UNSOLICITED NARRATIVES FROM CANCER SURVIVORS: A LONGITUDINAL, QUALITATIVE ANALYSIS

by

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Abstract

Being diagnosed with the ‘C’ word, also known as cancer, provokes a wide variety of psychological reactions for those newly diagnosed with the disease. The cannon of literature on how individuals cope and adjust to a cancer is diverse and suggests that how one copes and adjusts is influenced by such variables as age, gender, social support, cancer severity and cancer type. This qualitative study is a secondary analysis of unsolicited narratives written in the margins of survey questionnaires in a longitudinal study of how cancer patients emotionally adjust to a cancer diagnosis. The purpose of this study was to understand how the unsolicited narratives of 86 cancer patients might contribute to the broader context of the theory-laden scope of health and counselling research. Purposely, this research study pursued two lines of investigation: 1) the ambiguity of test items and 2) how standardized measures do not fully capture personal experience. Qualitative description was used to analyze the unsolicited narratives. Conventional thematic analysis was used to code the data that was then categorized into major themes that arose from the narratives. The results from the narratives added by 86 of the original 421 (20.4%) participants resulted in identifying six main sub-themes, namely: coping and adjustment to cancer, the effects of cancer, employment and RTW, other life events, social support and diagnosis and treatment. Themes arising from the narratives are commonly found within the cannon of cancer research and provide further supporting evidence about those issues most important to newly diagnosed cancer patients.
Preface

All of the work presented henceforth was conducted in collaboration with Dr. Wolfgang Linden in the Department of Psychology and with Dr. Marv Westwood in the Department of Counselling Psychology at the University of British Columbia. Furthermore, the original study would not have been possible without the collaboration and support of the British Columbia Cancer Agency, specifically, Regina MacKenzie and Diana Hass and University of British Columbia postdoctoral member, Dr. Andrea Vodermaier. All projects associated with this study were approved by the University of British Columbia’s Research Ethics Board and the British Columbia Cancer Agency Research Ethics Board, certificate # H09-02070.

During the original investigation, I was working for Dr. Wolfgang Linden as his Research Coordinator. In that position, I had many roles one of which was communicating with potential participants and those individuals who agreed to participate in the study. I also assisted the research team with study development, questionnaire preparation and took the lead in participant recruitment, and oversaw the study from beginning to almost completion (I began graduate studies 3 months before the last of the 12 month questionnaires were received). I also supervised Research Assistant, Duncan Greig and lab volunteers, Kosta Kudos and Alvina Ng who also worked on the project.

For the current study, I am the lead investigator and as such responsible for all major areas of concept formation, data collection and analysis, as well as manuscript composition. Kosta Kudos was involved in the early stages of concept formation and Alvina Ng assisted in the later concept formation and acted as secondary data coder. Dr. Wolfgang Linden assisted with statistical analysis, Dr. Leanne Currie assisted with manuscript edits and statistical analysis and Dr. Marv Westwood contributed to the manuscript edits and acted as the supervisory author on
this project. Lastly, preliminary findings of this study were presented in poster format in the Health Psychology section of the 2013 Annual Canadian Psychological Association Conference in Quebec City, Quebec on June 15th, 2013.
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Acknowledgements

“The journey of our lives is not just about the destinations we have reached. Our wisdom, education and personal growth come from the people we meet, the paths we choose to follow and the lessons we have learned along the way”

Unknown author

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Dedication

My journey back into academia after a sixteen-year hiatus would not have happened if I had not met my husband, Glen. His continued support, unconditional love, constant patience and understanding has brought me to this unbelievable place and allowed me to live a life I love and become the person I was meant to be. Glen, I thank you with every fiber of my being for being the most amazing husband, friend and confidant. I am eternally grateful that you came into my life and I dedicate this thesis to you.
1.1 Background on the Original Study

The genesis of this study began while I was working as a Research Coordinator for Dr. Wolfgang Linden in the Psychology Department at the University of British Columbia. In the original study, our team was interested in how cancer patients emotionally adjusted to their cancer diagnosis over a one-year period. Specifically, we were interested in examining illness intrusiveness, anxiety, depression, social support, and posttraumatic growth (PTG).

During the original study, part of my responsibilities was to communicate with potential and participating individuals. It is from these personal anecdotal comments both verbal and written that I began to understand that there was more to know about the participant’s experience with cancer than what the original study had anticipated. During recruitment, one individual explained to me that:

To get support you need to tell everyone in your life. If they don’t know, how can one be supported? Everyone in my office building knows I have breast cancer, from the elevator man to my co-workers. I am very supported.

My interest was also peaked by those participants who withdrew for the original study. These individuals cited a vast array of reasons why he or she could not continue and furthered my understanding of the range of experiences faced by those newly diagnosed with cancer. For instance, many individuals stated that the experience of cancer was overwhelming and either wrote or verbally shared that they were, “Too stressed out right now”, or had “Too much going on and too much mail to go through” or that “I am not feeling well” and “No longer in study group. Side effects too harsh for me. Lost my job due to drugs, now on disability. Thanks.” Likewise, I received communication from the spouses of study participants who shared that, “I
regret that my husband is on palliative care and too ill to do this.” or that the onset of dementia precluded further participation. In addition, some participants simply stated, “I do not want to talk about my illness” or that they had “…no emotional adjustment to make and I do not wish to participate further.” Another participant who withdrew shared that the “…questionnaire package was shallow, not meaningful and I do not want to be bothered” while another participant withdrew because he and his wife wanted to ‘”live for today” and decided to travel for the next 16 months. Still, another individual, he or she did not feel their participation would be of assistance and wrote:

Please be advised that due to my recent diagnosis, I do not feel I am a worthwhile candidate to this survey. I will not be taking ongoing treatment at the BC Cancer Agency as I have had surgery and am now cancer free.

As earlier stated, the original investigation was interested in how cancer patients emotionally adjusted to their cancer diagnosis over a 12-month period. Specifically we were interested in examining illness intrusiveness, anxiety, depression, social support and posttraumatic growth and factors relating to returning to work. Data was collected via mail-based correspondence at three time points, Baseline, 6-months and 12-months. Several quantitative measures were used and included the Psychosocial Screening Tool for Cancer, the Illness Intrusiveness Rating Scale, the-Post Traumatic Growth Inventory, a-Return to Work measure, the Assessment of Survivor Concerns and Demographic information. Interestingly, as the study progressed, it became clear that many of the participants were keen to provide more information than was originally asked of them and wrote in the margins of his or her questionnaire. The diversity of individual experiences described in these unsolicited narratives
speaks to the need for greater understanding of what living with cancer was like for these participants, hence the current study.

1.2 A Brief Synopsis on Cancer Prevalence in Canada

According to the Canadian Cancer Society ("Cancer statistics at a glance," 2013), it is estimated that 187,600 men and women will be diagnosed with cancer in 2013 and 75,500 will die from the disease and is the leading cause of death in Canada. Given that survival rates between 1992-1994 and 2006-2008 have increased from 56% to 63% for all cancers combined ("Cancer statistics at a glance," 2013), researchers, doctors, medical staff and counselling professionals are faced with a formidable challenge of understanding the psychological sequel of how cancer patients adapt to his or her cancer diagnoses.

1.3 Cancer, Stress & the Immune System

Previous research has concluded that being diagnosed with cancer can be a highly stressful and life changing event. As such, how cancer patients adapt to stress can have a profound impact in their ability to fight the disease. This is an important consideration in cancer care and treatment since psychological distress and stressors such as negative life events (e.g., cancer diagnosis) have been consistently associated with the downregulation of the immune system as a result of the physiological changes (e.g., fluctuations in hormone and neuropeptide levels) related to stress (Andersen, Kiecolt-Glaser, & Glaser, 1994). In terms of immune system functioning, acute stress (time limited) promotes adaptation and immune functioning by sending immune cells to fight against pathogens while chronic stress suppresses immune functioning and may cause allostatic overload (excessive wear and tear on the body) (McEwen, 2004).

While acute time limited stressors have been associated with several facets of immune downregulation, chronic stressors are correlated with a persistent downregulation of immune
responsiveness rather than adaptation (Andersen et al., 1994). Whilst Andersen et al. (1994) fail to prove a direct correlation between chronic stressors and the cancer experience, they authors contend that there are many commonalities between the two and reason that “Data from healthy samples suggest that stress variables are predictive of immune downregulation, and accumulating data with cancer groups support the same general conclusion” (p. 396). In a review paper by Reiche, Nunes, & Morimoto (2004), the authors maintain that persistent activation of the hypothalamic-pituitary-adrenal (HPA) axis as a result of a chronic stress response and in depression almost certainly weakens the immune response and contributes to the growth and progression of some types of cancer. Furthermore, the authors assert that the linear progression of immune system reactions either hindered or fostered as a consequence of previous or parallel stressors depending on intensity, type as well as animal species, strain sex or age. In a similar vein, a study on how stress influences the relapse in breast cancer patients concludes there is a predictive association between life stressors and breast cancer recurrence (Ramierz et al., 1989), thus supporting the notion that stress influences physical wellness and disease progression. Relatedly, one can conclude that the physiological consequences that co-occur with emotional and psychological experiences provide one avenue by which emotional states may interact with one’s physical health and subsequent disease progression.

1.4 Narratives & Emotional Expression

The myriad of possible reactions cancer patients have as a reaction to a cancer diagnosis presents formidable challenges for mental health professionals that are faced with the challenge of understanding what type of intervention works best and for whom. There are a several interventions that have shown to be effective in assisting cancer patients deal with their disease, but as Helgeson, Cohen, Schulz and Yasko (2000) suggest, not all patients benefit equally from all types of interventions. From this, mental health professionals must appreciate the importance
of individual preferences and the salience of how individualized treatment approaches address the specific needs of the individual. According to Zakowski, Morton, Johnson and Flanigan, (2004), emotional expression is a crucial component of many cancer interventions. For some cancer patients, wading into the abyss of feelings about their disease may be too taxing, yet for others, emotional disclosure may not only be needed, but welcome.

One technique that for emotional disclosure has been developed by J. Pennbaker. Pennebaker’s method uses writing as a therapeutic intervention as a vehicle for emotional processing. Studies on his method have shown to be effective in improving the physical and psychological symptoms of an array of stress provoking or traumatic events such as medical illness (Pennebaker, 1997; Pennebaker, Colder, & Sharp, 1990; Pennebaker, Kiecolt-Glaser, & Glaser, 1988) and may be most beneficial for those individuals with limited social support (Zakowski et al., 2004).

Research on using Pennebaker’s method with patient populations has been limited and has yielded mixed results. In some studies, there have been improvements in health outcomes in patients with asthma, arthritis and breast cancer (Smythe, Anderson, Hockemeyer, & Stone, 2002; Smythe, Stone, Hurewitz, & Kaell, 1999; Stanton & Danoff-Burg, 2002) yet some research suggests that written narratives were only successful in a subset of patients (Stanton & Danoff-Burg, 2002; Zakowski et al., 2004) or failed to yield any significant results (Walker, Nail, & Croyle, 1999).

In the above studies, expressive writing was the study focus whereas the current study is based on unsolicited narratives written in the margins of questionnaire packages of a larger quantitative study. As such, we must ask ourselves, *what questions did we not ask?* While we will never know for sure what prompted these participants to provide more information that was
asked, the argument exists that these unsolicited narratives may provide salient information that could inform medical and health professionals as well as policy makers about the diverse experiences of living with cancer. Moreover, this type of personal information may be pertinent to BCCA specifically, thus allowing the assessment of current screening protocols and perception of available support services.

Whilst it is accepted that survey research methodology is effectual in acquiring large amounts of specific research data and expanding our awareness of a phenomenon that affords generalizations to be made, what is clear from our data and the unsolicited data obtained from previous studies (Clayton, Rogers, & Stuifbergen, 1999; Warms, Marshall, Hoffman, & Tyler, 2005), survey data is not enough. What seem to be wanting from traditional survey data are the laden-rich personal perspectives and experiences that facilitate a holistic understanding of the individual. Without this, understanding the totality of individual experiences remains elusive. A review paper on illness narratives in health research suggests that personal narratives can serve many purposes for the writer and can be inspired by a yearning to help others, altruism or act as a caution sign about an event resulting in a negative outcome (O’Brien & Clark, 2010) or as previously discussed, have a therapeutic effect on the writer.

Interestingly, written narratives can differ from oral narratives, especially in terms of illness since the writer is able to freely express themselves without the constraints of having apprehension or fear about how it may affect others (Carlick & Biley, 2004; Lepore, Fernandez-Berrocal, Ragan, & Ramos, 2004). Personal narratives allow the writer to create meaning out of their experiences and as Hyden (1997) describes it is a formidable mode of being able to express one’s illness and suffering. Irrespective of the purpose a narrative serves, narratives about how one experiences and adjusts to an illness such as cancer share a common function by allowing
individuals to detail and record how cancer has affected his or her lives and the lives of his or her family and friends. From this understanding of narratives, it is clear that the illness narratives under study offer a unique view into understanding the inner world of how cancer patients make sense of his or her experiences. Furthermore, the growing acceptance of using narratives to inform medical research could fundamentally change “…the experience of disease or of doctoring” (Charon, 2001, p. 83) and by extension, better inform mental health professionals alike. Moreover, narratives provide a unique vehicle for those medical and counselling professionals who traditionally spend more time with patients to better understand how cancer patients are feeling and other individuals with chronic and/or fatal diseases.

While seeing written comments in the margins of quantitative questionnaire packages is certainly not a new phenomenon, recognizing its usefulness the unsolicited narratives as a source of additional information is (Malinski & Litwin, 2007). Moreover, the unsolicited narratives from medical populations such as the participants in this study allow the ‘narrator’ (the participant) to determine “the content of his or her story, and not the researcher” (Malinski & Litwin, 2007, p. 274). Given the recent interest in unsolicited narratives as a rich source of data (Clayton et al., 1999; Malinski & Litwin, 2007; Robinson, 2001; Warms et al., 2005), an argument exists relating to the authenticity of authorship, especially those found on the Internet (O’Brien & Clark, 2011).

1.4.1. Types of Narratives. Within narrative research, Smythe & Murray, (2000) suggest that there are three types of narratives: personal, archetypal and typal. The authors explain that personal narratives are the most familiar and include biographies, autobiographies and fictional works that focus on a main character or person. The authors propose that the aim in a personal narrative is to unearth the lived experience of an individual.
Archetypal narratives on the other hand are what the authors believe to be a more antiquated type of narrative that typically focus on mythological and religious writings (Smythe & Murray, 2000). The authors describe the focus of archetypal narratives as ones that do not focus on human individuality but allow major human themes to arise that speak to the fundamental existence of humanity such as mortality.

On the other hand, the Smythe and Murray (2000) suggest that typal narratives are of particular interest to social scientists because they include elements of personal and archetypal narratives that convey both psychological and social themes such as how do cancer patients emotionally adjust to a cancer diagnosis? The writers further explain that typal narratives are a relatively new development within social science research because they incorporate the lived experiences of individuals into a broader types or categories that are theoretically important to social scientists. The aim of the typal narrative is not to capture the world of one individual or rely on archetypal human themes, but to tangibly link narratives to the “…theory-laden categories of contemporary social science” (Smythe & Murray, 2000, p. 327).

1.5 Disclosure of Illness

What remains clear is that when individuals are confronted with a cancer diagnosis they are faced with not only making decisions about treatment and recovery, but they are also faced with the task of deciding whether or not to make the difficult decision to disclose their illness to those individuals on whom they rely for social support.

Having social support provides individuals the opportunity to discuss his or her feelings with those individuals with whom they feel loved, appreciated and safe. Previous research has concluded that social support is important to cancer patients and is associated with lowered
distress, fewer psychological disturbances and heightened physical recovery (Bloom, 1982; Cohen, 1988; Roberts, Cox, Shannon, & Wells, 1994).

Unfortunately, not all social interactions support disclosing stressful or painful experiences. Furthermore, social environments do not always inspire helpful discussion or encouragement when patients disclose their thoughts and feelings. As a result, some individuals may experience social barriers (Manne, 1998; Manne, Alfieri, Taylor, & Dougherty, 1999) when support is needed the most (Northhouse, 1988). One study examined how social challenges to emotional disclosure in different social contexts affected one’s cognitive, emotional and physiological adjustment to an acute stressor (Lepore et al., 2004). Outcomes from that study indicate that the social context of disclosure has a significant impact on one’s adjustment to that stressor.

While the above studies focus on an individual’s social networks, Maguire, Faulkner, Booth, Elliot, & Hillier (1996) focused on how health professionals are better able to assist patients in disclosing their concerns. Results from that investigation revealed that leading questions that focused on clarifying illness resulted in advice giving and reassurance which thwarted patient disclosure while open directive questions that focused on psychological features and empathetic statements promoted significant patient disclosure. In sum, it appears that cancer patients experience the added burden of not only dealing with their disease, but must also contend with the diverse reactions of both personal and medical relationships, all of which have the propensity to affect how cancer patients are able to manage with his or her illness.

1.6 Rationale for the Study

Within health research, there has been an increased interest in using qualitative research methods (Moffatt, White, Mackintosh, & Howel, 2006). The authors argue interest in qualitative
methods has occurred due to the contributions that qualitative research lends to understanding health and illness, improved methodological rigour in qualitative procedures, and that using a mixed methods design of qualitative and quantitative methods yields greater insights to understanding health research than either method singularly.

Traditionally, health research has mainly utilized survey methods as a means of investigation, which is valued because of its inherent ability to garner vast amounts of information from large number of participants. While valued for efficiency and usefulness, quantitative surveys have innate limits. Clayton et al., (1999) contend that limits in survey questionnaires include closed-response formats that limit the amount of information participants can provide and that the questions within the surveys are created by the researchers thus minimizing the amount and vastness of information that participants are able to provide. In light of these limitations, the personal significance of participant’s lives and experiences are lost thus, thwarting the ability of investigator’s ability to truly understand the importance of personal perspectives (Clayton et al., 1999).

In a systematic review by O’Brien & Clark (2010), the authors examine the use of unsolicited narratives in illness/health research. In that review, the authors acknowledge the “explosion” (p. 1672) of published and unpublished illness narratives (Bingley et al., 2006 as cited in O’Brien & Clark, 2010), which other investigations maintain, is a legitimate source of data (Robinson, 2001).

In the original quantitative study, 86 out of 421 participants (20.4%) wrote unsolicited narratives in margins of the questionnaires as well as hand written notes and letters. Given the original study sought to understand how illness intrusiveness, anxiety, depression and social support impacted one’s ability to adapt to a cancer diagnosis, the research team felt it was
ethically and socially responsible to give these participants a platform in which their voices could be heard. For this reason, this study seeks to acknowledge the time and effort of these participants by better understand the individual experiences of 86 cancer patients who were compelled to act beyond what was asked of them.

1.7 Purpose of the Study

The purpose of this study seeks to better understand how the unsolicited narratives of 86 cancer patients can contribute to the broader context of the theory-laden categories of health research and its implications for clinical practice. Purposely, this research study will pursue two lines of investigation: 1) The ambiguity of test items and 2) How standardized measures do not fully capture personal experience. To address these lines of investigation, five research questions are posed: 1) What are the participant characteristics of those who provided unsolicited narratives?; 2) Which questionnaires/questions garnered the most responses and how did participant’s respond?; 3) What are the major themes that emerge from the data?; 4) Do sex differences exist within the major themes and how males and females respond?; and 5) Do the narratives provide evidence that participants were able to successfully adjust to his or her cancer diagnosis over the course of 12 months?

1.8 Study Limitations

There are several limitations to this research study. First, because this study is rooted in unsolicited written narratives of cancer patients, it is impractical if not impossible to check the meanings of the written narratives. This is in part due to the lapse in time from the original investigation, which may certainly cloud participant’s memories and perspectives over the two years since the original study was completed. Additionally, it is possible that some of the original study participants have died, either from cancer or other causes. Second, given this
study is based on unsolicited narratives; it was impossible to control who responded and what participants were responding to. For this reason, a longitudinal analysis of how each participant fared over the course of the study was not possible. Third, because most narratives were handwritten, it is possible that the research assistants that transcribed and entered the data had difficulty interpreting the handwriting, which may have lead to incorrect interpretations of what was written. Fourth, for narratives that were made without reference to a particular question, more inference was made based on which questionnaire they were responding to. Fifth, the qualitative software, Atlas.ti 7 was entirely self-taught. As such, there is a possibility that a ‘small’ margin of error exists in the results.
Chapter 2: Review of the Literature

The literature review for the current research study was conducted after the data had been coded and analyzed. This was done partly in response to pragmatic timing issues but more importantly tied to the phenomenological tone thus delayed to ensure coding was not influenced by preconceived notions and perceptions (Remshardt & Flowers, 2007). Given the social constructionist nature of the original study, it was important to have an understanding of the topic but not be influenced to the degree that reading the narratives and later coding would be affected.

