password protected file, respectively. The researcher will be aware of participant's identities, as the data will be collected through face-to-face interviews. Participants will not be required to provide researchers with any other personal information, aside from their name on the consent form, and a means to contact them to provide transcripts/ preliminary data analysis/ a summary upon completion.

The voice will be the personal identifier in the audio recordings, however strict care will be taken to secure and restrict access of this information to the principle student researcher and the principle researcher supervisor. Only the principle researchers and the faculty research committee will have access to the data. The data will be confidentially shredded and electronically deleted once the study is complete, and following publications are completed.

## Appendix **B**

### **Participant Recruitment Flyer**

## PARTICIPANTS NEEDED

#### Who Can Participate

- Have experienced any type of cancer
- Are satisfied with their life
- Able to participate in verbal interviews
- Live in Ontario
- Are at least 18 years old

#### What Is Required

- Engage in one interview, approximately 1-2 hours in length at a location of your choice

- Interview will consist of questions discussing your leisure lifestyle and activities you do for enjoyment

#### Why it's Important

To help gain a better understanding of the role and meaning that leisure has in the lives of individuals living with cancer. This research aims to understand how to facilitate more positive leisure experiences for individuals living with cancer.

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board [13-127-CHUN].

If you are interested in participating in the study or if you have any questions or concerns, please contact: Tabitha @ tv11gl@brocku.ca

# Appendix C

## Participant Information Letter and Informed Consent toParticipate

Date: November 20, 2013 Project Title: Leisure as a Facilitator of Posttraumatic Growth in Individuals Living with Cancer.

Principal Student Investigator (PI): Tabitha Vercillo, Graduate Student Department of Recreation and Leisure Studies, Faculty of Applied Health Science Brock University tv11gl@brocku.ca

Faculty Supervisor: Dr. Sanghee Chun, Associate Professor Department of Recreation and Leisure Studies, Faculty of Applied Health Science Brock University (905) 688-5550 Ext. 5225 schun@brocku.ca

## **INVITATION**

You are invited to participate in a study that involves research. The purpose of this study is explore the meaning that leisure has in the facilitation of posttraumatic growth for individuals living with cancer.

## WHAT'S INVOLVED

As a participant, you will be asked to participate in a face-to-face interview that will be <u>digitally audio-recorded</u>. This interview will explore the role that leisure has in your daily life. Participation will take approximately 1-2 hours of your time, and you will have the opportunity to read the transcript of your interview and review preliminary data analysis.

## POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include the opportunity to share your experience, and contribute to research that aims to understand how to improve the quality of life of individuals living with cancer. Through participation, it may be possible to experience an emotional response and therefore psychological harm to sharing your story. However, the experiences you share in the interview are to your discretion, and will be focused on how leisure is used in your life to experience positive changes. To further reduce the risk of psychological harm, the interview questions will focus on the use of leisure, the experience of positive change in your life and not on the diagnosis of cancer. The primary researcher will be available to provide support resources in the event of emotional response.

# CONFIDENTIALITY

The information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, with your permission, anonymous quotations may be used with a pseudonym. Shortly after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

Data collected during this study will be stored in a password protected electronic file on the primary researcher's password protected personal computer. Data will be kept for up to one year, or until the research study is completed. Upon completion, electronic data will be deleted and paper consent forms will be shredded confidentially. Access to this data will be restricted to the primary researcher, the academic faculty supervisor and the research committee.

# **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty. The data collected prior to withdrawal will be electronically deleted and/or confidentially shredded immediately.

# **PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. The presentation of data will not include any identifiers, and will be anonymous. Feedback about this study will be available through the primary student researcher if you are interested.

# CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact Tabitha Vercillo, or Dr. Sanghee Chun using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University; File number 13-127- CHUN. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

# **CONSENT FORM**

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

# Appendix D

# **Interview Guide**

Date:	Interview Start Time:	End
Time:		
Location:		

- 1.1. Tell me a bit about yourself; your past, jobs, community roles, family roles, your leisure
- 2.
- 2.1. Please describe a typical day in your life.
- 2.2. Walk me through the highlights of your first year after diagnosis?
- 2.3. Tell me about activities that are important to you.
- 3.
- 3.1. What are some of the emotions you have experienced?
- 3.2. Have any emotional experiences surprised you?
- 3.3. How do you deal with these emotions?
- 3.4. What activities do you do that make you happy?
- 4.
- 4.1. Have any of the previous experiences or activities become more or less meaningful to you?
- 4.2. How has your leisure changed throughout your experience?
- 4.3. Has your value of leisure changed?
- 5.
- 5.1. Many people report different experiences with sensation during cancer and cancer treatments( eg, touch, taste, smell, seeing, hearing, proprioception, vestibular) Tell me about any that you would like to share.
- 5.2. Depending on the sensory experiences that you have had, what adjustments have you made, if any

5.3. How have your sensation experiences influenced other aspects of your life? How have they influenced or affected your leisure

# Appendix E

# **Themes and Subthemes**

- 1. Relationship Building
  - a. Strengthening meaningful relationships
    - i. With family
    - ii. With close friends
  - b. Companionship in a supportive environment
    - i. Leisure companionship
    - ii. Everyday life companionship
- 2. Developing a Sense of Self
  - a. Maintaining a sense of self
    - i. Maintain social/personal identity
  - b. Renewed sense of self
    - i. Renewed social/ personal identity
- 3. Positive Emotions
  - a. Joy
  - b. Interest (inspiration, curiosity, fascination)
  - c. Gratitude
- 4. Existential Observance
  - a. Positive outlook on life
  - b. Mindfulness
  - c. Finding a sense of/ having purpose

### Appendix F

#### **Certificate of Clearance – Research Ethics Board**



Brock University Research Ethics Office Tel: 905-688-5550 ext. 3035 Email: reb@brocku.ca

**Social Science Research Ethics Board** 

#### **Certificate of Ethics Clearance for Human Participant Research**

DATE:	12/24/2013			
PRINCIPAL INVESTIGATOR:	CHUN, Sanghee Recreation and Leisure			
FILE:	13-127 - CHUN			
TYPE:	Masters Thesis/Project	STUDENT: SUPERVISOR:	Tabitha Vercillo Sanghee Chun	

TITLE: The Role of Leisure in the Facilitation of Posttraumatic Growth

#### ETHICS CLEARANCE GRANTED

Type of Clearance: NEW	Expiry Date: 12/31/2014
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The Brock University Social Sciences Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 12/24/2013 to 12/31/2014.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 12/31/2014. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <a href="http://www.brocku.ca/research/policies-and-forms/research-forms">http://www.brocku.ca/research/policies-and-forms/research-forms</a>.

In addition, throughout your research, you must report promptly to the REB:

- a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- c) New information that may adversely affect the safety of the participants or the conduct of the study;
- d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

Jan Frijters, Chair Social Sciences Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.