This study used qualitative description (QD), which primarily relies on reporting and describing data versus interpretation (Sandelowski, 2000). QD differs from other qualitative approaches since it is “…founded in existing knowledge, thoughtful linkages to the work of others in the field and clinical experience of the research group” (Neergaard, Olesen, Andersen, & Sondergaard, 2009, para. 5). The following literature review is based on the major themes that were explored within the original study (illness intrusiveness, anxiety, depression, social support and RTW) which were reflected in how those themes translated as participant’s unsolicited narratives. I reviewed the literature on the above themes and how they relate to cancer using Google Scholar as well as PYSCHINFO, JUSTOR and ERIC databases for key words such as: “depression and cancer”, “anxiety and cancer”, social support and cancer”, “illness intrusiveness and cancer”, “narrative”, “unsolicited narratives”, “coping and cancer”, “RTW and cancer”, “sex differences and cancer”, “spirituality and cancer”, “qualitative research”, “Qualitative Description”, “sex differences and cancer”, “adjustment to cancer”, “marriage and cancer”, and “psychosocial and cancer”, “sarcasm and cancer”, “gender differences and coping”, “gender
differences and coping with cancer” “life events and cancer”. Lastly, I also consulted the references in the various peer-reviewed articles pertinent to this literature review.

2.1 Psychological Adjustment to Cancer

Being diagnosed with what is commonly referred to as the “C” word can have a profound impact on a cancer patient’s wellbeing. Researchers have been studying the impact of being diagnosed with cancer for the past three decades and according to Rodrigue, Behen, and Tumlin (1994), the study of how one adjusts to cancer has primarily focused on patient variables; including but not limited to emotions and characteristics of the patient, as well as age, gender and cancer type and severity (Linden, Vodermaier, MacKenzie, & Greig, 2012; Mosher & Danoff-Burg, 2005; Parker, Baile, De Moor, & Cohen, 2003). The vast array of negative psychological reactions to cancer are well documented and include but not limited to anger, guilt, anxiety, depression, helplessness and lowered self-esteem (Goldberg & Cullen, 1985) and in some cases, Posttraumatic Stress Disorder (PTSD) (Kangas, Henry, & Bryant, 2002).

Another area of study centers on how individuals cope and adjust to illness is based on the theoretical framework of illness intrusiveness. According to Devins (2010), illness intrusiveness is a common factor that impacts the quality of life of individuals affected by chronic disease such as cancer. Illness intrusiveness is caused by the effects of disease and treatment and results in disturbances in lifestyle, activity and hobbies. The central tenet of illness intrusiveness is that illness impacts one one’s psychological well being and levels of emotional distress via the effects of illness and related disruptions, which in turn have the ability to affect psychological outcomes (Devins, 1994; Devins, Bezjak, Mah, Loblaw, & Gotowiec, 2006; Devins, 2010). According to Devins (1994), psychological outcomes are affected when illness intrusiveness reduces positive outcomes by impeding one’s ability to engage in valued
activities and limits one’s personal control in his or her ability to successfully engage in valued outcomes or inability to avoid negative outcomes.

On the other hand, the literature also suggests that not all cancer patients experience maladaptive reactions to cancer and adjust well (Stanton et al., 2005) due to variables that potentially mediate the relationship between cancer and psychological adjustment (Rodrigue et al., 1994). One such line of investigation focuses on posttraumatic growth (PTG) (Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004), the positive growth as a result of a life crisis or traumatic event (Taylor, 1983). According to Tedeschi and Calhoun (1996), PTG occurs when individuals are able to recognize new possibilities, redefine priorities, develop new interests, experience positive changes in interpersonal relationships, recognize and appreciate one’s internal strengths, experience a change in spiritual beliefs and develop of a greater appreciation for life. Research on PTG has also revealed that PTG is not necessarily a linear and accumulative process (Lechner & Antoni, 2004) and thus is subject to individual differences in how an individual changes over time (Frazier, Conlon, & Glaser, 2001). These investigations support the idea that PTG is both a process and an outcome (Tedeschi & Calhoun, 2004). Research on PTG has also revealed that those who engage in PTG are more inclined to self-disclose, which in turn influences how individuals think about and narrate his or her life story (Tedeschi & Calhoun, 2004). Furthermore, research on PTG has revealed that females experience more PTG than males (Tedeschi & Calhoun, 1996).

2.1.1. Cancer, Depression & Anxiety. The study of cancer patients has revealed that there is a wide array of reactions to cancer. Psychological adjustment has been defined by Helgeson and Cohen (1996) as the “…adaptation to disease without continued elevations of psychological distress (e.g., anxiety, depression) and loss of role function (e.g., social, sexual,
Assessing psychiatric syndromes in individuals with cancer is often difficult given the continuum on which symptoms lie. Furthermore, a cancer patient’s mood is often fluid when faced with a life threatening illness, invasive and scary treatment regimes, fatigue and pain as well as comorbidity with other syndromes such as anxiety disorders or posttraumatic stress (Massie, 2004).

Depression has long been of interest in those studying the psychological effects of cancer, however a review by Massie (2004) suggests that a major limitation of many studies rests on those variables such as the effect of cancer treatment and non-cancer-related variables that affect mood but are frequently not considered. Moreover, writes Massie, notwithstanding cancer site, depression is higher among cancer patients that the general population.

Massie (2004) also concludes that certain cancer types are decidedly associated with high rates of depression and include pancreatic (33%-50%), breast (1.5-46%), lung (11%-44%) and pharyngeal (22%-57%) whilst studies of other cancer types such as colon (13%-35%), gynecological (12%-23%) and lymphoma (8%-19%) reveal lower rates of depression. In the same meta-analysis, Massie (2004) writes that gender differences and depression in cancer patients have also been examined but have yielded mixed results depending on the subset of patients, diagnostic criteria, type of cancer and specific methodologies and cancer severity. Another study by Linden, Vodermaier, MacKenzie, and Greig (2012), examined anxiety and depression in over 10,000 cancer patients after diagnosis. Results from that study revealed that across cancer types, 19% of patients presented with clinical levels of anxiety and over 22% presented with subclinical symptoms. In addition, 12.9% of patients reported clinical symptoms of depression with subclinical levels found in 16.5% of patients. Furthermore, examination of cancer type and time of diagnosis revealed that patients with lung, gynecological and
hematological cancer reported the greatest amount of distress at diagnosis. Gender differences revealed that women demonstrated the highest rates of anxiety and depression and that in some cancer types, was two to three times higher than their male counterparts. The authors also discovered that age and emotional distress was inversely related with younger adults having much higher rates of anxiety and depression than older adults. Additionally, for some types of cancer such as lung, gynecological or hematological, there was no effect for age, which implies that, all age groups are affected equally in cancers with a poor prognosis. What remains striking according to the authors is that despite cancer site and stage of illness, examination of more than 100 studies of cancer patients reveals that cancer is highly correlated with depression (Linden et al., 2012).

Reviewing the literature on the correlation between cancer, depression and anxiety is paramount to this study because of the prevalence of clinical levels found in cancer patients. This is especially important information for those medical and mental health professionals that specialize in assisting cancer patients cope with the vast array of emotional and psychological reactions to one’s disease. Moreover, not all cancer patients may display clinical levels of depression and anxiety, however their emotional and psychological wellbeing is just as important given how the body responds to stress. For these reasons, understanding the literature will help inform how the data may contribute to development and assessment of interventions given the considerable variability that exists between cancer and psychological adjustment.

2.1.2. **Cancer & Age.** Research has shown that age is one the factors associated with how cancer patients adapt to a cancer diagnosis. While it is recognized that a cancer diagnosis is a stressful life event at any age, inquiry has revealed that the age of diagnosis is an important consideration in a patient’s ability to cope with the disease and subsequent treatment. In one
study that examined the role of age in a cancer survivor’s long-term adjustment to cancer, the authors report that patients younger than 65 years reported more depressive symptoms three months after diagnosis than similarly matched controls however; the same group did not report more depressive symptoms compared to matched controls long-term (Schroevers, Ranchor, & Sanderman, 2004). For all age groups, the authors observe that the long-term reports of depressive symptoms were comparable to similarly age matched controls. The study also reported that after 3 months of being diagnosed, all age groups reported increases in functional limitations and physical symptoms compared to age matched controls. In terms of physical symptoms and functional limitations, all age groups reported more distress than their counterparts and those survivors between the ages of 45 and 65 years continued to report elevated levels of functional difficulties 15 months post diagnosis. Interestingly, at 8 years after diagnosis, all age groups reported functional limitations similar to their age matched controls except for the 45-65 year-olds. The authors postulate that this finding supports the idea that having cancer as an older adult may hasten the normal aging process and highlight the changes in physical prowess experienced with normal aging (Schroevers, Ranchor, & Sanderman, 2004).

In another study, Harrison and Maguire (1995) investigated the role that age plays in a cancer patient’s psychological adjustment within a few weeks of their cancer diagnosis. The results from that study revealed that younger patients compared to older patients had more difficulty adjusting to their diagnosis and were more apt to report concerns relating to the cancer itself, treatment, feeling different and upset as well as concerns about the future, finances, physical symptoms, difficulty with activities and work and the amount of received social support. The authors also noted that despite older patients having less concerns than their
younger counterparts, older patients were just as likely to report difficulties with physical symptoms and the practical matters of everyday living and work (Harrison & Maguire, 1995).

As suggested by the literature, one’s age can influence how one adapts emotionally and psychologically to a cancer diagnosis. This review is important to this investigation given the data for the current study was generated from individuals aged 25 to 96. For this reason, it is key that medical and counselling professionals understand the specific types of challenges faced by cancer patients of all ages. Without this knowledge, suggesting one type of intervention that is clearly not age-appropriate may be akin to fitting a square peg into a round hole given the fluidity of developmental life-span stages.

2.1.3. Sex Differences. Within pop culture exists the notion that men are from Mars and women are from Venus. Whether or not this is true, remains a topic of debate given the Gender Similarities Hypothesis, which states that males and females are alike for the most part, on all psychological variables (Hyde, 2005). More simply stated, states the author, males and females are more similar than different. Conversely, Kiss and Meryn, (2001) believe that being male or female has important implications for health and illness since males and females differ biologically but also in how they “…think, feel, and behave.” (p. 1055). The authors further explain and argue that:

The physical difference is called sex, influenced by genes and biology; the psychological difference is called gender, in which environmental, cultural, and psychosocial factors also have a prominent role.

2.1.3.1. Coping Styles. If males and females are for the most part similar with respect to psychological variables, do males and females differ in terms of stress and coping styles? To answer this question, Matud (2004) examined gender differences in stress and coping style in
2816 individuals (1250 males, 1566 females). Results from that study reveal that gender differences exist and are consistent with the socialization hypothesis which proposes that society socializes males to use active and instrumental coping behaviours whereas females are socialized to be more passive and use emotion-focused coping behaviours (Matud, 2004). Furthermore, the author argues, females report both more daily stressors and more chronic stress than males and females are more prone to emotion focused coping versus problem focused coping seen in males.

2.1.3.2. **Coping & Adjustment.** In a review paper on the gender differences on psychosocial aspects of prostate and breast cancer, the authors point to the paucity of research on how males and females cope with cancer (Kiss & Meryn, 2001). The authors also state that females with breast cancer were more prone to talking about their illness and emotions whereas males with prostate cancer were more inclined not to talk about their disease. Moreover, the authors reveal, when males and females access support groups for prostate and breast cancer, “Men in support groups prefer to share information whereas women prefer to share emotion.” (Kiss & Meryn, 2001, p. 1056).

Anecdotal evidence by clinicians who investigate psychosocial variables associated with cancer believes that indeed, males and females differ in how they cope with a cancer diagnosis (Volkers, 1999). Specifically, Matthew Loscalzo, director of patient and family services and co-director of the Center for Cancer Pain Research at the Johns Hopkins Oncology Center in Baltimore concludes that the genders differ in how males and females cope which have, “…profound differences with important implications in how you engage women and men in the disease process.” and that “Women generally cope better than men…” (Volkers, 1999, p. 1712).

In an investigation on gender differences in outcomes among cancer patients referred to home care, Greimel, Padeilla and Grant (1998) claim that males recounted more cancer-related
impairments and more limitations in activity levels than their female counterparts. Furthermore, the authors also reveal that females report better outcomes than males (Greimel et al., 1998). These findings are similar to those reported by Rodrigue and Park (1996) who observed that males may be more prone to develop “…general and illness-specific psychosocial adjustment difficulties.” compared to females (p. 34).

2.1.3.3. Social Support. Social support has been cited as being positively associated with emotional and psychological adjustment to cancer (Goldberg & Cullen, 1985), do males and females differ in terms of need, availability and utilization? A study on the influence of social support on depressive symptoms in male and female cancer patients revealed that larger support systems were linked to less depression in females and younger individuals however, this was not the case for males and older individuals (Hann et al., 2002). Moreover, the authors postulate that females are more prone to utilize several support sources thus positively impacting their emotional wellbeing whereas the type of support versus the size of support system may be more important to males. Investigation on the patterns of how male and female cancer patients confide in a crisis, Hann et al. (2002) insists that males generally confided in one confidant whereas females were more likely to utilize a larger support system and have a greater amount of confidences overall. Relatedly, findings from a study that examined gender differences in outcomes among cancer patients referred to homecare, the authors demonstrate that males have inferior social support systems than females (Greimel, Padilla, & Grant, 1998).

2.2 Psychosocial Variables & Cancer

Whilst being diagnosed with cancer is a life changing experience for most, understanding the totality of a cancer patient’s experience entails examination into the psychosocial determinants as well. This is particularly important considering that “…50% of the emotional
distress of cancer patients can be accounted for my nonmedical issues” (Weisman & Warden, 1972-1976 as cited in Goldberg & Cullen, 1985, p. 805).

In a study by Ness et al., (2013) the authors examined the concerns of 337 cancer survivors (female, 251; male, 86) across a broad spectrum of the survivorship trajectory since the time of diagnosis and reported thirteen extreme concerns (rated 4-5 on a 5 point scale) of cancer survivors. Table 1 provides a breakdown (in descending order) of what concerns cancer patients the most.

What remains clear from the above study is that cancer survivors have more to contend with than just their cancer, much of which extends well into 20-year cancer survivorship (Ness et al., 2013). According to Salovey, Rothman, Detweilder, & Steward (2000), additional life stressors may pose additional problems for those individuals who struggle with pinpointing the source of their physical discomfort. The authors maintain that negative emotional states can shift one’s attention to themselves and away from the more poignant stressors in their lives thereby exacerbating their physical distress.

The literature review of the psychosocial variables that impact a cancer patient’s ability to cope with their disease is critical to this investigation as it helps us understand that cancer patients have multifaceted lives. Moreover, if we as medical and mental health professionals recognize the types of psychosocial challenges cancer patients face, clinical teams can work together towards recognizing which patients need the support with overcoming the various types of barriers that may impede their ability to emotionally and psychologically adjust to his or her disease and inform the practice of person specific interventions.

2.2.1. Cancer & Social Support. One of the most consistent findings across the literature of cancer survivorship is the effect of positive social support on emotional and
psychological adjustment to cancer (Goldberg & Cullen, 1985; Meyerowitz, Kurita, & D’Orazio, 2008; Rodrigue & Park, 1996). Within the literature, social support has been defined as the interpersonal relationships that safeguard individuals from the detrimental effects of stress (Wortman, 1984) thereby buttressing an individual’s ability to cope with illnesses such as cancer (Cohen, 1988). It is well documented that having a life partner is consistent with better emotional outcomes than those without a life partner and that having a perceived strong social support network or intimate confident is an important predictor of positive emotional adjustment (Meyerowitz, Kurita, & D’Orazio, 2008).

In one study that examined the predictors of Japanese cancer patients’ mental adjustment to cancer, Akechi, et al. (1998) specifically looked at patient characteristics and social support factors as predictors of the patient’s response to his or her disease. In that study the authors looked at two types of mental adjustment: fighting spirit and helplessness/hopelessness. Results from that investigation indicate that physicians were the only sources of social support that were significantly related to having a fighting spirit. This finding supports a similar finding by Slevin et al., (1996) and others (Slevin et al., 1996) in which the authors report that cancer patients rated emotional support from their senior doctors as highly as their families and more significant than any other source. Furthermore, the authors also note that a patient’s perception of social support is related to their ability to deal with their disease (Akechi et al., 1998).

In a review article of descriptive, correlational and intervention research, Helgeson and Cohen (1996), examined how social support interacts with one’s adjustment to cancer. In that review, the authors cited three main types of supportive social interaction: emotional, informational and instrumental. Emotional support comprises verbal and nonverbal communiqué of caring and concern that can facilitate feeling loved and valued. It can also lead
to superior interpersonal relationships based on increased attention thereby improving one’s ability to make meaning out of one’s illness experience. Informational support on the other hand involves the delivery of information that can lead patients to greater perceptions of control as they learn to manage their illness and learn to cope with their symptoms. Furthermore, informational support allows patients to better grasp the cause of their illness, the possible course their illness may take and various treatment options. Lastly, instrumental support entails the provision of material goods and practical assistance. The authors argue that this type of support has the propensity to counterbalance the feelings of loss of control that patients may feel during cancer treatment by providing concrete resources they can utilize in to gain some semblance of control over their illness. Major findings from this review reveal that cancer patients identify emotional support as the most helpful (irrespective of source) however it is most harmful if absent from an intimate partner, family or friend. Alternatively, informational support was only helpful when delivered by health care professionals and was most helpful for those patients with a poor prognosis.

The study of the importance of social support and cancer has also focused on specific types of relationships (e.g., marital status, quality and family relationships) as predictors of how one emotionally adapts to cancer. Study of marital satisfaction reveals that a positive relationship exists between spousal support and marital satisfaction in both healthy couples (Brunstein, Dangelmayer, & Schultheiss, 1996) and couples experiencing hardship (Vinokur, Price, & Caplan, 1996) as well as couples dealing with cancer (Manne, 1998). In the Manne (1998) review paper, the author examined the effect of cancer in the marital context and reports that cancer patients frequently rely on their intimate partners for social support, which plays a major role in their ability to adapt to cancer. Furthermore, the author contends that only a small
percentage of marriages struggle adjusting to the stress of a cancer diagnosis thus cancer does not appear to be correlated with deterioration in the quality of the marital relationship (Manne, 1998).

In addition to the stress experienced by the cancer patient, there are some reports that reveal that their intimate partners may suffer greater emotional and psychological distress than the patient (Carlson et al., 2000; Gotay, 1984; Lichtman, 1986 as cited in Ell et al., 1988). Moreover, in the Carlson et al., (2000) review, the authors conclude “…that the partners of cancer patients experience significant amounts of distress at different phases of the illness trajectory” (p. 57). There have also been, albeit less, interest on how a cancer diagnosis affects a cancer patient’s family (Carlson, Bultz, Speca, & St. Pierre, 2000; Ell, Nishimoto, Mantell, & Hamovitch, 1988; Gotcher, 1993) and marital status and quality (Hagedoorn et al., 2000; Rodrigue et al., 1994). For the cancer patient, knowing that their partners and families are distressed may compound their own illness related stress.

Another area of interest is the impact of interpersonal communication on the psychosocial adjustment of cancer patients. One particular study by Gotcher (1993) investigated the effects of family communication on psychosocial adjustment of cancer patients. In that study, findings indicate that patients who reportedly adjusted well to the cancer experience also had the highest quality of family communication thus mitigating many cancer related stressors. The authors observe that emotionally supportive family communication seems to be a vehicle by which psychological distress is reduced. Intrinsically this makes sense since “…adjustment to illness takes place in the home environment” (Gotcher, 1993, p. 185) where cancer patients are free to be themselves and express their anxiety and fear and the uncertainty that a cancer diagnosis often conjures for those afflicted with the disease.
Another important factor to consider when thinking about social support is the types of support and subsequent timing. Jacobson (1986) proposes that a stressor (such as cancer) has three distinct phases: 1) a crisis phase; 2) a transition phase; and 3) a deficit phase. Furthermore, the author argues that the timing and type of support is important. For example, the author concludes that emotional support may be most important during the crisis phase (e.g., dealing with a new cancer diagnosis) whereas information is most needed during the transition phase when individuals begin to cope and instrumental support may be most helpful during the deficit phase when one’s resources cannot meet the demands of the stressor.

As the literature suggests, social support plays a vital role in how cancer patients cope with their disease. As such, the review of the social support literature is salient to this study given it helps explain how social support can help or hinder how one emotionally and psychologically adapts to his or her disease.

2.2.2. Cancer & Spirituality. According to Schnoll, Harlow and Brower (2000) research on spirituality and disease is limited and has been plagued with several limitations including: 1) a limited number of empirical studies which examine the relationship between psychosocial adjustment to cancer and spirituality, 2) narrow definitions of spirituality and 3) how religious/spiritual beliefs correlate with both disease and demographic variables that have been thought to effect how one’s ability to adjust to a cancer diagnosis. The authors contend that the available literature suggests that a straight line does not exist between these variables and psychosocial adjustment to cancer but may be influenced by patient variables such as coping style (Staton & Snider, 1993 as cited in Schnoll et al., 2000). Some research suggests that religious coping may be distinct from traditional emotion or problem focused coping (Laubmeier, Zakowski, & Bair, 2004) and may require specific measures that address the
possibility that religious/spiritual coping may have emotional, cognitive and behavioural components (Thune-Boyle, Stygall, Keshtgar, & Newman, 2006).

According to Statistics Canada’s 2001 census (Statistics Canada, 2001), over 29 million Canadians report some kind of religious affiliation with over 19 million of them over the age of 25. Given that psychosocial variables may mediate how cancer patients deal with the psychological and social impact of a cancer diagnosis, Folkman, (1997) writes that many cancer patients use religion and/or faith as a coping mechanism.

Several studies have revealed that religion and spirituality are commonly relied upon as a coping strategy (Koenig et al., 1995; Koenig et al., 1992) and assist in improving one’s emotional status thus allowing patients to positively cope with the stress that illness often manifests (Easton & Andrews, 2000). In another study that examined the psychosocial needs in cancer patients, McIllmurray et al., (2003) report that those patients who claimed to have religious faith had less need for information, were less concerned about maintaining independence and needed less assistance dealing with feelings of guilt, sexuality or everyday matters. In a similar vein, a study examining spirituality, demographic, disease factors and patient’s adjustment to cancer found that greater levels of spirituality were associated with higher levels of psychosocial adjustment (Schnoll, Harlow, & Brower, 2000). Moreover, the authors also report that having a lower disease stage, a longer illness duration and being a woman was associated with greater life purpose and religious and spiritual beliefs, which was correlated with greater levels of family and social adjustment and better psychological health. Whilst these studies are encouraging in our attempt to understand the role spirituality and religion plays in the life of cancer patients, a systematic review by Thune-Boyle, Stygall, Keshtgar and Newman (2006) suggest that due to methodological problems and failure to control for stage of illness and
perceived social support, firm conclusions on the positive and negative effects of religious coping with cancer patients could not be made.

A systematic review by Thune-Boyle, Stygall, Keshtgar, and Newman (2006) examined 17 studies on whether religious/spiritual coping affects one’s adjustment to cancer. In that review, the authors also contend that research related to the role of religion and spirituality in coping with illness is still in its infancy. General findings of that review state that religious coping was helpful in reducing stress or improving one’s ability to adjust to illness. On the other hand, the authors also revealed that four of the studies included in their review found religious coping had negative effects. Specifically, the authors noted that religious coping may vary as a function of cancer type and increases distress in Catholics and increases anxiety in breast cancer patients. They also found that negative religious coping (e.g., distancing oneself from their faith, questioning) was correlated with increased levels of distress and cancer-related stress and lowered levels of emotional wellbeing and wellbeing related to interpersonal relationships (Thune-Boyle et al., 2006). Lastly, similar to comments made by Schnoll et al., (2000), Thune-Boyle et al., (2006) claim that methodological issues plague much of the research because of how religious coping was conceptualized and measured as well as inconsistencies within research design.

The literature review of the role of spirituality/religion and cancer is important to this study because it highlights one of the many ways in which cancer patients may use spirituality and religion as a coping mechanism or as a way to make sense with his or her cancer experience.

2.2.3. Cancer & Employment. Advances in early detection and treatment of cancer have resulted in a rising number of cancer survivors (Coebergh & van der Heijden, 1991 as cited in Spelten, Sprangers, & Verbeek, 2002). According to the BCCA website ("British Columbia
Cancer Agency," 2013), there are almost 200,000 British Columbia residents with a cancer diagnosis, 65% of those are adults. Moreover, the same website asserts that cancer survivorship is on the rise and therefore, it can be expected that a considerable percentage of both younger and middle age adults will be actively employed at the time of diagnosis. For this reason, returning to work (RTW) is a critical aspect of this group’s ability to reintegrate back into the workforce after cancer.

In a literature review examining the factors affecting the ability of cancer survivor’s ability to RTW, Spelten et al. (2002) summarizes the importance of returning to work and states that being able to RTW and stay at work is economically beneficial for society and the individual by alleviating financial loss, social isolation and reduced self-esteem. Moreover the authors also indicate that RTW also allows cancer patients to re-claim their lives before cancer thus improving the quality of life. Findings from this literature review suggest three main themes that affect one’s ability to RTW after cancer: 1) work related factors; 2) disease and treatment related factors; and 3) person-related factors.

According to the authors, the factors positively associated with RTW included workload, control of hours worked and encouraging co-workers (Spelten et al., 2002). In terms of work specific factors, the authors noted that manual labour and physical demands were negatively associated with RTW. The review of disease and treatment related factors showed that the only positive association found was the number of months since the end of treatment citing a successful RTW was more probable when a more time had elapsed after completing treatment. Moreover, examination of person-related factors and RTW revealed that marshaling social support was positively correlated with RTW whereas the majority of person-related factors such as a change in attitude towards work were negatively correlated with returning to work. The
only other major sociodemographic variable that was statistically significant was age, however results were mixed which is interesting since increasing age is thought to impede successful RTW (Spelten et al., 2002).

In a qualitative study that examined 28 cancer survivors and RTW, Main, Nowels, Cavender, Etschmaier, and Steiner (2005) write that their study participants reported varied and multifaceted patterns of RTW and faced a sundry of issues that influenced their post-treatment decisions. Results indicate that most participants made some kind of change in their work life with over half reporting changes in work responsibilities or reduction in hours worked. Participants in that study also explained a myriad of factors that influenced their RTW decisions. Many participants indicated that their RTW decisions were rooted in financial concerns and although almost all reported that financial considerations influenced their decision to RTW despite diverse socioeconomic circumstances. In addition to financial concerns, many participants revealed that their RTW decisions were influenced by changes in how they were able to respond to the physical and psychological challenges of cancer and its treatment. Some participants shared that the impact of fatigue, nausea and continued pain influenced their decisions whilst others described changes in memory, all of which can influence RTW and one’s ability to work efficiently (Main et al., 2005).

Another theme that arose in RTW Main et al., (2005) was the lack of advice and support participants received from their doctors. Luckily, the participant’s employers did not mirror this lack of direction and concern and most reported significant support by both employers and colleagues, which positively affected their ability to RTW or continue working. In addition, the authors reveal that participants also shared that their work life added meaning in their lives and played a significant role in their ability to refocus their attention (Main et al., 2005).
In a narrative study that examined factors that influenced breast cancer survivors RTW (Johnsson, Fornander, Rutqvist, & Olson, 2010), the women who were on medical leave as a result of their cancer care and treatment experienced resistance from their employers when they tried to RTW. Furthermore, this group also received less social support from colleagues who also discounted the participant’s desire to remain in the workforce. As the authors note, the latter may have been a particularly hard blow to the psyche of these women given RTW acted as a signal that they had conquered their disease and were able to reclaim their pre-cancer life. This conclusion is further supported by Spelten et al. (2002) who insists that RTW is an indicator that individuals are reclaiming his or her pre-cancer lives.

Although some cancer patients take full medical leave during treatment, some cancer patients do not. A study conducted in the United Kingdom by Pryce, Munir, and Haslam (2007), the authors investigated RTW concerns of 328 cancer survivors. Findings from that study reveal that working during treatment and RTW is not always associated with cancer type or treatment. For those participants who decided to continue working during treatment, the authors report that his or her level of fatigue is greater than those who do not work during treatment. The authors also suggest that those participants who continue to work through treatment received more work-related accommodations than those who did not continue to work through treatment. In terms of managing physical changes due to cancer and treatment, participants who reported more physical limitations were less likely to RTW than those who did not report physical changes (Pryce et al., 2007).

The review of RTW for cancer survivors is of particular interest to this study given the lack of empirical investigation on the challenges and factors that influence how cancer survivors
weigh the pros and cons in their decision to continue to work through cancer treatment or those that RTW following cancer.

In sum, there are a multitude of factors that influence cancer patient’s ability to cope and adjust to his or her cancer diagnosis. Research has revealed that coping and adjustment is highly variable from one person to another and can be influenced personal characteristics such as sex and age. Furthermore, successful coping and adjusting is associated with one’s coping style and positive social support from a variety of sources. The literature also suggests that cancer patients have often have to make difficult decisions with respect to taking time off work or deciding to continue working during active treatment. Investigations on cancer and returning to work indicate there are 1) multiple factors which influence one’s decision to return to work; and a 2) variety of factors that determine whether someone successfully or unsuccessfully returns to work after cancer treatment.
Chapter 3: Methodology

In this study, patients were recruited via a close working relationship with the Patient and Family Counselling Service at the British Columbia Cancer Agency. Participants were recruited via an information and consent to contact sheet about our study during their first visit to the British Columbia Cancer Agency (BCCA) (Appendix A). If patients were interested in participating in our study, they signed the consent to contact form, which were collected by BCCA staff and then were picked up by myself twice per week during the recruitment phase. Based on the consent to contact sheets that were collected, patients were contacted via a telephone call within a few days, and verbally informed about the study and asked whether they were interested in participating (Appendix B). If patients agreed to participate, the first of three questionnaire packages were mailed to them along with a consent to participate form (Appendix C) and returned within one month for a Baseline reading and was repeated at the 6-month and 12-month follow-ups. To measure how these cancer patients were adjusting to their cancer diagnosis, our questionnaire package included a introductory letters for each time point (Appendix D, E and F) along with an evolving Demographic form for Baseline and the 6-month and 12-month follow-ups (Appendix G, H, and I). In addition, several quantitative measures were used including the Psychosocial Screening Tool for Cancer (PSSCAN; baseline collected as a psychoscreening tool at BCCA [used since July 1, 2004] and then included in the 6-month and 12-month follow-up questionnaire packages) (Appendix J), the Illness Intrusiveness Scale (IIRS; Appendix K), the Post Traumatic Growth Inventory (PTGI; Appendix L). Furthermore, additional measures were added at the 12-month follow-up and included the RTW (RTW; Appendix M) and the Assessment of Survivor Concerns (hereafter referred to as ‘Worries’; Appendix N).
The primary outcome variable, psychological distress was measured with the PSSSCAN, which is a 21-item PSSCAN assesses anxiety and depression, perceived social support, desired social support, and health-related quality-of-life in cancer patients (Linden, Yi, Barroetavena, MacKenzie & Doll 2005). The format of the PSSCAN is diverse and asks participants to respond to dichotomously (e.g., yes or no), fill in the blank, and two types of Likert scales; one of which requires the participant to circle a specific number (e.g., 0 = No, not at all to 10 = very much) and another that requires the participant to check a box that best describes their situation (e.g., not at all, a little bit, moderately so, quite a bit, very much so).

The PSSCAN has sound psychometrics including high internal consistency (alpha averaging .83, and acceptable test-retest stability over 2 months (averaging r=. 64). Moreover, the PSSCAN subscales intercorrelate moderate to high with similar instruments that measure the same or similar constructs. Clinical validity of the PSCCAN was established via computation of receiver-operating characteristics comparing the PSSCAN anxiety and depression subscales with the Hospital Anxiety and Depression Scale (HADS), an extensively validated measure commonly used in health research (Bjelland, Dahl, Haug, & Neckelmann, 2002; Linden et al., 2009).

Secondary outcome variables were assessed with the Illness Intrusiveness Rating Scale (IIRS) and the Posttraumatic Growth Inventory. The IIRS is an assessment tool designed to measure the impact of chronic illness on numerous areas of functioning (Devins, 1994). The IIRS taps into disturbances in 13 discrete life domains that are individually measured (e.g., How much does your illness and/or your treatment interfere with your health?). Devins (2010) reports that the IIRS has high internal consistency (Cronbach’s alpha) of the IIRS ranges from the .80s to .90s (aside from prostrate cancer .78) and test-retest-reliability ranges from .79 to .85.
The IIRS also has an established stable factor structure in both psychiatric and medical populations (Bieling, Rowa, Antony, Summerfeldt, & Swinson, 2001) and with individuals with various types of cancer (Devins, 2010). The IIRS questionnaire seeks to ask how much the participant’s illness affects various aspects of life. The IIRS has 13 questions and offers a Likert response format ranging from 1 = *Not Very Much* to 7 = *Very Much*.

As previously stated, the PTGI (Tedeschi & Calhoun, 1996) assesses PTG, the positive growth as a result of a life crisis to traumatic event (Taylor, 1983). The PTGI consists of 21 items and five factors and includes: new possibilities, relating to others, personal strength, spiritual change, and appreciation of life. Internal consistency of the total scale is $\alpha=.90$. Subscale reliabilities for the PTGI range from $\alpha=.67$ to $\alpha=.85$ and test-retest-reliability is $r=.71$. Furthermore, the PTGI’s ability to measure PTG has been extensively studied and has been found to be a reliable and valid measure extensively with specific types of populations, including individuals with cancer (Tedeschi & Calhoun, 2004). The PTGI consists of 21 items and five factors and includes: new possibilities, relating to others, personal strength, spiritual change, and appreciation of life. The questionnaire asks participants to reflect on perceived personal change and offers an explanatory scale (e.g., 1 = *very small*; 2 = *small*; 3 = *moderate*; 4 = *great*; 5 = *very great*) for which participants are asked to rate each of the 21 items.

At the twelve-month follow-up, our team also was interested in how our participants viewed fear of recurrence as well as the challenges of returning to work. To examine these phenomena, two additional measures were added: the Assessment of Survivor Concerns (Worries) and Return to Work (RTW).

The RTW questionnaire was broken into 3 parts: 1) RTW; general questions regarding work life; 2) RTW A; for those participants who continued to work during cancer treatment or
had returned to work; and 3) RTW B; for those participants who had not returned to work or were considering never returning to work. There were no narratives written in the RTW B questionnaire and therefore will not be included in the analysis.

The Worries questionnaire is a brief questionnaire and was developed to measure fears about recurrence and health in cancer survivors (Gotay & Pagano, 2007). The authors report that the revised five-item Worries questionnaire is reported to have excellent internal consistency (0.93) and validity (discriminant, convergent) in both short-term and long-term cancer survivors. The response format of the Worries questionnaire requires only a check in the appropriate box.

The RTW questionnaire has recently been developed by Dr. Andrea Vodermaier and colleagues to assess RTW concerns for cancer survivors and is currently undergoing reliability and validity testing.

Lastly, parts of the Demographic questionnaires were used. The purpose of presenting these data is twofold; first, it enables the reader to gain a multidimensional understanding of who the participants are, and second, it provides context to the participant’s narratives.

In sum, the current study poses five research questions: 1) What are the participant characteristics of those who provided unsolicited narratives?; 2) Which questionnaires/questions garnered the most responses and how did participant’s respond?; 3) What are the major themes that emerge from the data?; 4) Do sex differences exist within the major themes and how males and females respond?; and 5) Do the narratives provide evidence that participants were able to successfully adjust to his or her cancer diagnosis over the course of 12 months?

3.1 Research Design

The current qualitative study explored the unsolicited narratives of cancer patients written in the margins of a previously conducted quantitative study (thus making them archival in
nature). Due to the uniqueness in how the data was collected (unsolicited narratives) this research study did not seek to fit a square peg into a round hole in terms of theoretical underpinnings. Instead, this study drew upon several philosophical concepts to explain how the narratives were read and interpreted. By doing so, it is this author’s hope that analysis of the unsolicited narratives will be understood and described in terms of how the author(s) intended.

To begin, this study is postmodern in nature if understood in terms of what Burr (1995) suggests: there is no ultimate truth and one’s reality is situation-dependent and cannot be understood as an over-reaching system of knowledge. The ontological perspective is that of a relativist perspective: that one’s story is only real to them in a given context. Case in point, this study sought to understand the salience of unsolicited narratives of cancer patients and what they can tell us about how they psychologically adapt to a cancer diagnosis over a twelve-month period. The epistemology for this study has ‘elements’ of social constructionism because it emphasizes how our culture shapes the way in which we see and feel things (Crotty, 1998, p. 58). Expressly, the original quantitative study from which the data for this study was generated was rooted in a positivist philosophy and therefore within a specific culture, namely, the empirical study of cancer. For this reason, the original study, methodology and questionnaires certainly influenced and guided how participants thought about their cancer experience. Combined, it is facile to extrapolate how the combination of the experience of being diagnosed with cancer and how the ‘culture’ of cancer care and treatment and study of cancer interact with one another as participants answered the questionnaires and both directed and influenced how cancer patients chose to think about their experience and their decision to add the additional unsolicited narratives.
3.1.1. Qualitative Description. The current research study used qualitative description (QD) and thus lacks and ‘official’ theoretical perspective (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000. QD has been described as “less sexy” (Sandelowski, 2000, p. 334), “…the crudest form of inquiry” (Thorne, Kirkham & MacDonald-Emes as cited in Sandelowski, 2000, p. 334) and the “…least theoretical of the qualitative approaches.” (Neergaard et al., 2009, para. 12; (Sandelowski, 2000). As such, one might ask, why use QD?

To understand why QD is considered the most useful method for this study, one must understand what is QD? QD has been described as having adhering to the general tenets of naturalistic inquiry with low inferences and presenting the facts in everyday language (Neergaard et al., 2009; Sandelowski, 2000; Sullivan-Bolyai, Bova, and Harper, 2005). Whilst QD can be understood as ‘atheoretical’, that is not to say that a study using QD cannot have “…hues, tones and textures” found in other qualitative approaches (Sandelowski, 2000, p. 337). Specifically, Sandelowski (2000) suggests that studies that use QD may indeed attend to particular words; phrases and experiences yet not produce a product that is explicitly tied to other qualitative approaches that are explicitly linked to an a priori theoretical view of the phenomenon under study.

The decision to use QD as a qualitative method for this study is based on many factors. As Sandelowski (2000) clearly writes, no qualitative method is necessarily good or bad but rather more or less appropriate depending on its purpose. First, given that the data for this study came in the form of unsolicited narratives written in the margins of a quantitative questionnaire package, which makes it archival data which according to Sandelowski (2000), it is a good fit for QD. Furthermore, because the data are archival, it is impossible to ask the participants for clarification or further description about their written narratives. For this reason, it became clear
that keeping as close to the data was paramount thereby avoiding incorrect inferences that might result if using a pure phenomenological, narrative, ethnographic or grounded theory paradigm (Neergaard et al., 2009; Sandelowski, 2000).

Second, the original study used a purposeful sampling technique (selecting newly diagnosed cancer patients to longitudinally follow their emotional adjustment to cancer), which allows, “…selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research…” (Patton 1990, p. 169 as cited in Coyne, 1997, p. 624).

Third, because participants were responding to pre-selected questions within the questionnaires, it only seemed natural to offer a comprehensive summary of the major themes found within the data and link the data to what is already known within the field of cancer research which has been cited as a strength of QD by Neergaard et al., (2009) and how patients adapt to a cancer diagnosis. For these reasons, it is this researcher’s opinion that QD is the most useful method to explore these unsolicited narratives because it will focus on the experiences of cancer patients and offer a firsthand perspective of their views and experiences. This is of utmost importance given oncologists are notoriously lacking in their ability to identify patients who are in distress, perceived social support and in need of psychosocial counselling (Sollner et al., 2001).

3.1.2. Overtones of Phenomenological & Narrative Research. In light of arguments previously presented for the use of QD (Neergaard et al., 2009; Sandelowski, 2000), this research study will undoubtedly attend to the data in ways that tap into overtones found in phenomenological and narrative research.
To understand this study’s phenomenological overtones, it is helpful to review how phenomenology relates to the current study. As Crotty (1998, p. 79) suggests, phenomenology demands that we engage with phenomena (e.g., diagnosis of cancer) and make sense of it (e.g., how do cancer patients emotionally adapt to having cancer). As such, phonological research requires the researcher to set aside preconceived notions or understandings and ‘bracket’ our understanding in such a way that allows “…the experience of phenomena speak to us first hand” (Crotty 1996b as cited in Crotty, 1998, p. 79) thus allowing this researcher to understand the true essence of a cancer patient’s subjective and everyday experiences of how they emotionally adapt to cancer.

In terms of how this study may take on a narrative overtone, it is important that we remember that the data being analyzed is archival in nature (the unsolicited narratives) written in the margins of quantitative questionnaires. For this reason, the unsolicited narratives can be understood as participants engaging “…in the practice of storytelling” (Riessman, 2008, p. 7) in such a way that allows them to socially interact with the research team that “…other modes of communication do not” (Riessman, 2008, p. 7-8), namely quantitative questionnaires which were used in the original study.

Specifically, the unsolicited narratives were read and understood as “typal narratives” (Smythe & Murray, 2000, p. 327). The authors suggest that typal narratives are a relatively new development within social science research because they speak to issues important to social scientists, such as the original study’s quest to investigate how cancer patients emotionally adapt to having cancer. The authors explain that typal narratives are not merely personal narratives that explore the personal perspective of a particular individual nor are they archetypal narratives that focus on human individuality and themes such as morality, life and love. Instead, the
authors suggest that typal narratives “concretely exemplify the theory-laden categories of contemporary social science” (Smythe & Murray, 2000, p. 327). Given that the participant’s unsolicited narratives were in response to a quantitative social science study, it only seems fitting that these narratives are understood within the context of the theory-laden categories that underlie the original study, how do cancer patient’s emotionally adapt to cancer and previous work in the field.

3.1.3. My Role as Researcher. As previously discussed, the essence of QD lies in describing the data and not interpretation of the data (Neergaard et al., 2009; Sandelowski, 2000). For this reason, my role as researcher is to provide a precise account of the unsolicited narratives. Although I have had close family members die of cancer, I have not had cancer myself thus I posit myself as an ‘outsider’ given I seek to study a group for which I am not a member (Dwyer & Buckle, 2009). Unlike qualitative studies that rely on interviewing participants directly, this study seeks to understand archival narrative data. For this reason it is impossible to confirm the meaning of the narratives with neither participants, nor am I able to claim that I understand what it means to have cancer.

3.2 Procedures

As previously discussed, the current research study is a secondary analysis of a completed quantitative study conducted in the Psychology Department of the University of British Columbia. To begin, the raw data was entered into a table in a Microsoft Word document and double-checked by two independent research assistants. Next, the data documents were imported into Atlas.ti 7 for coding by two independent coders. After the initial coding, both coders (myself and a research assistant) compared codes and major themes and sub-themes and
worked towards complete agreement generated by the data. As data analysis progressed, codes were collapsed and/or expanded based on the totality of the participant’s experiences.

3.2.1. Criteria for Study Inclusion. This study utilized archival narrative data found in the margins of questionnaire packages collected at three time points: Baseline, six months and twelve months. Eligibility for the current study was based on whether or not participants wrote in the margins of the questionnaires or included hand written notes or letters when questionnaire packages were mailed back to us. Data was considered narrative if it was a single word, phrase, sentence or paragraph that was clearly distinct or added to what was originally being asked.

3.2.2. Data Sources. The sources of data for this study included cancer patients who agreed to be part of a large longitudinal study on the emotional adjustment to cancer. Specifically, unsolicited narratives were the primary source of data although the original questionnaires may be included to triangulate participant responses when narratives do not ‘jive’ with the quantitative responses. Additional information gathered by the Demographic data collected throughout the study was also used to describe the characteristics of the participants.

3.2.3. Ethical Considerations: Confidentiality and Data Representation. In the systematic review of using unsolicited illness narratives in research, O’Brien and Clark (2010) pay considerable attention to the ethics of publically available material. Whilst the data for this study is not publically available, there are ethical considerations to be made, namely, participant confidentiality. For the original quantitative study, each participant was assigned a consecutive participant number by which they were identified. This participant number was used to identify each participant in the original SPSS file used in the quantitative analysis. For this study, the same participant number has been used and is the only identifier, as the original questionnaire packages did not include any identifying information. In terms of reporting the data, any
identifying information has been replaced with a pseudonym to ensure participant confidentiality and will be acknowledged by (*) after the name. Furthermore, I have chosen not to include the participant’s ID number, thus taking an additional step towards ensuring the participant’s confidentiality. The only deviation from changing identifying information is when participants made reference to Wolfgang and Andrea, who acted as the principal investigators in the original study.

Another ethical consideration consists of the use of verbatim quotations in qualitative research. A useful discussion on this topic is offered by Corden and Sainsbury (2006). The authors assert that the inclusion of verbatim quotations has become standard practice in applied qualitative research reporting and further state that certain funding agencies require direct quotations. This is in part, suggest the authors, an attempt to improve critical appraisal and evaluation of policy studies that aim to improve policy and practice.

In the Corden and Sainsbury (2006) study, the investigators invited participants to critique and comment on how their words were presented in an initial report and their views were also considered for the final version. Results reveal that there were different interpretations on how the data were presented which the authors conclude raises issues about how well participants understood the research process. Participants revealed that referring to age and gender was helpful in describing the individual and that describing people by age group versus specific ages maintained participant anonymity, which was important to all participants. Additional findings revealed that participants felt that their words added quality to the research process and that verbatim quotations made reading more enjoyable. Furthermore, participants felt that the investigators were able to balance different perspectives, thereby allowing everyone’s voice to be heard. Finally, the authors reveal that there were strong disagreements
about how some participants were presented, specifically those who may be perceived in negative light or labeled with a category indicative of negative perceptions, beliefs or judgments (Corden & Sainsbury, 2006).

In light of the ethical issues raised with respect to using verbatim quotations, my personal view is that using verbatim quotations is the only way to truly value the time and effort participants expended in narrating their cancer experience and to let the participant’s words speak for themselves. It is my hope that relying on the use of verbatim quotations conveys the strength of thoughts and emotions in this sample of cancer patients. The latter point is consistent with findings from Corden and Sainsbury (2005) who confirm that when individuals are presented with a report that includes their own verbatim quotations, the participants feel that “Quotations could bring a report to life, and personalize the findings in a way that the researcher’s narrative text did not”, thereby facilitating a deeper understanding for the reader (p. 11).

### 3.2.4. Data Analysis.

The method for data analysis for this research was Thematic Analysis; specifically Conventional Content Analysis (Hsieh & Shannon, 2005). According to Neergaard et al., (2009) and Sandelowski, (2000), content analysis is the preferred strategy for QD because it is data driven thus interpretation is kept to a minimum thereby allowing the data to stand on its own. In addition, to avoid researcher bias and to address many of the criticisms of qualitative research, a research assistant coded and analyzed the data independent of myself thus addressing concerns that many qualitative studies lack interrater reliability (Barbour, 2001; Ryan & Bernard, 2003) which is also known as investigator triangulation in qualitative research (Thurmond, 2001) and according to Pratt (2009), is particularly important when working with archival data.
To analyze the narrative data, Atlas.ti version 7 qualitative software (ATLAS.ti Scientific Software Development GmbH, Cologne, Germany) a well-known computer software tool for qualitative analysis was used. In addition to the narrative data, analysis also included data found on the Demographic questionnaires and included: age, gender, education level, household income, marital status, spirituality and ethnicity. My interest in including this data was to ascertain whether or not those participants who provided unsolicited narratives were representative of the total sample in the original study. Quantitative statistical analyses were computed via SPSS version 20.0 for Macintosh (IBM SPSS Statistics for Macintosh, Version 20.0. Armonk, NY: IBM Corp). To discover whether those participants who provided unsolicited narratives were representative of the original sample, basic statistical methods were used. Specifically, the Mean and Standard Deviation were computed to describe age. In addition, a t-test was used to discern whether the two samples differed in age. Percentage Cross Tabulation was also used to explain the basic properties of variables that allowed comparison of those participants who provided narratives against the original sample who did not write narratives.

Three participants also wrote letters to the research team and BCCA. One letter was included with the return of the baseline questionnaire package and the two remaining letters were included in the 12-month questionnaire package. For analysis purposes, the letters were broken down into meaning units thus allowing the letters to be coded similarly with those comments written in the margins of the three questionnaire packages.

3.2.4.1. Eight Steps to Conventional Content Data Analysis. According to Hsieh and Shannon (2005), the process of analyzing data content is comprised of eight steps. First, data was read and viewed repeatedly, allowing both investigators to immerse themselves with the data
thus providing each of us a sense of ‘who’ the participants are as individuals and as a group. Second, each of the coders read the data to derive codes by first highlighting the exact words from the text that appeared to capture key thoughts or concepts. Third, the coders approached the text by making notes of our first impressions, thoughts, and initial analysis. As this process continued, labels for codes emerged that were reflective of more than one key thought. These often came directly from the text and are then became the initial coding scheme. Fourth, codes were then sorted into categories based on how different codes were related and linked. Fifth, the coders then used these emergent categories to organize and group codes into meaningful clusters. Sixth, the coders narrowed down the numbers of clusters to 42 to keep it broad enough to sort a large number of codes. Seventh, the coders combined this larger number of subcategories into six categories. Eighth, definitions for each category, subcategory and code were developed. To prepare for reporting the findings, exemplars for each code and category were identified from the data. At this point, the coders assessed if any relationships existed between the categories and subcategories based on their concurrence, antecedents or consequences.

The advantage of using the conventional approach to content analysis is the ability to directly gain information from the study’s participants thus rejecting imposing preconceived categories or theoretical perspectives. The disadvantage is the failure to fully understand the context of the data thus resulting in a failure to identify key categories. To this end, my reasoning for proposing interrater reliability is to ensure that Guba’s (1981) criterion for dependability is met (Gruba, 1981 as cited in Krefting, 1991).

Analysis of the data has also involved triangulation as outlined by Mathison (1988). The author reports that, “Good research practice obligates the researcher to triangulate, that is, to use multiple methods, data sources, and researchers to enhance the validity of research findings”, (p.
To accomplish this, I have used both the participant’s unsolicited narratives and the Likert responses for those narratives that are clearly linked to a specific question within each of the questionnaires as well as demographic data that was collected at each of the three time points.

3.3 Establishing Trustworthiness

Throughout the writing process, I have focused on balancing description: facts given in the narratives, analysis: the breakdown and recombination of data allowing myself to see the data in new ways, low-level interpretation; as well as both reflexivity (taking a critical look at the work once it is completed) and being reflexive (my own reactions to the study).

Furthermore, my emphasis focused on the actual narratives and I have relied heavily on using verbatim quotations thus allowing the participant’s own words tell his or her personal stories. I feel this is in line with Polkinghorne (2007) who suggests that narratives are not about the accuracy of events, rather it is the meaning attached to those events because narratives are evidence of one’s personal meaning. The reporting voice is that of third-person objective. To accomplish authenticating trustworthiness, I have relied on Truth Value and Fidelity as evaluation criteria.

3.3.1 Truth Value. The importance of accurately analyzing and reporting a narrative study cannot be overstated. Based on Lincoln and Guba’s definition (1985; as cited in Krefting, 1991), Krefting (1991) concludes that truth-value determines the confidence to which the researcher is with the truth and precision of the outcomes based on the research design, context and participants. More specifically, Sandelowski (1986) contends that truth-value is achieved when the data are presented in such a way that individuals with similar experiences would instantly relate.
3.3.2. Fidelity. According to Blumenfeld-Jones (1995), the unsolicited narratives of the cancer patients can be evaluated based on the researcher’s exactness and the honesty in interpreting and reporting the data. If the researcher acts with integrity and authenticity when interpreting and reporting the data, the participant’s narratives will not be misconstrued which the author suggests values, “the worth and dignity of the teller” (Blumenfeld-Jones, 1995, p. 27). For this study, I focused on the Verstehen approach (Schwandt, 2000; as cited in Polkinghorne, 2007) specifically, being able to set aside any personal historical reference and/or circumstance that would impede my ability to replicate the meanings or intentions of the writer.
Chapter 4: Results

The results of this study were generated from the unsolicited narratives of 86 cancer patients who wrote unsolicited narratives in the margins of a mail based quantitative, 12-month longitudinal study that explored how patients emotionally and psychologically adjusted to a new cancer diagnosis. Two participants who wrote narratives in their questionnaires were not included due to withdrawing from the original study. This chapter is broken into four main parts. The first part of this chapter will focus on addressing the first research question, namely, “What are the characteristics of the participants who took the time to offer more than what was originally asked of them?” The second part of this chapter will address the frequency by which specific questionnaires garnered responses and the specific questions with the most responses at all three time points. The third part of this chapter will report on the major sub-themes that emerged from the data namely: Coping and Adjustment to cancer, the Effects of Cancer, Employment and RTW, Other Life Events, Social Support and Diagnosis and Treatment. Lastly, the fourth part of this chapter will focus on sex differences with respect to questionnaire responding and how the sexes differed in terms of the six sub-themes.

4.1 Participant Characteristics

The following section will address the research question: “What are the participant characteristics of those individuals who provided unsolicited narratives?” To assess whether the participants in the current study are a representative sub-set of the original study, data was obtained from three different Demographic forms gathered at Baseline and the 6-month and 12-month follow-ups for each participant (APPENDESES G, H, I). The specific types of information include the participant’s gender and age, education level, household income,
ethnicity, spirituality and/or religious affiliation, marital status, caregiving and additional health concerns.

4.1.1. Age & Gender. In the original investigation, 421 participants completed all three phases of the study. Of the 421 participants, 194 were male (46%) and 227 were female (54%). In the current study there were 86 participants (20.4% of the original sample). Of the 86 participants who offered unsolicited narratives, 29 were male (15% of the total males in the original study) and 57 females (25% of the total females in the original study). Proportional analysis of gender between the current study and the original sample reveals that there were 11.7% more males in the 21 to 50-year-olds and 9.1% less in the 51 to 75-year-olds. Proportion analysis of females indicates there were virtually no differences between groups.

For description and analysis purposes, the participant’s ages were broken down into three age groups: 1) 29 – 50 years; 2) 50 – 75 years; and 3) 76 – 96 years. T-Test comparisons reveal that the mean age and standard deviation for those who provided narratives (M=59.80, SD=13.73) versus those who did not (M=60.94, SD=12.23) conditions; t (436), p = .451, thus there is no significant difference between the two samples. Additional analysis of the proportionality of the age groups between the participants in the current study versus the original sample reveals that that the age of this study’s participants were largely representative of the total sample. The only minor differences were that there were 3.4% more participants in the current study in the 21 to 50-year-olds and 3.6% less participants in the 51-75-year-olds. Table 2 offers an overview of the participant’s age and gender compared to the original sample.

4.1.2. Education Level. The participants also cited a diverse range of education levels. One participant has less than a grade six education, seven participants completed grades 7-12 without graduating high school, four participants graduated high school or had a high school
equivalent and 15 participants had partially completed some kind of post secondary education. A large majority of both females and males completed some kind of post secondary education. Eleven participants graduated from a two-year post secondary program, 16 participants graduated with a four-year post secondary education, five participants completed a partial graduate degree and 27 participants completed some kind of graduate or professional program. Analysis of the original data set reveals that the education levels of the participants in the current study are representative of those in the original study aside from an 11.1% difference in those who graduated high school or high school equivalent. See Table 3 for a complete itemization of education levels for this study’s participants and those in the original study.

4.1.3. Household Income. There was a wide array of household incomes among the participants and five out of the 86 participants made no response. Out of the 81 participants who responded, 22.2% (N = 18) had a household income less than $40,000, eight of which fell below the poverty line with less than a household income of $20,000. Thirty-eight percent of the participants (N = 31) revealed a household income between $40,000 and $79,000 and the remaining 39% (N = 32) reported a household income of $80,000 or more with 28% (N = 23) of those with an income over $100,000. Comparison of household income for this study’s participants and the total sample in the original study reveal that on the whole, the participants in the current study were generally representative of the original sample. The only significant difference was that there were 8.3% more participants in the $20,000 to $39,000 income bracket who did not offer narratives thus the participants in the current study had a slightly higher household income than the total sample educated than the total sample. Table 4 provides a full description of household income of this study’s participants and those in the original study.
4.1.4. Ethnicity. Seventy-six (89.4%) of this study’s participants stated they were Caucasian which is representative of the 390 (88.0%) who stated the same in the original sample. The remaining ethnicities were largely underrepresented in both the current study and the original study. Table 5 offers a summary of the ethnicity of the study’s participants compared to the original sample.

4.1.5. Spirituality. In the current study, 40 (46.5%) of this study’s participants identified with a major religion or were spiritual which is representative of the 200 participants (47.5%) in the original study. Furthermore, comparison of religious affiliation of this study’s participants with the original sample reveals that, overall; this study’s participant’s religious affiliation was proportional to those in the original sample. The largest denomination cited in this study was Christian (27.5%), which is representative of the 47 (23.5%) of the participants in the original sample who also identified as Christian. The only major discrepancy between this study’s participants and the original sample was that only five (12.5%) of the participants in the current study identified as Catholics, which is in sharp contrast to the 48 (24.0%) of participants in the original sample. Moreover, it is noteworthy that the spiritual make-up of this data set shows only 13 out the original 20 possible religious affiliations were reported by this study’s participants compared to the original sample. Table 6 reveals the number of participants who reported on specific religious denominations compared to the original data set.

4.1.6. Marital Status. The marital status of the 86 participants varied greatly. Fifty-two (60.5%) participants in the current study stated they were married or had a common law partner which is slightly lower compared to the 303 (68.4%) participants who reported the same in the original sample. Comparison of this study’s participants compared to the original sample also indicates that nine (10.5%) participants in the current study were widowed which is similar to the
30 (6.8%) of participants in the original sample. In sum, the participant’s marital status was largely similar to the original sample. Table 7 describes the participant’s marital status compared to the original sample.

4.1.7. Caregiving. In addition to dealing with a cancer diagnosis, six female participants also made reference to being a caregiver for others or alluded to caring for others. Caregiving included caring for parents, children and spouses with both medical and mental health issues. When comparing reports of caregiving in the original data set, this study’s participants were representative of the original sample with three (3.6%) of this study’s participants citing caregiving for others which is only slightly lower than the 18 (4.1%) who reported the same in the original sample.

4.1.8. Health. Almost half of the participants also reported that they had suffered from a serious medical condition in the past (N = 34), and included chronic diseases such as diabetes, arthritis, HIV, COPD, and gastrointestinal diseases. Participants also shared that they suffered from acute health problems such as broken bones, organ transplants and underwent various types of surgery. Comparison of the original data set revealed that there were differences between this study’s participants and the original sample with respect to health. Specifically, compared to the original sample, 40.5% (N = 34) of this study’s participants reported a serious non-cancer medical in the past versus 32% (N = 140) in the original sample who reported the same, indicating this study’s participants had more experience with chronic or serious illnesses. In addition, 71 (85.5%) of this study’s participants reported the current cancer was his or her first whereas 365 (61.6%) of the total sample that reported the current cancer was his or her first, revealing a higher percentage of first time diagnoses for the participants in the current study. In terms of whether the current cancer was a recurrence of the same cancer, only two (2.4%)
participants in the current study stated his or her cancer was a recurrence, which is similar to 21 (3.5%) in the original sample. Lastly, 10 (12.0%) participants in the current study indicated that his or her cancer was a second and different type versus the 50 (8.4%) in the original sample, signifying that this study’s participants had more personal experience with different types of cancer.

4.2 Questionnaires & Questions

This section describes which questionnaires participants responded to, how often participants responded to specific questions and the specific time point for which he or she responded (e.g., Baseline, 6-months, 12-months). See Figure 1 for a breakdown of the questionnaires at all three time points.

4.2.1. PSSCAN. As earlier stated, the PSSCAN is used as a screening tool at BCCA and as such no comments were made at baseline given this questionnaire was completed along with additional BCCA paperwork during the participant’s initial visit to BCCA.

The frequency of responses for the PSSCAN were most robust at the 6-month follow-up (N = 39) and declined almost by half at 12 months (N = 21) with a total number of 60 comments. The most frequently responded to question(s) included how many days poor health interfered with one’s lifestyle (N = 13) and how many days participant’s health was not good (N = 9), both of which garnered the most responses at the 6-month follow-up. The majority of comments ranged between one and five responses for both the 6-month and 12 month follow-ups combined. The fewest number of General Comments (GC; the narrative was not attached to a specific question) were seen at the 6-month follow-up and the greatest number of GC comments was found at 12-month follow-up (N = 7). Table 8 provides a detailed description of the questions
for which participant wrote narratives and the specific time point for which those narratives were written.

4.2.2. *Post Traumatic Growth Inventory.* Responses for the PTGI were most robust at Baseline and at the 6-month follow-up, 18 and 19, respectively. Only one response was given at the 12-month follow-up. Responses to the individual questions for all three time points ranged from one to three and the most frequently responded to the statement was: “I learned a lot about how wonderful people are.” Furthermore, the most responses on the PTGI were GC(s). Furthermore, the 26 GC were evenly distributed between Baseline (N = 13) and the 6-month follow-up (N = 12). A detailed review of the PTGI across all three time points can be seen in Table 9.

4.2.3. *Illness Intrusiveness Scale.* The IIRS garnered the most responses at Baseline (N = 39) and the least number of responses at the 12-month follow-up (N = 5) with a total number of 62 responses for the IIRS at the three time points combined. The most frequently responded to question across all three time points was “How much does illness and/or treatment interfere with your health?” (N = 7), with five out of the seven responses at Baseline. Additional questions that received frequent responses included how much one’s illness was interfering with sex life, how much one’s illness was interfering with relationship with spouse, how much one’s illness was interfering with finances and how much one’s illness was interfering with self-expression/improvement. The question that received the fewest responses across all three time points was “How much does illness and/or treatment interfere with your religious expression?” (N = 1) and was found at Baseline. In addition, the IIRS received nine GC, five at Baseline and four at the 6-month follow-up. For a detailed breakdown of the responses to the IIRS across all three time points, see Table 10.
4.2.4. **Demographics.** The Demographic questionnaire morphed over the course of the original study. Participants were asked to mark a check next to the appropriate field that described their situation and included questions regarding: age, current marital status, education level, employment status, household income and ethnicity, social support, religion, if participants had children or were a caregiver of someone with serious health problems that resides with participant and mental health etc. The most responded to question(s) across all three time points were employment status (N = 8), two of which were recorded at Baseline and six at the 6-month follow-up and social support (N = 8), which was added to the 12-month follow-up. In addition, several questions received only one response. There were only four GC across all three time points for demographics. Table 11 describes the pertinent Demographic information participants responded to at all three time points.

4.2.5. **Return To Work.** The most frequently responded to question(s) in the two RTW questionnaire(s) was found in the RTW questionnaire: “How many months did you take off from the diagnosis of cancer until you went back to work?” Most questions received one or two responses and the total number of responses for the RTW questionnaires was 19 and there were no GC. A full description of the RTW questionnaires and the number of responses can be found in Table 12.

4.2.6. **Worries.** The Worries questionnaire received the fewest number of responses from participants. The questionnaire asked participants to comment on the extent to which he or she was concerned about further testing, developing another type of cancer, a recurrence of their cancer, dying and overall health. The one question that received a direct response was: “To what extent are you concerned about another type of cancer?” and two participants made a GC.
4.2.7. **Handwritten Letters/Notes.** Participants also wrote letters to the research team. One letter was included with the return of the baseline questionnaire package and the two remaining letters were included in the 12-month questionnaire package.

4.3 **The Narratives**

The following section will describe in detail the 213 unsolicited narratives of 86 cancer patients. As previously stated, participant narratives ranged from one word to short phrases, full sentences, paragraphs and handwritten letters and notes. Initial analysis revealed that the narratives fell into three categories: 1) Additive, the narrative was not attached to a specific question and was coded as a General Comment (GC); 2) Descriptive; the narrative was clearly attached to a specific question; and 3) Clarifying; the narrative clearly responded to a particular aspect of the questionnaire itself. Table 13 provides a breakdown of the three categories of narratives across all three time points.

Two broad themes arose from the narratives: 1) The ambiguity of test items and nature of participant responses; and 2) Psychosocial functioning. With respect to the latter, six sub-themes emerged from the narratives, namely: 1) Coping and Adjustment; 2) Effects of Cancer; 3) Employment and RTW; 4) Other Life Events; 5) Social Support; and 6) Diagnosis and Treatment.

Lastly, given the disproportion of females to males in this study, I acknowledge that many of the narratives penned by males were given more weight in my analysis. This was done primarily to highlight those narratives written by males and to allow comparisons between the sexes.

4.3.1. **Ambiguity of Test Items & Participant Responses.** The unsolicited narratives offered by this study’s 86 participants were diverse in content and quantity.
Of the 86 participants, 32.5% (N = 28) made more than one comment on a single measure with one 58 year-old female participant making 12 comments on the IIRS at Baseline. Most participants that made more than one comment limited their comments to between two and eight per measure.

For some participants, the ambiguity of the specific questions caused them to respond with answers that made sense to them. For example, one 77-year-old female responded to the IIRS question: “How much does you illness and/or its treatment interfere with your health?” with “Assuming you mean the rest of my health. Clearly having breast cancer and previously having melanoma have to be up there pretty high”. Another question that participants seemed to find ambiguous was the PSSCAN question: Have you lost your life partner within the last few years?” Participant responses included, “My brother Gerard (*)”, while another wrote, “Lost mother”, and two added “Best Friend”. An additional finding that emerged was that participants seemed to have difficulty differentiating what the question was asking. For example, PSSCAN questions that asked participants to respond to how many days their physical health was not good or prevented them from carrying out his or her usual activities, several participants did not comment on their cancer. Instead, participants commented on how many days they had been down with a “bad cold” or were suffering some kind of physical injuries or additional illnesses that were not cancer related.

Another finding that emerged was whether or not the participant ‘correctly’ answered the question being asked. For instance, several participants responded in the opposite direction of what the question was asking. For example, in response to one of the questions in the PSSCAN, “For the past 30 days, for how many days did poor physical or emotional health keep you from
doing your usual activities, such as self-care, work or recreation?” one participant responded “0 days, but still can’t jog which was a major part of life before.”

Furthermore, 10 participants responded positively to questions asking about how cancer may be negatively affecting his or her family relationships. In response to an IIRS question: “How much does your illness and/or its treatment interfere with your relationship with your spouse?” participants responded in the affirmative and scribed, “In a good way. My husband loves me much more than ever.” while another wrote “Made things better; don’t know how to answer.” Similarly, in response to the IIRS question: “How much does your illness and/or treatment interfere with your family relations?” one participant penned, “Spouse, sibling, and children are very supportive.”

For 12 participants, the written narratives contradicted the recorded quantitative responses on the questionnaires. In these cases, the qualitative or narrative response was more informative. For example, the 12-month Demographic questionnaire asked: “Did a major change in your life occur since you began the study?” one participant added “No. Found a spot on liver and what turned out to be a cyst on pancreas. Cyst was drained after radiation. Has improved my health and wouldn’t have been found without CT scan result of cancer diagnosis.” In this example, it is clear that this participant experienced a major change in their life, specifically; an improvement in health yet circled ‘No’ instead of ‘Yes’.

Further examples highlight how Likert scale responses may be confusing for some participants. In the first example, the participant’s Likert response was a 5 (e.g., I experienced this change to a very great degree as a result of my experience with cancer) to a PTGI statement: “I established a new path for my life”, yet the narrative is clearly contradictory and more accurately captures the participant’s experience, writing “I did not. I enjoy the old path in life
more.” Similarly, another participant’s Likert response is contradicted by the written narrative. In this example, the participant’s response was a 3 (e.g., 1 = not very much to 7 = very much) to the question: “How much does your illness and/or its treatment interfere with your relationship with your spouse?” and responded “Positive due to all the support.” Once again this example illustrates how Likert responses in conjunction with questions that do not fully capture all possibilities may lead to inaccurate responses.

Analysis of how participants responded also revealed that some participants did not answer the question directly yet offered a narrative response in lieu of what was being asked. For instance, in response to: “Now thinking about your physical health which includes illness and injury, for how many days during the past 30 days was your physical health not good?” the participant declined to give the expected numerical answer and scribed, “Not as good as it used to be.” Correspondingly, in response to the PTGI question: “I have a better understanding of spiritual matters” the participant declined to respond in the negative or the affirmative and set forth to defend the non-response by stating, “This Q. assumes that spiritual matters can be understood – the definition of spiritual is too vague.” In addition, several narratives clearly indicated that the question being asked did not apply to them. One participant responded to the Demographic question: “Who has supported you since your cancer diagnosis?” and clearly stated, “I did not need support.” For one 70-year-old male, the question: “How much does your illness and/or its treatment interfere with your sex life?” did not apply to him and scribed, “No sex life.” Another participant took issue with one of the PTGI statement: “I learned a great deal about how wonderful people are” and offered the politely chastised response, “It reinforced my conviction about how wonderful people are rather than learned.” For others, the written narrative offered an intimate peak into the participant’s life as evidenced by the response to the
PSSCAN question: “Now thinking about level of stress, depression, and problems with emotions, for how many days during the past 30 was your mood not good?” and scribbled in the margin, “My husband wants to leave.”

In addition to confusion of how to answer, missing responses and questions that do not capture all possibilities, six participants also made GCs about how their responses might be skewed by other life events and additional medical concerns. One GC from a 64-year-old female wrote:

I have not been feeling well of late, but don’t believe it is necessarily due to cancer. I am waiting for diagnosis, but believe at least one of the kidney stones is “acting up” and causing nausea, some fever and chills, as well as feeling “not right”. This could also be due to a “parathyroid” issue. Thus far, all cancer checkups have been positive.

Along the same line, one 68-year-old male wrote, “My responses are greatly skewed by the fact that I suffer very debilitating COPD.”, while another participant explained how a recent accident was skewing her responses:

My responses are at present influenced by the fact that while in the middle of my cancer treatment, I was the victim of a vehicle accident. I was run over by an SUV and was thrown out of my scooter (I am crippled by a vehicle accident in the past) and suffered head and neck injuries and my scooter landed on top of me.

4.3.2. Psychosocial Variables Related to Coping & Adjustment to Cancer. Analysis of the data revealed a multitude of reactions in how participants coped and adjusted to his or her disease. Furthermore, given the original study was longitudinal in nature, this section will present the participant narratives chronologically in an attempt to describe how participants coped and adjusted to his or her disease from Baseline through to the 12-month follow-up.
Taking into consideration the time points for which the narratives were written, results indicate coping and adjusting to cancer was most salient for participants at the 6-month follow-up, followed by the 12-month follow-up and to a lesser degree at Baseline.

4.3.2.1. **Baseline: Coping & Adjustment to Cancer.** The Baseline narratives reveal a continuum by which the participants of this study were challenged in his or her ability to cope and adjust to a new cancer diagnosis. For this reason, analysis has been broken into: 1) Challenges with coping and adjustment; and 2) Successful coping and adjustment.

For many of this study’s participants, the diagnosis of cancer understandably shook his or her world resulting in a host of emotional and psychological reactions and states. One of the more unique responses came from a 29-year-old female who responded to a PTGI statement: “New opportunities are available which wouldn’t have been otherwise” and scribed, “Undergoing surgery, radiation, chemo, drugs, recovery, and other such dark ironies.” Yet another reaction was disbelief and one 57-year-old female wrote, “My hardest mental challenge has been accepting that I needed chemo and was found to be in the early stages of III when I feel so healthy…” Other participants commented on the ambiguity of recently being diagnosed. For instance, a 61-year-old female penned, “Note: a person’s time is on “hold” while being diagnosed, waiting for surgery and recovery followed by Tx i.e., medication/chemo. It’s difficult to make plans.” Likewise, a 51-year-old female describes the challenges of dealing with uncertainty of her situation and noted, “…I am anxious for positive news…Waiting for treatment has been very hard.”

Other participants were more direct with stating his or her emotional reactions with one 65-year-old female asserting, “…I am angry. I don’t want or need anybody…I will deal with my own problems…” and another participant jotted down, “…I was very distraught.” For one 57-
year-old male, he describes his reaction to being newly diagnosed with cancer and his perception of support and wrote, “The support at the time of diagnosis needs to be improved. This is the most critical time, and you are virtually left alone to wonder what happens after a doctor tells you that you have cancer.”

Another stop along the continuum of the challenges of coping and adjustment to one’s cancer diagnosis was participant’s commenting that they had recently been diagnosed and thus had not had enough time to let it sink in. For instance, a 46-year-old male commented on how he had not changed his priorities in life and wrote, “I haven’t had enough time yet since diagnosis.” Correspondingly, a 74-year-old male noted, “Please note I have been just recently been diagnosed and there is more testing to undergo before deciding which treatment I will have. Responses may change after Tx is under way i.e., health status etc.” Still, another participant responded to the IIRS with a GC and penned, “Please keep in mind I haven’t started chemo therapy.”

At the opposite end of the coping and adjustment continuum, many participants reported a different experience. For one participant, cancer was described as a “…minor inconvenience…” while others reported that cancer had not disrupted his or her life. For example, one 34-year-old female stated, “I’m not sick. I just had a small skin cancer removed (melanoma). It did not affect my life. Thanks!”

For one 57-year-old female, prior exposure to cancer in someone else seemed to have somehow prepared her for the challenges of being diagnosed with her own cancer. In this narrative, this participant explained, “I have been in a very good state of mind as my husband went through cancer and a family friend’s child (3½) died of leukemia, so my priorities have been affected long ago.” Likewise, a 66-year-old male explained how a previous illness may
have prepared him and scribed, “As an educator my whole life, and as someone who almost died from pneumonia, 3 years ago, I already had a very healthy respect for self, others and existence itself…”

Faith and/or spirituality also seemed to play an important role in terms of how one 58 year-old female was able to effectively cope and adjust to her cancer diagnosis and penned, “My faith has been very helpful.” and later writes:

My faith is an important source and consolation. I feel it is presumptuous to pray to be cured and spared from having cancer, but I pray for the strength to deal with whatever comes my way, and this gives me comfort and confidence.

4.3.2.2. 6-month Follow-up: Coping & Adjustment to Cancer. Like the narratives at Baseline, the 6-month follow-up continues to demonstrate the range by which the participants of this study were able to cope and adjust to his or her cancer diagnosis.

The 6-month follow-up reveals that some participants continued to be challenged by his or her diagnosis and treatment. For instance, a 55-year-old female seemed to have a different reaction to her cancer. In response to a statement on the PTGI about establishing a new path in life, this participant explained, “The new path is determined by my poor health, not me.” An additional response to the PTGI came in the form of a GC and this 59-year-old female penned, “Cancer left me with less sense of control, reduced sense of resilience…” Moreover, a 74-year-old female describes how she felt about her cancer and noted, “…Cancer was a big experience…”

The 6-month follow-up also demonstrates that some participants experienced a decline in their mood. For one 59-year-old female her mood was not good for, “Part of most days.” Yet for another, 63-year-old female, thinking about recurrence was a concern and jotted, “…Afraid
cancer is going to come back.” In addition, the treatment that participants underwent also seemed to have a negative effect on participant’s moods. One 57-year-old female shared that she was, “…extremely depressed for 10 days around my chemo session…” while 45-year-old male shares a slightly different experience with respect to treatment and writes, “Post treatment has been much harder than during treatment.”

Other life events also appeared to influence how the participants were able to cope and adjust to his or her cancer diagnosis. One narrative by a 64-year-old female is of particular interest as it encapsulates how life continues to go on despite a cancer diagnosis:

I feel that in order not to give you a skewed perspective on my answers, I must tell you that at the same time as my cancer diagnosis, surgery and Tx, my husband had multiple heart attacks, and we were building a house, and as a result of our coinciding illnesses, our finances were affected. So, because I was dealing with more than my own cancer (which I accepted well), I had a great many more stresses to contend with than my own illness...

Yet, for a 69-year-old female, her perception of the lack of care received by her doctor speaks volumes:

I felt that there was a lack of compassion with the plastic surgeon. Maybe they have no choice but releasing the patient the day after surgery. From my experience (and I think I am emotionally strong) it was too soon to be released. I felt vulnerable and not cared for.

At the 6-month follow-up, many participants seem to be effectively coping and adjusting to his or her cancer diagnosis. Once again, for some participants, prior life experiences seemed to mitigate the cancer experience via prior life changes. For instance, a 57-year-old female was very specific in her response and penned, “Need to know that many of these things (Q1-Q10, Q
12 – Q21) were changed in my life prior to my diagnosis in May 2010. I made major life changes in Nov. 2008.” Relatedly, a 55-year-old female made a GC on the PTGI and described how her previous cancer diagnosis had already effected change and shared, “Changes happened in 1999 when I had breast cancer. I didn’t change as much this time as I already had.” Yet, for an 81-year-old female who had been a single mother of 3 and the mother of a child with physical and mental disabilities had much to contend with before her cancer diagnosis and described her current cancer experience as a, “…bump on the road.”

For others however, the experience of cancer was the impetus to make change. For instance, in response to the IIRS, one 66-year-old male made a GC and wrote that his compromised immune system had resulted in social isolation and that he was not currently engaging as he had before but shared that his, “…meetings are by Skype for me, as an example.” One 60-year-old female also indicated she had made change as a result of her cancer diagnosis and penned, “I’m actually taking more time to do what interests me.”

A different kind of change also occurred for a 77-year-old male who responded to the content of the questions on the PTGI and stated, “These really didn’t define for me how I was affected. Mostly, I’ve developed a greater appreciation for the skill & compassion of our medical people, and I feel very fortunate to have had this help.” Likewise, in response to the PTGI statement: “I learned a great deal about how wonderful people are” one 96-year-old female noted, “Especially medical staff and doctors.” Yet, another type of change occurred for a 60-year-old female who presumably had experienced distress as a result of her diagnosis and penned, “Having been told by the surgeon and plastic surgeon that I’m cancer free has given me a great relief. I’m grateful for the speed of getting the operation done.” Another participant who made a GC on the IIRS also seemed to be in a period of change with respect to adjusting to her
disease and shared, “I found this somewhat confusing to answer for a couple of reasons: 1) While the surgery, radiation, and chemo affected me during the treatment, the illness is no longer affecting me, at least not much.”

Still for others, having a cancer diagnosis may not have had a much of an impact on the lives of some participants. For example, one 80-year-old female shared that she was, “Grandparenting two times per week and on vacation. Cloud 9, a great place for dinner.” While there is no direct link between how this participant was coping and/or adjusting to her diagnosis, it is clear from her response that she was not letting her cancer diagnosis get in the way of enjoying her life, thus we might infer that she was adapting well.

Faith also emerged as a positive way in which participants seemed to cope and adjust to his or her cancer diagnosis. A GC on the PSSCAN written by an 86-year-old female illustrates, “I believe in Jesus and I have not had any other problems, as He was with me during surgery. There was no pain or any other problems.”

4.3.2.3. 12-month Follow-up: Coping & Adjustment to Cancer. The narratives at the 12-month follow-up indicate a shift in many of the participant’s narratives regarding coping and adjustment to cancer. Specifically, there was a marked decrease in the number of comments compared to Baseline and the 6-month follow-up.

The narratives at the 12-month follow-up indicate that some participants continued to have face challenges with coping and adjustment to his or her disease. For instance, a 65-year-old female who at Baseline made one comment and explicitly expressed; anger, mourning the death of her brother Gerard (*) in November 2008, as well as insistence that she didn’t need or want anybody. Although this participant made no comments at the 6-month follow-up, this participant continued to narrate that she was still mourning her brother and was still very angry at
the 12-month follow-up. Anger was also expressed in a GC made by a 67-year-old male who wrote, “Pissed off that I can only walk four blocks.” Although it is impossible to determine if he was unable to walk due to his cancer diagnosis or was a result of a prior medical condition, this participant was clearly describing the challenges of a marked decline in his activity tolerance.

Denial also continued to be a coping strategy as evidenced by the following narrative by a 56-year-old female who penned, “Even though I am aware about my disease, I am positive and do not think a lot about it. Appointments are stressful though as it is hard to use denial then.”

Non-disclosure was another theme that emerged at the 12-month follow-up. Two participants made reference to not disclosing their illness to family or friends with one 68-year-old male stating that, “I did not tell anyone about my cancer diagnosis. We never talk about it.” A recently divorced 29-year-old female participant noted that, “…My ex never knew I had cancer.” Non-disclosure in the workplace was also on the mind of a 33-year-old male who indicated neither his colleagues nor supervisor had been informed of his cancer diagnosis.

The 12-month follow-up demonstrated that some participants were effectively coping and adjusting to his or her disease. For example, the female participant who explained that she was angry and was mourning the death of her brother, Gerard (*) also seemed to experience a cognitive shift and acknowledged that she had sought professional help from her EAP provider and that she, “Would like some CBT therapy.” Moreover, this participant also seemed to gain ‘something’ from participating in the original study and scribed the following to BCCA and our research team, “Hospital doctors, techs, and your team study thank you Andrea and Wolfgang your support replaced my faith. Without Gerard (*) I am lost.”

In a letter written by an 87-year-old female, the participant not only made reference to her advanced age, but also a seemingly positive attitude and scribed, “Although I’m 87 years old, I
think I am OK.” A positive attitude can also be inferred by the following response to the PSSCAN question: “For how many days during the past 30 days did poor physical or emotional health keep you from doing your usual activities such as self-care, work, or recreation?” A 50-year-old female responded by stating, “0 days, but I cannot ride a bike or garden due to pain – this is an everyday problem.” While riding a bike and gardening can certainly be considered recreational activities, this participant seems to have acknowledged what she was and wasn’t able to do but still responded with “0 days”, possibly inferring a positive attitude and that she was not letting her illness get the best of her. A more direct example of a positive attitude can be seen in the narrative of a 65-year-old female who shared, “I accept the challenge. Make every day a good day.” Positive coping and adjustment to cancer can also be seen in a narrative written by a 51-year-old female who describes how she developed new interests as a result of cancer and writes, “Jogging, desire to play badminton, reading, learning new languages, enjoying mother-daughter bond and being a mom, yoga exercises, being in a clean environment.”

Faith and/or spirituality also continued to be a way in which participants used to positively cope and/or adjust to his or her illness. In particular, one 45-year-old female shared that she had developed new interests as a result of her illness and wrote, “Support group; more involved with church.” while a 56-year-old female stated that she was supported by “…religious group/church…” A letter written by an 87-year-old female also shared that she was Christian and found solace in her faith.

One 59-year-old male made a GC on how the support and information he received from medical professionals influenced the trajectory of his recovery trajectory:

I found it very helpful to know from my BCC doctor that [there] can be a let down following treatment. After being so busy with treatments and feeling so well cared for, I
felt a little lonely and sad after everything ended. I’m dealing with that, but it was good to know that it can happen.

Lastly, a response to the Demographic question asking if participants had experienced a major change in their life since beginning the study elicited a response that has overtones of being grateful for her cancer diagnosis as this led to the discovery of an additional illness and wrote, “…Found a spot on liver and what turned out to be a cyst on pancreas. Cyst was drained after radiation. Has improved my health and wouldn’t have been found without CT scan result of cancer diagnosis.”

**4.3.3. The Effects of Cancer: Relationships, Health, Lifestyle, Mood and Finances.**

The effects that cancer had on the lives of the study participants varied in content and across all three time points. The Participant’s narratives indicate that cancer had an effect on family, one’s overall health and lifestyle.

**4.3.3.1. Relationships.** Many participants commented on the effect cancer had on family relationships. In response to the IIRS question: “How much does your illness and/or treatment interfere with your family relations?” one 70-year-old male wrote “Closer” at 6-months while another 58-year-old female wrote “Spouse, siblings and children are very supportive” at Baseline, while another 51-year-old female was more descriptive at 12 months and wrote “…enjoying mother, daughter bond & being a mom.” In response to the IIRS question asking how much his or her illness was interfering with their relationship with their spouse, five participants answered in the affirmative and wrote, “Made things better…” and “Positive due to all the support” and “Closer”. One 58-year-old female also commented on how her diagnosis was affecting her husband and scribed, “Spouse (male) is very worried”.

Conversely, one 49-year-old female reported that illness and treatment at Baseline was “Difficult
with kids”. In a similar vein, participants also commented on how treatment was affecting his or her sex life.

4.3.3.2. Health. Participants also chose to comment on how cancer was affecting their health. Several participants cited pain and wrote, “Back pain” or pain because of surgery while other participants commented that their health was “Not as good as it used to be” or that cancer was impacting her health “…most days”. One 66-year-old male was clearly concerned about the state of his immune system and scribed, “The issue is that one must be isolated for so long while the immune system revives…” Yet for another 69-year-old female, her cancer had returned and simple wrote, “The cancer has returned and it is incurable.”

4.3.3.3. Lifestyle. Another area that received a lot of attention was how cancer was affecting participant’s lifestyles. Some participants seemed to take their disease in stride and adjusted their lives accordingly. For example, in response to a PSSCAN question inquiring how many days their poor health interfered with their lifestyle, one 52-year-old male penned the following five months before his death, “0 days. I just don’t do demanding activities, so I have changed to not demanding.” Similarly, a 77-year-old female made a GC in the PTGI and shared, “After therapy I went back to normal life and I feel very good…and I refuse it let it interfere with the rest of my life.” In a similar vein, one 60-year-old female scribbled the following GC on the IIRS, “The illness is no longer affecting me, at least not much.”

Conversely, other participants report a different kind of experience in terms of how his or her disease affected their lives. For example, one 55-year-old female explained that her new path in life was, “…determined by my poor heath, not me”. One of the most descriptive narratives was penned by a 61-year-old female as a GC on the PTGI and captures the essence of time and the unknown and wrote “Note: a person’s time is on “hold” while being diagnosed,
waiting for surgery and recovery followed by Tx, i.e. medication/chemo. It’s difficult to make plans”.

Participants also responded with vigor with respect to how cancer was affecting both their active and passive recreation. Responses at Baseline focused on how active recreation was temporarily impaired due to recovery from surgery such as, “Have to take 6 weeks off” or the cessation of an activity as seen in a 58-year-old female who penned, “I was volunteering during the Olympics but had to drop out”.

Responses at the 6-month follow-up continued to be mixed. Participants wrote that their active recreation continued to be compromised and one 37-year-old male stated, “…but still can’t jog which was a major part of life before” and a 70-year-old male penned, “Physical limitations limit what I can do” while a 60-year-old female indicated that she was, “…getting back into it now”. One comment at the 12-month follow-up clearly demonstrates how one 50-year-old female’s cancer continued to spoil her active recreation and scribed, “…but I cannot bike or garden due to pain – this is an everyday problem”. For three participants, cancer also affected their passive recreation with one 58-year-old female sharing that, “I’ve been studying Spanish, but I have lost interest, hopefully temporary” while a 49-year-old male wrote that his passive recreation was compromised due to, “Hearing loss from chemo” and a 58-year-old female cited that cancer was affecting her concentration. In addition, two participants, one widower (70 years) and one married female (59) both wrote “No sex life”, although it is difficult to ascertain whether this is due to cancer. Two women in their fifties also commented that their sex lives were being impacted due to recovery from recent cancer surgery.

Conversely, some participants had a different experience and cited that their active recreation had improved or had not been affected. One 51-year-old female communicated that
cancer had sparked new interests in jogging, badminton and yoga, while one 81-year-old female wrote at the 12-month follow-up that she continued to keep busy with, “…handcrafts, knitting, etc.” Another 65-year-old female, also penned that her usual activities had not been affected. For one 56-year-old male, he related at Baseline that changes in his lifestyle had occurred prior to cancer and penned:

   Just for clarification when I decided to take early retirement, 12 months ago, I made changes to lifestyle, activities, etc. (All for the better of course). So changes I made in advance of knowing about my diagnosis for cancer had already been made.

### 4.3.3.4. Cancer Effect on Mood.

The analysis of how cancer affected the participant’s mood revealed that for some participants, being diagnosed with cancer had a negative effect. While there were no comments offered on how mood was affected at Baseline, this was not the case for the 6-month and 12-month follow-ups. At the 6-month follow-up, two participants shared how cancer had negatively affected their moods. One 57-year-old female wrote, “…I was extremely depressed for 10 days around my chemo session on Jan.18” while a 63-year-old female expressed her fear of recurrence of her disease and jotted, “…Afraid cancer is going to come back.” A similar response was written by a 65-year-old female at the 12-month follow-up writing, “Several days more than one; I was very angry.”

### 4.3.3.5. Cancer Effect on Finances.

For many participants, how one’s cancer diagnosis might affect his or her financial situation was a concern. Baseline comments revealed that concern over how cancer might affect finances began shortly after diagnosis. One 74-year-old male wrote, “Still working. Would not like to lose income” while a 30-year-old female shared that cancer, “Has the potential to affect finances/employment depending on how much time off is needed.”
4.3.4. **Employment & RTW.** Analysis of the written narratives revealed that Employment and RTW were major concerns for many of this study’s participants. Moreover, the narratives offered increased incrementally for each time point as participants. Baseline received 12 responses, 20 at the 6-month follow-up and with the inclusion of the RTW questionnaire at the 12-month follow-up, 50 at the 12-month follow-up as many participants commented on time taken off for treatment or indicated they were making plans to RTW or had already RTW to some degree.

4.3.4.1. **Medical Leave/Time Off.** The greatest number of responses to Employment & RTW centered on the amount of medical leave and/or time off required to tackle one’s cancer diagnosis and treatment. Participants at Baseline revealed that they were concerned with if taking medical leave would somehow affect his or her finances. This may have been more of a concern for those participants such as one 51-year-old female who, “…had to take time off work without pay after surgery.”

Narratives at the 6-month follow-up shared a common theme of recently or currently being on medical leave. For instance, in response to Employment Status question on the Demographic questionnaire, one participant wrote, “Have business, but currently taking a break due to recent surgery and chemo” and “…I am still on medical leave…” Still, other participants commented that they had taken medical leave but were planning to RTW and wrote, “Employment was full time initially (Then off on medical leave and returning for part-time in July” and “…although I have not been able to return to my 60 + hour job, but I am preparing to go back next month.”

The 12-month narratives were more diverse in content and were generally more descriptive. In response to the RTW question: “If you were working at the time of your cancer
diagnosis, have you returned to work since? If yes, how many months did you take off from the
diagnosis of cancer until you went back to work?” one 45-year-old female wrote, “Total of 3 ½
months. 2 weeks for the first surgery, 2 weeks for the second surgery, and 10 weeks for the
radiation healings.” Another participant (49-year-old female) also shared her experience:

I hope this is of help. I was diagnosed July 2010, did radiation and chemo. I beat that
cancer but in Feb. 2010 was re-diagnosed. During that time I worked from Jan. 2011 to

While some participants took extended medical leave such as one 54-year-old female who stated
she was off for nine months, other participants continued working to some degree. One 61-year-
old female penned, “Worked some ¼ - ½ days during this time”, which is similar to the
experience of a 32-year-old female who wrote, “I took time off periodically during chemo but I
was never completely off…”

Participants also described additional experiences with respect to their disease,
employment and medical leave. One 45-year-old female shared that she was unable to continue
working during her active treatment because treatment facilities were not available in her
hometown. A 45-year-old male had a much different experience and stated that he had to
“…find a new job to return to.” For one 49-year-old female, her medical leave was extended
when it was discovered that she had been, “Re-diagnosed with 2 tumors” and was only back to
work for 6-months before having take medical leave for a second time.

4.3.4.2. Challenges with RTW and/or Unable to Meet Demands. Several participants
who indicated they were planning to RTW or had RTW faced challenges with returning to pre-
diagnosis work schedules or were now unable to meet the demands of their jobs. A 45-year-old
female illustrates this dilemma and writes, “But went back to work to early; should have went
back ½ time instead of full time. However doctor felt full time best for me.” Relatedly, a 79-year-old female shared that “Shift” work was more of a burden than it used to be. Similarly, a 56-year-old female was also unable to meet the demands of her employment and, “Retired due to fatigue.”

4.3.4.3. Miscellaneous Employment & RTW Narratives. Participants also indicated that changes in their work life decisions occurred either prior to their cancer diagnosis or shortly afterwards. One 29-year-old female shared that she was, “…not working at the time of diagnosis due to other health issues” while a 56-year-old male, wrote:

Just for clarification: when I decided to take early retirement, 12 months ago, I made changes to lifestyle, activities, etc. (All for the better of course). So changes I made in advance of knowing about my diagnosis for cancer had already been made.

Still, another narrative offers yet another perspective on her employment situation. In addition to dealing with her cancer diagnosis, one 45-year-old female who reported working in a white-collar job scribed, “Still haven’t really resigned my self-employment”. Another participant described at Baseline what could be a challenge for newly diagnosed cancer patients. In response to an IIRS question asking how much one’s illness and/or treatment was interfering with work life, a 51-year-old female wrote, “This related to multiple medical appointments, currently.”

Another issue that arose up with respect to employment and RTW was disclosing one’s illness to his or her employer. At the 12-month follow-up, a 33-year-old male responded to RTW questions asking if his colleagues and supervisor were considerate of his disease. For reasons unknown, this participant indicated he had not told his colleagues or his supervisor about his disease and penned, “They don’t know” and “Doesn’t know”, respectively. While the next
example requires more interpretation than the previous exemplars it speaks to the complexity of the decision making process with respect to balancing one’s work life and one’s need for self care. In response the RTW question: “Did your position change when you returned to work?” a 51-year-old female wrote, “No, I was being eyed for a designation but declined as I had already, quietly, jumped over several hurdles just to avoid un-necessary confrontations. It was accepted.”

4.3.5. Other Life Events. Analysis of the participant’s narratives revealed that in addition to cancer, other life events were important enough for participants to comment on and included motor vehicle accidents, additional health issues, interpersonal stressors, loss of a loved one and multi-layered life events. One such GC by a 64-year-old female exemplifies the complexity of the totality of how other life events can complicate one’s life and add additional stressors to having a cancer diagnosis:

I feel that in order not to give you a skewed perspective on my answers, I must tell you that at the same time as my cancer diagnosis, surgery and Tx, my husband had multiple heart attacks, and we were building a house, and as a result of our coinciding illnesses, our finances were affected. So, because I was dealing with more than my own cancer (which I accepted well), I had a great many more stressors to contend with than my own illness…

4.3.5.1. Additional Health Issues. The most predominant of the other life events was participants commenting on illnesses that were not cancer related. The frequency of responses were seen across all time points with eight comments at both Baseline and 6-month follow-up and 15 comments at the 12-month follow-up.

The narratives of many of the study’s participants revealed that ‘other’ health issues were more problematic or interfered more with their lives rather than his or her cancer diagnosis.
These illnesses included Chronic Obstructive Pulmonary Disease (COPD), asthma and chronic arthritis, injury due to broken bones and sprains, parathyroid issues, arterial venous malformation, water problems and osteoporosis. A GC made by a 64-year-old male on the Baseline IIRS illustrates, “Asthma, rather than cancer interferes more with my life”, which is similar to another GC on the IIRS made by a 68-year-old male who wrote, “I believe that most of my negative health effects are the result of Chronic obstructive pulmonary disease (COPD).” Similarly, a GC made on the PSSCAN by a 64-year-old female at the 12-month follow-up also illustrates how her symptoms may not be cancer related and writes:

I have not been feeling well of late, but don’t believe it is necessarily due to cancer. I am waiting for diagnosis, but believe at least one of the kidney stones is “acting up” and causing nausea, some fever and chills, as well as feeling “not right”. This cold also be due to “parathyroid” issue. Thus far, all cancer checkups have been positive.

For other participants, mobility was a major concern. Several male participants described how recent injuries were affecting their mobility. In response to the PSSCAN question inquiring for how many days their emotional or physical health prevented them from engaging in their usual activities, a 56-year-old male shared that he was, “Unable to play hockey (4 days), whilst a 71-year-old male shared that he was suffering from an, “Achilles sprain (14 days).” In response to the PSSCAN question asking how many days was one’s physical health not good, one 63-year-old male penned beside his answer of 60 days, “Broken leg and ankle.” One 64-year-old female also shared at 6-months that her health was interfering with her lifestyle and wrote, “14 days approximately. This is not necessarily related to cancer as I have a broken ankle, and this situation was limiting...”
Participants also made reference to other diseases in response to various questions about his or her health. One 86-year-old female included a letter when she returned her 12-month follow-up and wrote, “…I have a water problem and osteoporosis…” and a 67-year-old male shared, “I am on oxygen 24x7. I have severe breathing problems. I go 20 ft, I’m out of energy.” In a letter penned by a 67-year-old male, the participant explained why he was printing instead of writing and explained, “I print instead of writing. 15 years ago, a friend told me that no one could read my writing. According to neurologist Dr. Dave Davis (*), this is a side effect of toxoplasmosis.” In addition, participants also responded to how other illnesses were temporarily affecting his or her health. In response to the PSSCAN question asking how many days their physical health was not good, one 67-year-old female wrote, “3 day illness was due to a bad cold”, which was an exact experience also shared by a 68-year-old male. For one 67-year-old male, his response to the PSSCAN statement: “During the past week I have felt that my heart races and I tremble” the participant checked the response box, ‘Not at all’ but also added, “Health issues, not panic attacks.”

4.3.5.2. Interpersonal Life Stressors. As previously noted, several of the study participants shared that not only were they dealing with their own cancer diagnosis but also were also a caregiver for his or her children, parents and other close family members. Whilst most did not make reference to this being a burden, one can extrapolate that being a caregiver may have taxed the participant’s available resources thus adding additional stress. The same inference can also be made for those comments relating to the health of the participant’s spouses. For example, in response to the PSSCAN question: “Have you lost your life partner within the last few years?” one 54-year-old female replied, “No, but my husband was recently diagnosed with lymphoma.” Relatedly, one 6-month response to a Demographic question: “Are you a caregiver
of a person that resides with you and has health problems” a 57-year-old female penned, “I am not care giving my husband, but he has lymphoma and has had post herpetic neuralgia for 21/2 years, so he has health challenges as well.”

For other participants, the interpersonal stressors with their spouses evoked a markedly more succinct yet insightful response. One such example was seen in three narratives written at the 6-month follow-up by a 55-year-old female. In response to the PSSCAN questions asking if she was able to count on anyone for help with daily tasks or if she had anyone to provide emotional support, the participant indicated ‘No’ on the forced choice response and further elaborated by penning, “Not husband.” Furthermore, in a response to the PSSCAN question asking how many days during the past 30 was her mood not good, this participant’s marriage difficulties were further evidenced by her numerical response of 20 days and her written narrative stating, “My husband wants to leave.” While the previous example highlights the absence of perceived caring by a spouse, the following example highlights a slightly different experience of a 29-year-old female. In response to the 12-month Demographic question asking if there had been a change in the participant’s relationship status, this participant wrote, “Yes; Divorce/breakup; Feb 9. I finalized my divorce. My ex never knew I had cancer.” While the aforementioned examples shed light on immediate interpersonal difficulties with spouses, one 70-year-old female described how she felt about her ex-husband in response to the PSCCAN statement: “I have had 2 years or more in my life when I felt depressed or sad most days even if I felt OK sometimes.” In her response, the participant wrote, “When I was married to my first husband....”

4.3.6. Social Support. Analysis of the participant’s narratives revealed that social support was a dominant theme across all three time points and responses increased dramatically
from Baseline to the 6-month follow-up and stayed consistent throughout the course of the study. The sub-themes that emerged for social support included: sources of social support, availability of social support, and feelings about social support, the timing of social support, social support needs and non-disclosure.

4.3.6.1. Sources of Social Support. At the onset of analysis, it became apparent that the participants in this study were generally well supported and received support and care from more than one source. In descending order, the most cited source of support came from medical professionals, friends, family, spouses, support groups and alternative medicine.

The experience by most participants was that the support and care they received from medical professionals was overwhelmingly positive as evidenced by the 15 narratives espousing gratitude for care received. Narratives espousing the care and support from medical professionals included, a response from a 79-year-old female who penned, “Home care workers, nurses, occupational therapists, and physiotherapists.” as well as, a 64-year-old female explained, “My care and treatment by the medical community, especially BCCA (except for the awful food at the Kamloops hospital) were truly exemplary.” Another 58-year-old female wrote, “My confidence in the expert and compassionate care I have received to date from the BCCA is a major factor affecting my ability to cope with my cancer diagnosis.”

Analysis of the data revealed that participants were also well supported by their friends. For example, one 86-year-old female described in a letter the frequency by which she was in touch with a close friend and penned, “I have been a widow for over 33 years. I have a friend, and we talk a lot for the past 15 years.” One 46-year-old male spoke to the support he received from his friend in filling out the Baseline questionnaire and scribed, “My friend helped me fill this out. (Until I felt better)” and another 67-year-old male shared his appreciation for his
friendship and wrote, “I am lucky to have my friend of decades, Dan Daniels (*), Medical Social worker (retired).” Another simply stated, “Friends are very supportive.”

Family and spouses were also a source of social support for participants as evidenced by 14 narratives. One 58-year-old female wrote that her, “Spouse, siblings and children are very supportive” while another participant, a 60-year-old female describes how her cancer diagnosis had changed her family relationships and shared, “…my family relations have improved somewhat because people are staying in close touch.” Likewise, one 70-year-old male responded to the IIRS question: “How much does your illness and/or treatment interfere with your family relations?” and simply wrote, “Closer.” For other participants, cancer resulted in positive changes with one’s spouse. In response to the IIRS question asking how much her illness had interfered with her relationship with her spouse, one 56-year-old female wrote, “Made things better; don’t know how to answer.” Two additional responses to the same question elicited this response from a 45-year-old female, “In a good way. My husband loves me much more than ever.” whilst another 58-year-old female stated that her “Spouse (male) is very worried.”

Four external sources of social support were also reported at the 12-month follow-up by four of this study’s participants. Each of these participants wrote their response to the Demographic question: “Who has supported you since your cancer diagnosis?” One 45-year-old participant twice mentioned she had reached out to what we can assume to be a cancer support group penciled, “Support group – local organized by hospital employee.” The second participant, aged 57 shared that she had been supported by “Additional non-profit organizations: Inspire Health and Friends for Life.” and a 61-year-old also disclosed that she had been, “…inspired by a health herbologist (Supported by Inspired Health Herbologist)”. Lastly, one 91-
year-old male responded to a PSSCAN question asking if he was able to count on anybody to help with daily tasks such as shopping, cooking and transportation for which he scribed, “Paid help.”

4.3.6.2. Longitudinal Analysis of Feelings About Care, Social Support & Disclosure.

During the course of the original study, many participants disclosed how they felt about the care and support he or she received from various sources over the 12-months. As evidenced by the narratives in the previous section on sources of social support, an overwhelming majority of this study’s participants had positive supportive experiences while, others participants revealed negative experiences. The narratives in this section offer yet another unique view of how cancer patients perceive and feel about the care and social support he or she received. Because few narratives explicitly state how participants felt, analysis required going beyond pure description and necessitated a certain amount of interpretation. Moreover, there were marked differences over the Baseline, 6-month and 12-month follow-ups in the frequency and content of the narratives.

The Baseline narratives on how participants felt about the care and support they received was diverse. Many participants shared that their experiences were positive and two females wrote, “It reinforced my conviction about how wonderful people are…” while another participant shared that she felt confident in the, “…expert and compassionate care I have received to date from the BCCA is a major factor affecting my ability to cope with my cancer diagnosis.”

Conversely, a 57-year-old male had a much different encounter and commented on the timing and availability of social support:

The support at the time of diagnosis needs to be improved. This is the most critical time,
and you are virtually left alone to wonder what happens after a doctor tells you that you have cancer. It is a very difficult time.

Still for others, social support was not wanted. For instance, one participant stated, “I am angry. I don’t want or need anybody—family, friends, church—I will deal with my own problems…” Correspondingly, another participant also shared:

At this point in time I am just having a hysterectomy (tomorrow) and no other treatment. I consider it a minor inconvenience and am not telling my friends as I would like to have a nice little holiday and not have to be answering phone calls all the time. I know I can always contact any of them should I feel the need.

The narratives at the 6-month follow-up also demonstrate the multiplicity of experiences of the participants. Once again, it is clear that some participants felt well supported, especially by medical professionals. One 77-year-old male wrote, “…I’ve developed a greater appreciation for the skill and compassion of our medical people, and I feel very fortunate to have had this help.” In a similar vein, a 96-year-old female simply jotted, “I can count on medical system.” Participants at the 6-month follow-up also made reference to the availability of social support. For some participants, his or her cancer diagnosis had a positive effect on spousal and family relationships. For instance, a 70-year-old male clearly stated that both spousal and family relationships had become, “Closer”, thus inferring social support was available to him. A similar inference can be made from a response of a 60-year-old female who explained, “…my family relations have improved somewhat because people are staying in close touch.”

Conversely, several participants shared that he or she was not receiving the social support desired. For example, in response to the PSSCAN question: “Can you count on anyone to provide you with emotional support?” a 59-year-old female scribed, “Sometimes.” A succinct
response to the PSSCAN question asking for how many days was her mood not good, a 55-year-old female penned, “Not husband” and, “Husband wants to leave.” One narrative written by a 69-year-old female emphasizes the need for compassionate care and the timing by which it is expressed by medical professionals:

I felt that there was a lack of compassion with the plastic surgeon. Maybe they have no choice but releasing the patient the day after surgery. From my experience (and I think I am emotionally strong) it was too soon to be released. I felt vulnerable and not cared for.

Participants also reported that social support was not always readily available to them. One 65-year-old female indicated that her husband worked abroad 6 months of the year and stated, “…during that time I live alone”, thereby implying that the support she may have received may be sporadic or at the very least, less personal. Two additional narratives also highlight how social relationships may become infrequent thereby possibly limiting the availability of social support. A 70-year-old male responded to the IIRS question: “How much does your illness and/or treatment interfere with other social relations?” and plainly stated, “Limited social interaction.” Correspondingly, a 66-year-old male described why his social interactions had changed and how he was able to adapt to those changes and wrote, “The big issue is that one must be isolated for so long while the immune system revives. So clearly you cannot engage as you did before…” Still, another narrative by an 81-year-old female speaks to both to the resilience of this participant and how prior life events may prevented her from seeking or accepting support:

I am 81. I have been on my own for 40 years with no child support. I have 3 girls. The middle girl is deaf and has many mental problems. I have learned to be independent. I
have also learned how little help and co-operation I have received when it came to receiving help for my middle child. This cancer is a bump on the road.

Feelings regarding social support at the 12-month follow-up continued to exemplify the range of experiences of the study’s participants. In addition to citing support from medical professionals, family and friends, participants also revealed immense gratitude they seemed to have received throughout the year. In addition, a 59-year-old male also divulged his thankfulness for specific informational support from medical professionals and penned:

I found it very helpful to know from my BCC doctor that can be a letdown following treatment. After being so busy with treatments and feeling so well cared for, I felt a little lonely and sad after everything ended. I’m dealing with that, but it was good to know that it can happen.

Interestingly, for one 65-year-old female, who had clearly indicated at Baseline, “…I don’t want or need anybody…I will deal with my own problems…” seemed to experience somewhat of a cognitive shift in at the 12-month follow-up. Despite her insistence at the beginning of 12-month follow-up that she, “…did not need support”, this participant also wrote later in the PTGI questionnaire, “Hospital doctors, techs and your team study thank you Andrea and Wolfgang your support replaced my faith. Without Gerard (*) I am lost.”

Furthermore, participants at the 12-month follow-up continued to comment on the availability of social support. For one 56-year-old female, having friends and family did not equal having support. Her response to a Demographic question asking who had supported her through her cancer diagnosis, this participant scried, “There weren’t any at the time I needed them.” Participants also continued to report the loss of family members and friends when asked if they had lost their life partner in the last few years. While there is no direct connection
between these narratives and social support, one can infer that the loss of these individuals also meant a loss of social support.

Another theme that emerged within social support at the 12-month follow-up was non-disclosure. One can assume that if an individual makes the decision not to disclose his or her illness, one cannot receive support. For instance, a 68-year-old male responded to the Demographic question: “Who has supported you since your cancer diagnosis?” and stated, “I did not tell anyone but my wife about my diagnosis. We never talk about it”, while another male (aged 33) noted in his RTW questionnaire that he had not disclosed his illness to his colleagues or supervisor.

Yet another theme to emerge within the social support milieu at the 12-month follow-up was that some participants seemed to identify their need for support and/or change. Responding to the RTW question: “Have you developed new interests or activities as a result of having gone through the cancer experience?” one 45-year-old female indicated that she had discovered her need for support and wrote, “Support group; more involved with church.” Likewise, two participants responded to the Demographic question: “In the last year, have you received the services from a psychiatrist, psychologist or counsellor outside of the BCCA?” one 65-year-old female jotted, “EFAP (Employee + Family Assistance Program) 2 weeks. Would like some CBT therapy”, while another 45-year-old female, stated, “No, but planning to within the next month.”

4.3.7. Diagnosis & Treatment. The participants in this study exhibited a vast range of reactions to his or her cancer diagnosis and treatment. While most times it is not clear if these reactions are tied to the type of cancer, stage or severity, the participant’s narratives offer a
unique and panoramic view of their experiences with a cancer diagnosis and differing modalities of cancer treatments.

As previously discussed, the original study did not ask participants what type of cancer they had been diagnosed with however; 11 participants (10 females, 1 male) of the 86 participants made some kind of disclosure in their written narratives. Two females (ages 58 and 64 years old) reported having a hysterectomy, indicating some kind of gynecological cancer. Two females (ages 51 and 70-years-old) shared that they had been diagnosed with breast cancer whilst a 55-year-old female reported that she had survived breast cancer in 1999. One 81-year-old female shared that she had her right kidney removed writing “…(it was cancerous)…” and the four remaining females and one male indicated that they had been diagnosed or previously diagnosed with some kind of “…low level skin cancer…” or melanoma.

Whilst both the 6-month and 12-month Demographic questionnaires asked participants to check which treatment type he or she had undergone, none of the unsolicited narratives emerged as a response to this question. Instead, the narratives on treatment type were offered to assist in describing various aspects of how these individuals were coping and/or adjusting to cancer. While some participants underwent a single treatment modality, others endured as many as four different treatment modalities. Of the 41 responses for treatment type, nine made reference to chemotherapy, radiation or a combination of the two. The remaining 32 responses indicated that 23 participants had surgery alone and nine had surgery in combination with and not limited to radiation, chemotherapy and/or medication. See Table 14 for a full breakdown of reported treatment modalities.

The participants of this study all had different experiences with respect to treatment planning, treatment timing and treatment availability. The two narratives with respect to
treatment planning both occurred at Baseline and shared a common theme of testing to plan treatment. One GC made by a 68-year-old male reported, “…The treatment for me begins in a week. To this point it has all been testing to plan treatment” and a 74-year-old male shared, “Please note I have just recently been diagnosed and there is more testing to undergo before deciding which treatment I will have. Responses may change after Tx is under way i.e. health status etc.”

For other participants, the timing of treatment elicited responses that shared a common theme of waiting. At Baseline, one 51-year-old female wrote, “…I am waiting for radiation treatment and results from a following mammography. I am very anxious for positive news of the latter. Waiting for treatment has been very hard.” This is similar to another Baseline response from a 65-year-old female who indicated she was waiting for stereotactic treatment. A more descriptive response of waiting comes from a Baseline response of a 61-year-old female who penned, “Note: a person’s time is on “hold” while being diagnosed, waiting for surgery and recovery followed by Tx i.e. medication/chemo. It’s difficult to make plans.”

While the above narratives were recorded at Baseline and share the immediacy of treatment, participants at the 6-month follow-up share a different experience. One 69-year-old female scribed, “…I’m grateful for the speed of getting the operation done” while another 51-year-old female shared that the time she would spend waiting was not discrete given she needed regular check-ups and wrote, “Every 3 months must visit my dermatologist for the next 2 years to check moles for melanoma.”

In terms of treatment availability, one participant’s narrative speaks volumes for those individuals who are not geographically situated close to a cancer treatment centre. This 45-year-
old female responded to a RTW question asking if she was able to continue working during active treatment and stated, “No, because it wasn’t available in my home town.”

Although participants revealed the effects of treatment were experienced at all three time points, Baseline had only two comments, the 12-month follow-up fell in the middle with six comments and the 6-month follow-up had the most with 10 comments. Given the different types of treatment this study’s participants underwent, it is not unexpected that analysis would expose an eclectic breadth of treatment effects. The narratives of the effects of treatment fell into three categories: 1) positive experiences; 2) temporary negative effects of treatment; and 3) lengthy and/or unspecified length of the negative effects of treatment.

The three narratives of the positive effects of treatment were diverse in content. An 86-year-old female scribed one GC on the 6-month PSSCAN, “I believe in Jesus and I have not had any problems, as He was with me during surgery. There was no pain or any other problems.” The two remaining narratives were written at the 12-month follow-up one of which was offered by a 69-year-old male who wrote, “Immediate improvement – dramatic” in response to a Demographic question asking if he had experienced a major change in health since beginning the study. The third comment was also in response to a 12-month Demographic question asking if the 45-year-old female had experienced a life change since beginning the study. Although her response appears contradictory, it speaks to how her cancer diagnosis may have been a blessing and penned, “No. Found a spot on liver and what turned out to be a cyst on pancreas. Cyst was drained after radiation. Has improved my health and wouldn’t have been found without CT scan result of cancer diagnosis.”

Other participants revealed that the effects of his or her treatment were temporary. One 57-year-old female stated at the 6-month follow-up that she became “…extremely depressed for
10 days around my chemo session on January 18”, while another participant (a 64-year-old female) shared at Baseline that her, “Surgical recovery was temporary.” Further, three additional participants also offered insight in response to PSSCAN questions asking about how poor health was affecting lifestyle and how many of the past of the past 30 days did the participant have physical health problems and responded, “Poor health was due to chemo reaction, health improved a week later” and “14 days, illness was due to minor radiation, burns and fatigue.”

Still, other participants were more descriptive in recounting the effects of their cancer treatment. One 50-year-old male described at the 6-month follow-up how the side effects of the drug, Sutent gave him, “gastric distress, some calluses on feet, hands and scrotum” whereas another male (49 years) reported, “Hearing loss from chemo.”, which in some cases can become permanent. Other participants shared that they suffered decreased appetite from post surgical drugs, disrupted sleep patterns and side effects from catheters.

4.4 Sex Differences

A review of the totality of the narratives provided by this study’s participants exposes several over arching differences between the sexes. First, an obvious distinction can be seen with respect to the number of males and females in the study. Specifically, there were 29 males and 57 females thus females out numbered males with a ratio of 1.97:1. Second, there was a marked difference in how males and females expressed themselves. For instance, males were far less inclined to express their feelings and more apt to focus on their physicality and provide information whereas females tended to focus on feelings and emotions and provide information. Third, in terms of how additional health issues interfered with one’s health more than cancer, males clearly reported respiratory illnesses such as asthma and COPD were more problematic
than their cancer. Fourth, none of the males in this study commented on how cancer affected their mood however, this was not the case for females.

The remainder of this section will discuss the similarities and differences between the sexes with respect to the six major themes identified.

4.4.1. **Coping & Adjustment to Cancer.** There were a number of commonalities between the sexes with respect to how males and females coped and adjusted to his or her cancer diagnosis. Both sexes described difficulties with the side effects of treatment and recovery and one male stated that, “Post treatment has been much harder than during treatment.” Both sexes also made comments with respect to other illnesses. While there was some similarity in terms of how other illnesses were interfering with participant’s lives more than cancer, this was especially so with the males of the study. Moreover, males were more apt to specifically describe the type of illnesses that included but not limited to COPD, heart issues, toxoplasmosis and severe breathing issues.

One of the largest barriers to coping and adjusting for the males of this study was expressed was by how their cancer diagnosis limited their lifestyle and/or physical abilities. By extension, we can infer that participant’s physical prowess was impeded and thus negatively impacted their usual active recreation such as ‘jogging’ or inability to ‘exercise’. Relatedly, several males seemed to engage in problem focused coping as they described how they made the necessary adjustments in their lives. One participant describes how he handles activities that were now more demanding and writes, “…I just don’t do demanding activities, so I have changed to not demanding” while another participant shares how he adapted to the loss of regular social interaction and jotted, “The big issue is that one must be isolated for so long while
the immune system revives. So clearly you cannot engage as you did before. My meetings are by Skype for me, as an example.”

For another participant, his coping and adjustment to his disease included a change in self-expression and penned, “I now express what I “really” think.” Another male participant, his way of coping and adjusting to his disease within the workplace was non-disclosure stating that neither his colleagues nor supervisor were aware of his disease.

Two participants also commented on their ‘spirituality’. Although both noted that they were not ‘religious’ or did not believe in ‘organized religion’, inference can be made that being connected to their spirituality may have facilitated an easier adjustment to their diseases.

For females, a theme that may have impacted their ability to cope and adjust to their cancer diagnoses was the continued impact of a death of close family member or friends. For one participant in particular, her Baseline and to a larger extent, her 12-month narratives speak volumes to the effect losing her brother had on her life and clearly stated, “…Without Gerard (*) I am lost.”

For some participants, denial was a way in which they coped with their disease. One participant stated that she, “…did not believe them…” when the doctors told her she had cancer, while another participant stated that while she didn’t think a lot about her disease, it was, “…hard to use denial…” given the stress experienced around medical appointments.

The females of this study also described how prior experiences with cancer (either a previous diagnosis or someone they knew had cancer) had caused them to make changes in their lives prior to their participation in the original study thus affecting their ability to cope and adjust to their disease. One participant noted, “I have been in a very good state of mind as my husband
went through cancer and a family friend’s child (3 ½) died of leukemia, so my priorities have been affected long ago.”

The theme of religious faith and/or spirituality was an important theme for several of the females in this study. For instance, participants made reference to being more involved with their church as a source of social support. For others, their narratives clearly express how their faith was an important factor in their ability to cope and adjust to their diseases. For example, participants explained how their faith, “…has been very helpful” and that a belief in Jesus was the reason for not having any problems, “…as He was with me during surgery. There was no pain or any other problems.” For another participant, she describes how her faith allows her to face the challenges of cancer and scried:

My faith is an important source and consolation. I feel it is presumptuous to pray to be cured and spared from having cancer, but I pray for the strength to deal with whatever comes my way, and this gives me comfort and confidence.

4.4.2. The Effects of Cancer. Overall, the multitude of the effects of cancer was more pronounced for females than males. There were however, some similarities between the sexes. For instance, with respect to references to time off work and/or medical leave for treatment, both sexes shared their experiences, though this was far more predominant in females than males. Conversely, although both sexes reported on physical changes and/or limitations that impeded his or her ability to engage in active recreation, the narratives revealed that this appeared to be more of an issue for males than females. Both sexes also made reference to how having cancer may affect finances but once again, this was more pronounced in the narratives written by females. Additional commonalities on the effects of cancer between the sexes were fears of how cancer may affect finances and how cancer caused both positive and negative changes in
lifestyle. Furthermore, both males and females commented how having cancer improved their relationships with their spouses and family however this was referenced more by females than males.

Aside from the shared effects of cancer with their female counterparts, there were no unique narratives that spoke to the effects cancer had on the male participants of this study.

As previously stated, the females in this study were keen to report on their experiences with respect to the effects of cancer. For some participants, having cancer resulted in changes in mood with specific references to depression and anger. In addition, females reported on feeling a loss of control while survival instincts seemed to kick in for others. Having cancer also caused the loss of interest or cessation of hobbies and activities for some participants while others reported that cancer caused them to develop new interests. Another major theme found within the narratives written by females was the difficulty in the unknown; namely waiting for results, treatment outcomes and fear of cancer recurrence. Additional themes that emerged were changes in diet and nutrition, the negative impact cancer had on spouses and children as well as changes in employment status and/or work schedules.

4.4.3. Employment & RTW. Analysis revealed that the participants who commented on Employment and RTW questions were primarily female. Common themes shared between the sexes with respect to Employment and RTW were comments on employment status, type of employment and taking time off work and/or medical leave for treatment although only one male commented on type of employment and taking time off and/or medical leave.

The male participants made few comments with respect to Employment and RTW. One participant responded to a RTW question: “If you were working at the time of your diagnosis, have you returned to work since?” and wrote, “I had to find a new job to return to” while another
explicitly stated he had been an, “educator” his entire life. Another participant also responded to whether his colleagues and supervisor were considerate of his disease for which he scribed, “They don’t know” and “Doesn’t know”, respectively.

The female participants offered numerous narratives that were distinct from those offered by the male participants. For example, females made reference to not being able to meet the demands of their employment. For instance, some participants cited “Shift” work had become more onerous or that they had retired due to fatigue. Additional comments focused on how much time was taken for time off and/or medical leave and several females made reference to RTW part-time or made specific reference to their work schedules. Several females also stated that although they had taken time off or were on medical leave during treatment, they continued to work part days. Females also mentioned that their employment status had changed due to an unrelated prior health issue and also expressed that medical appointments interfered with her work schedule.

4.4.4. Other Life Events. There were marked similarities between the sexes with respect to Other Life Events in the participant’s narratives. The largest issue for both sexes and for which received a relatively similar number of responses was the impact of additional illnesses. Male participants tended to report heart problems, severe breathing issues, toxoplasmosis, COPD, asthma and undisclosed health issues. On the other hand, additional illnesses for the female participants included kidney stones and/or parathyroid issues, water retention, osteoporosis, hemorrhages, chronic arthritis, undisclosed health issues, heart attacks and physical disabilities. Furthermore, both sexes also shared they suffered from mobility problems. While both sexes noted that they also suffered other short-term illnesses such as having a bad cold, the overwhelming majority came from the male participants and several were
related to physical injuries related to active recreation. Similarity between the sexes was also seen with respect to responses to the PSSCAN question: “Have you lost your life partner within the last few years?” Responses to this question included losing one’s brother, mother and best friend. Likewise, a few participants also shared that his or her cancer diagnosis was not their first cancer diagnosis. The only deviation between the sexes with respect to Other Life Events was seen in three female participants. One participant commented on how having exposure to cancer in others caused her to re-define her priorities, and the second recalled how she felt depressed and fearful in a previous marriage. For the third participant, a chain of events that occurred at the same time she was diagnosed resulted in additional non-medical related stress.

4.4.5. Social Support. With respect to social support, females overwhelming responded more than their male counterparts. Despite the difference in quantity of responses between the sexes, there was both some unity and differences in terms of social support sources and experiences. Both males and females remarked that they had received support from family and friends. Equally, both males and females scribed that they were well supported by their spouses; moreover, both sexes indicated that the experience of cancer had improved his or her relationship with their spouse. Contrariwise, one male and one female also shared that they experienced a lack of support from his or her spouse.

One male participant made reference to an additional source of support and jotted, ‘Paid help” in response to the PSSCAN question: “Can you count on anybody to help with daily tasks like grocery shopping, cooking, and giving you a ride?”

As indicated, females penned a majority of the narratives with respect to social support. Several females indicated that they experienced a lack of social support. One single mother alluded to a lifetime absence of support and another indicated there was a lack of compassion
and support from her plastic surgeon. Furthermore, females also made reference to a lack of social support from family and friends.

Alternatively, males and female participants also were generous with accolades espousing their gratitude for the support received although this was more prevalent in narratives penned by females. Participants also cited additional sources of support such as support groups, church groups and/or congregations, siblings and children. The lion's share of cited sources of support for female participants was the medical community; with specific references to nurses, doctors, technicians, physiotherapists, BCCA, and even the research team that conducted the original study.

4.4.6. Diagnosis & Treatment. Women wrote the bulk of the narratives offered by this study’s participants for Diagnosis and Treatment. Like the previous sections on Sex Differences, there were similarities and differences between the sexes. For example, both sexes wrote narratives that described his or her feelings at diagnosis although they differed in content and degree of description.

Similarities were also seen for both sexes as both males and females shared the type of treatment(s) he or she underwent although females responded 4:1 over males. Males and females also mentioned to having to take time off work and/or medical leave for treatment. Once again, this was more prominent in the female narratives and often included references to specific amounts of time off and working part-time during treatment. Furthermore, in terms of the side effects of treatment, males were just as likely to report the details as females. Both sexes also penned his or her experience with recovery but once again this was seen more in the female narratives. Interestingly, one of the more illustrative narratives was written by a male participant as he shared how he felt about recovery and wrote, “Post tx has been much harder than during
Females on the other hand, were more concerned about expressing how much time was needed to recover or that they were currently recovering. Another similarity between the sexes was comments made with respect to how his or her health had improved as a result of treatment.

Two males shared their experience, one of which is unique among all of the narratives written by males because of the transparency by which he communicated his feelings:

The support at the time of diagnosis needs to be improved. This is the most critical time, and you are virtually left alone to wonder what happens after a doctor tells you that you have cancer. It is a very difficult time.

In addition to those themes shared with their male counterparts, females in this study also made specific reference to the type of surgery received and the need for ongoing check-ups. Females were also more prone to comment on the uncertainty surrounding waiting for results and treatment planning. Lastly, two females also shared that they had experienced a recurrence of their cancers and one additional participant feared her cancer would return.

4.4.7. Questionnaires & Response Types. This section will describe 1) How the sexes were similar and different in terms of the responding to each questionnaire and most frequently responded to questions; 2) How the sexes were alike and unalike in regards to the three types of responding (e.g., Descriptive, Additive [GC], Clarifying) at specific time points; and 3) Similarities and differences between the sexes in terms of the content of the narratives. Analysis of both the questionnaires and the questions participants responded to indicate there were similarities and differences between the sexes.

4.4.7.1. PSSCAN. Overall, the PSSCAN garnered 52 responses from both males and females. Descriptive responses by gender reveal that males offered 13 responses and females offered 30. The most frequently responded to question for males was: “During the past 30 days,
for about how many days did poor physical or emotional health keep you from doing usual activities, such as self-care, work, or recreation?” Unanimously, the responses offered by males made reference to physical limitations. Likewise, this question was also the most responded to question by females however, responses by females included both emotional and physical difficulties. The number of Additive responses offered by males was two and females, eight. Further analysis of the content of both the Descriptive and Additive responses for both sexes will be discussed in an upcoming section.

4.4.7.2. **PTGI.** The PTGI received a total of 36 responses. Males wrote a total of two Descriptive responses and females wrote nine. The most frequently responded to statement(s) by males were: 1) I changed my priorities about what is important in life; and 2) I am more willing to express my emotions. For females, the most frequently responded to statement was: I learned a great deal about how wonderful people are. The number of Additive responses written by males was six, and 19 by females.

4.4.7.3. **IIRS.** The total responses penned for the IIRS was 60. Males penned a total of nine Descriptive responses while females penned 44. For males, Descriptive responses were equally distributed among nine questions. Conversely, females provided the most Descriptive responses (7) to the question: “How much does your illness and/or treatment interfere with your health?” Additive responses penned by both males and females were three and four, respectively.

4.4.7.4. **Demographics.** Across all three time points, the Demographic questionnaire(s) received a total of 32 responses. The total number of Descriptive responses scribed by males was four; all of which were equally distributed among four questions. Contrariwise, females penned a total of 25 Descriptive responses. The most routinely responded to question for
females was employment status. Additive responses by gender reveal that males were the only ones who scribed a response, totaling three.

4.4.7.5. **RTW & RTWA.** The RTW questionnaire received a total of 16 responses. Males composed two responses and females composed 14. Male participants responded to two questions: “Provided that you were working at the time of your cancer diagnosis, did you continue to work during active treatment?” and “If you were working at the time of your diagnosis, have you returned to work since?” For females, the most responded to question was: How many months did you take off from the diagnosis of cancer until you went back to work?” Neither males nor females composed any Additive comments.

The RTW A questionnaire collected a total of three responses. Males composed a total of two Descriptive comments while females composed one. Descriptive comments for males were in response to two statements namely: 1) “My job supervisor is considerate of my disease”; and 2) “My colleagues are considerate of my disease.” The singular comment offered by one female was in response to the statement: “The physical demands of work are now more of a burden than they used to be.” Like the RTW questionnaire, no Additive comments were made by either sex.

4.4.7.6. **Worries.** The Worries questionnaire received three responses, the least amount of responses of all of the questionnaires and was only responded to by females. The lone question that elicited a response was: “To what extent are you concerned about another type of cancer?”

4.4.7.7. **Letters and/or Hand Written Notes.** Three letters and/or hand written notes were received. One note was received from a 74-year-old female at Baseline and yielded only one narrative. Two letters were received at the 12-month follow-up, one from a 67-year-old
male that yielded three narratives and one from an 89-year-old female that yielded four narratives.

4.4.7.8. 3 Types of Responses by Age, Gender & Time Point. In terms of the 3 types of responses (Descriptive, Additive and Clarifying), the root content did not vary between the three types of responses or between genders. It is however, noteworthy that only three females made clarifying comments about specific questions. For example, one participant commented on the ambiguity of the PTGI and wrote, “Poorly designed statement/questions. E.g., Q#19 presumes positive answer or seems to when responses are considered. Q #20 presumes people are wonderful, and Q# 21 is ambiguous.” Another participant commented on the IIRS and penned, “In some cases the interference, which implies a negative, might be a positive. E.G., my family relations have improved somewhat because people are staying in close touch.”

A review of the data revealed that there were marked differences with respect to how the 29 males and 57 females chose to respond. For both males and females, the greatest amounts of generated narratives came from those participants between the ages of 51 – 75 and the least amount of responses were generated from those participants between the ages of 76 – 96. Table 15 provides a detailed review of the differences in responding by sex and age group.

It is also noteworthy to discuss which time points generated the most narratives given the original study was designed to track how newly diagnosed cancer patients were able to emotionally and psychologically adjustment across time. Of the three time points, males responded with equal vigor with 18 narratives at each of the 6-month and 12-month follow-ups and 15 at Baseline. For females, a slightly different pattern emerged; the highest number of responses (64) was seen at the 6-month follow-up, 53 at the 12-month follow-up and 45
responses at Baseline. Figure 16 provides an overview of the type of responses by gender and time point.

**4.4.7.9. Sex Differences: Response Styles.** Analysis of gender and the narratives as a whole reveals notable differences between males and females. One interesting observation was made with respect to how males and females responded. Overall, the major differences can be seen in the length of the written narratives, the amount of detail given and the degree of emotive content. Generally, the male narratives were shorter in length, more succinct and largely void of any emotive content. Conversely, the narratives written by females were often longer, provided more detail and expressed a higher degree of emotivity. In sum, males were more inclined to share information whereas females were more apt to share emotion.

The length of the written narratives varied both within and between the sexes although males commonly offered more succinct responses. For example, in response to the PSCCAN question: “How much does your illness and/or treatment interfere with your relationship with your spouse?” one male’s response yielded a succinct one word answer, “Closer.” yet the answer to the same question from a female yielded, “In a good way. My husband loves me much more than ever.” Notice that the female narrative was longer and provided more details, it also had overtones of emotivity. Another example of the difference of the length of response between the genders can be seen in response to the PSSCAN question: “During the past 30 days, for about how many days did poor physical or emotional health keep you from doing your usual activities such as self-care, work or recreation?” Similar to the first example, the male participant penned, “Achilles sprain.” versus a female response, “0 days, but I cannot ride a bike or garden due to pain – this is an everyday problem.”

Examination of the narratives also revealed that the opposite was true, namely, males
sometimes offered longer responses and females also gave shorter responses. For instance, a GC written by a male on the PTGI illustrates:

The support at the time of diagnosis needs to be improved. This is the most critical time, and you are virtually left alone to wonder what happens after a doctor tells you that you have cancer. It is a very difficult time.

Contra wise, female participants also wrote short and sometimes ‘stinging’ narratives. In response to the PSSCAN question: “Can you count on anyone to provide you with emotional support?” one female wrote, “Not husband.”

There were also distinct differences between the sexes in the amount of detail given in the written narratives. An excellent example can be seen in how males and females discuss religion and/or spirituality. One male discusses his spirituality and penned, “Do not believe in organized religion but consider myself to be very spiritual.” whereas a narrative written by a female offers manifestly more detail about her faith and/or religious beliefs and scribed:

My faith is an important source and consolation. I feel it is presumptuous to pray to be cured and spared from having cancer, but I pray for the strength to deal with whatever comes my way, and this gives me comfort and confidence.

A further example of can be seen in how males and females discussed his or her experience of changing priorities. One man wrote, “I haven’t had enough time yet since diagnosis”, which is succinct but does not offer any further explanation. On the other hand, one female discusses how her prior exposure to cancer in others caused changes prior to her own cancer diagnosis and writes, “I have been in a very good state of mind as my husband went through cancer and a family friend’s child (3 ½) died of leukemia, so my priorities have ben affected long ago.”

As previously mentioned, males sometimes wrote narratives with distinctly more detail
than their female counterparts. When discussing how additional illnesses were more challenging than one’s cancer diagnosis, males were generally more descriptive and shared, “Asthma, rather than cancer, interferes more with my life.” and, “My responses are greatly skewed by the fact that I suffer very debilitating COPD” and, “I am on oxygen 24x7, I have severe breathing problems. I go 20 ft, I’m out of energy.” Similarly, a look at how the sexes differed in discussing the side effects of treatment provides a graphic example. Although both narratives are similar in length, the narrative written by a male is far more descriptive and shared, “Side effects of the Sutent (a drug): gastric distress, some calluses on feet, hands and scrotum” whereas a female narrative was less graphic, “14 days, illness was due to minor radiation, burns and fatigue.”

Overall, there were clear differences between the sexes in the amount and degree of emotivity. Male participants were more inclined to report on facts and information versus expressing how they feel whereas females were often inclined to offer both emotive responses and information. For instance, in describing a loss of a loved one, a male participant stated, “Lost mother May 2008 after 2 months in home-palliative care.” whereas one female participant wrote, “Without Gerard (*), I am lost.” A further example can be seen in how males and females described non-disclosure. One male explained, “I did not tell anyone but my wife about my cancer diagnosis. We never talk about it.” Conversely, one female writes, “I am angry. I don’t want or need anybody – family, friends, church – I will deal with my own problems. I am trying to do the right thing…”

Despite the fact that most narratives written by males were not emotive in nature, there were some exceptions. For instance, one male was very clear about how he felt about his challenges with mobility and penned, “Pissed off that I can only walk four blocks” which is
patently more emotive than a response about mobility offered by a female participant who jotted,
“"I have a mobility problem unrelated to cancer.""
Chapter 5: Discussion

The purpose of this study was to investigate how the unsolicited narratives of 86 cancer patients can contribute to the broader context of the theory-laden categories of health and counselling research. To accomplish this, two lines of investigation were pursued, namely: 1) The ambiguity of test items and 2) How standardized measures do not fully capture personal experience. To answer these questions, I posed five research questions: 1) Which questionnaires/questions garnered the most responses and how did participants respond?; 2) What are the participant characteristics of those who provided unsolicited narratives?; 3) What are the major themes that emerge from the data?; 4) Do sex differences exist in within the major themes and how males and females respond?; and 5) Did the participants demonstrate psychological adjustment or psychological improvement over time?

In answering these research questions, I sought to understand the experiences of the study participants as accurately as possible. To accomplish this, I stayed as close to the data as possible given the data was archival in nature and was unable to confirm or dispel hidden meanings and inferences or ask for clarification. For this reason, I purposely chose QD and avoided marking inferences when possible. When and if inferences were made, I often relied on using triangulation with the original quantitative data and sometimes reviewed the original questionnaires to reduce the possibility that my inferences were incorrect.

Reflecting on my own experiences as the primary recruiter for the original study and my position as a Research Coordinator, it was a privilege to be allowed into the participant’s lives. I was able to speak to almost all participants at least once during recruitment and often during the course of the study. During this time, my discussions with participants included conversations about treatment, social support, death, and even motorcycles. Moreover, I also spoke to the
family members of participants when they called to inform that their loved one had lost his or her battle with cancer. For these reasons, I feel particularly maternal with respect to honoring the time and energy it took for the participants of this study to offer more about themselves than was originally asked. My findings therefore are as concrete as possible, and I believe did answer the research questions.

5.1 Which Questionnaires & Questions Garnered the Most Responses & How did Participants Respond?

Analysis of the narratives revealed that the participants of this study responded in a multitude of ways. Participants shared their thoughts and feelings about his or her disease and his or her life using a single word, a short phrase, full sentences, to lengthy paragraphs and handwritten notes and letters. In some instances, the participants revealed that the questions were ambiguous or participants answered questions in the opposite direction of the question being asked or in some cases, offered responses that were in conflict with the Likert response format on the questionnaire. It is difficult to determine why many of the participant’s narratives did not follow the expected response format on measures that had been validated for use with cancer patients. One might expect that for some participants, literacy may have been an issue. After extensive examination of the narratives and reviewing the education and household income levels of this study’s participants, this author argues the majority of the participants were well educated and thus, this was not the case. It is possible however, that some participants may have misinterpreted the question being asked. While it is impossible to know this for certain, analysis of the narratives by a second data coder and myself conclude that for most participants, it seems that he or she had full knowledge that his or her responses were in contrast to the expected response. It appears that for many participants, the questions that they were being asked did not
correspond with the story he or she wanted to tell. This conclusion is supported by Malinksi and Litwin (2007) who emphasize that unsolicited narratives allow the ‘narrator’ (e.g., the participants) to determine, “…the content of his or her story, and not the researcher” (p. 274).

In the original quantitative study, a total of six questionnaires were included in the participant’s questionnaire packages. The Baseline package consisted of the Demographic questionnaire, the PTGI and the IIRS. Similarly, the 6-month questionnaire packages included the Baseline questionnaires and also included the PSSCAN. At the 12-month follow-up, two additional measures were added: the RTW and Worries questionnaire. The narratives offered by participants were broken down into 3 types of responses: 1) Additive, the narrative was not attached to a specific question and was coded as a ‘GC’; 2) Descriptive; the narrative was clearly attached to a specific question; and 3) Clarifying; the narrative clearly responded to a particular aspect of the questionnaire itself.

5.1.1. PSSCAN. In the original study, the PSSCAN was not included in the Baseline questionnaire packages because the PSSCAN is used as a psycho-screening tool when cancer patients arrive for his or her first appointment at the BCCA. For this reason, there were no written narratives for the PSSCAN at Baseline. The total number of questions that participants responded to in the PSSCAN was 15 and was the questionnaire that provoked the most activity among the study’s participants. The most frequently responded to question received 13 Descriptive responses and asked, “During the past 30 days, for how many days did poor physical or emotional health keep you from doing your usual activities, such as self care, work or recreation?” Participants responded to the above question the most at the 6-month follow-up with a total of eight responses.
5.1.2. **PTGI.** The PTGI received responses to nine questions. The most commonly responded to question was, “I learned a great deal about how wonderful people are”. This question received three Descriptive responses, two at Baseline and one at the 6-month follow-up.

5.1.3. **IIRS.** The IIRS garnered responses to 13 questions. The most popular question for which participants provided responses was, “How much does illness and/or treatment interfere with your health?” with a total of seven Descriptive responses. Participants responded to this question the most at Baseline with five comments and one comment at both the 6-month and 12-month follow-ups.

5.1.4. **Demographics.** The Demographic questionnaire morphed over the three time points and received responses to 10 questions. Two questions tied for receiving the most responses with a total of eight Descriptive responses each. Across Baseline and the 6-month and 12-month follow-ups, Employment Status received the most responses and all were Descriptive in nature. The second most responded to question was added at the 12-month follow-up and asked, “Who has supported you since your cancer diagnosis?”

5.1.5. **RTW & RTW A.** The RTW questionnaires were added at the 12-month follow-up and received responses to 12 questions. The most frequently responded to question in the RTW questionnaire was, “How man months did you take off from the diagnosis of cancer until you went back to work?” and received a total of six Descriptive responses. The RTW A questionnaire had three questions that received a total of one Descriptive response each.

5.1.6. **Worries.** The Worries questionnaire received the least amount of responses with only one Descriptive response to the question; “To what extend are you concerned about my cancer coming back?” in which the participant crossed out the word ‘cancer’ and added ‘hemorrhage’. It is unclear why this questionnaire received such little attention compared to the
other questionnaires. One possible explanation could be its placement near the end of the questionnaire package. For this reason, it is possible that participants had already told his or her story by the time he or she got to it. Another possible explanation could be that the formatting of the questionnaire itself did not leave enough room for a written response.

5.1.7. Longitudinal Summary of Questionnaire Responses. The frequency of responses for each questionnaire across the course of the study revealed that each of the questionnaires resonated with the study’s participants at different time points. The following longitudinal analysis will address the variability in when participants chose to respond and the content of the participant’s narratives across the course of the original study.

5.1.7.1. Baseline. The questionnaire to elicit the most responses at Baseline was the IIRS, capturing 36 narratives. This finding is unsurprising given participants had just been recently diagnosed, had their first appointment with BCCA and presumably would have included testing and the planning and/or beginning of treatment which interfered with physical functioning for many participants. Although we do not know exactly what treatments these participants were undergoing, this finding is consistent with Schroevers, Helegson, Sanderman, and Ranchor (2010) who report that treatment can be associated with severe physical side effects which in turn, is consistent with the literature on illness intrusiveness (Devins, 2010; Devins et al., 2006; Devins, 1994).

The PTGI received 18 responses, which indicates that participants may have been engaging in intrusive rumination immediate after diagnosis which is found to be associated with PTG (Taku, Cann, Tedeschi, & Calhoun, 2009).

Lastly, the Demographic questionnaire received seven responses regarding various aspects of the participant’s lives including additional health concerns that resulted in medical
leave from work prior to his or her current diagnosis, a second cancer diagnosis, caregiving, social support and spirituality. Interestingly, the tone of the narratives that discussed his or her cancers were more informative and lacked the emotive content that was seen at the 6-month and 12-month follow-ups. This may be in part due to having previously survived cancer in the past. This inference is supported by a meta-analysis on the psychological sequelae of a cancer diagnosis authored by Van’t Spiker, Trijsburg, and Duivenvoorden (1997) who state that anxiety levels in cancer patients tend to decrease over time. For the rest of the participants who provided narratives, they may have unconsciously viewed their participation as an opportunity to self-disclose his or her disease, a by-product of PTG (Tedeschi & Calhoun, 1996) and being able to do so without having to be concerned about the reactions of others (Carlick & Biley, 2004; Lepore et al., 2004), especially if he or she was still in the process of understanding his or her own feelings about their diagnosis.

5.1.7.2. 6-month Follow-up. The inclusion of the PSSCAN at the 6-month follow-up resulted in 32 responses, the most of all of the questionnaires. This finding is consistent with the fact that the PSSCAN is a measure developed to measure psychological distress and assesses anxiety, depression, perceived social support, desired social support and health-related quality of life (Linden, Yi, Barroetavena, MacKenzie, & Doll, 2005). The robustness of responses are supported by various lines of investigation. For example, Linden et al., (2012) argue, that age, gender, cancer type and severity affect how one adapts to his or her disease. One narrative by an 86-year-old female illustrates, “I believe in Jesus and I have not had any other problems, as He was with me during surgery. There was no pain or any other problems.” and is supported by research on age and gender which states that older cancer patients adjust better to cancer than younger patients (Harrison & McGuire, 1995; Schroevers, Ranchor & Sanderman, 2004).
Additional investigations also present evidence of the importance of social support (Goldberg & Cullen, 1985) and the salience of perceived social support (Meyerowitz et al., 2008) which can be seen in one female’s narratives when she states that she cannot depend on her husband for emotional support or help with daily tasks. Participants also had diverse reactions to how his or her quality of life was affected by cancer or cancer treatment. For instance, one participant shared that cancer impacted her lifestyle, “Most days…” yet another participant who died shortly before his 12-month follow-up explained that his health was not affecting his daily living because, “…I just don’t do demanding activities, so I have changed to not demanding.” These narratives add support to the diversity of reactions to changes in quality of life as a result of cancer treatment (Meyerowitz et al., 2008).

The responses for the IIRS declined from 36 responses at Baseline to 21 at the 6-month follow-up. While the narratives provide evidence that the participant’s disease and treatment continued to interfere with his or her life and is supported by the illness intrusiveness literature (Devins, 2010; Devins et al., 2006), for others, there may have been a decrease in the illness’ intrusiveness due to non-life threatening cancers, the cessation of treatment, or temporary recovery from surgery. These conclusions are congruous with Mah, Bezjak, and Loblaw (2011), who reason that some cancer types evoke more illness intrusiveness than others post treatment. Additional support for this finding can also be found in literature that suggests that there is substantial variability in terms of how individuals adjust to cancer (Meyerowitz et al., 2008; Rodrigue et al., 1994; Stanton et al., 2005).

The PTGI increased from 18 responses at Baseline to 19. This finding is consistent with the PTG literature by Tedeschi and Calhoun (2004) who suggest that PTG is both a process and an outcome. As such, participants may have been engaging in various aspects of PTG such as
discovering new possibilities, relating to others in a different way, recognizing personal strengths and finding a new appreciation for life.

The Demographic questionnaire increased from seven responses at Baseline to 10 responses at the 6-month follow-up. This increase was in part due to the inclusion of two questions, one asking if the participant was a caregiver of someone with health problems and the what type of treatment participants were undergoing. For those females who reported being caregivers, this may have been an additional source of stress while they worked on their adjusting to their disease. Support for this inference can be found in three lines of investigation. First, It has been reported that, that women’s lives are more stressful than men’s lives (Matud, 2004). Second, Lee (1999) maintains that most caregivers are primarily female. Third, past research argues that, “…approximately 50% of the emotional distress of cancer patients can be accounted for by nonmedical issues” (Weisman & Warden, 1972-1976; as reported in Goldberg & Cullen, 1985, p. 805). Taken together, the evidence suggests that the females who were caregivers in this study may have experienced additional stress in conjunction with the stress of trying to cope with their own diseases.

5.1.7.3. 12-month Follow-up. The questionnaire that reverberated the most with participants at the 12-month follow-up was the PSSCAN, which received 21 responses. The questions that continued to provoke participants to offer written narratives were questions relating to losing a life partner, impaired physical health, impaired mood and disruptions in daily activities or recreation. Support for these findings include the importance of social support (Corney, Everett, & Howells, 1992; Goldberg & Cullen, 1985; Slevin et al., 1996), the lasting effects of treatment (Griffin et al., 1996; Mah et al., 2011; Schroevers et al., 2010), the variability in how individuals cope and adjust to cancer (Meyerowitz et al., 2008; Rodrigue et al., 1994;
Stanton et al., 2005) and the effect cancer has on one’s physicality (Welch-McCaffrey, Hoffman, Leigh, Loescher, & Meyskens, 1989) and by extension, illness intrusiveness (Devins, 2010; Devins et al., 2006; Devins, 1994). Interestingly, participants were more apt to report how his or her disease was interfering with their life on the PSSCAN than the IIRS. This could be in part due to the order in which the questionnaires were presented; in this case, the PSSCAN was presented before the IIRS.

The RTW and RTW A received 19 responses, the second highest number. The inclusion of the RTW questionnaires at the 12-month follow-up was a stroke of insight for the primary investigators. The participant’s narratives revealed that RTW issues were a concern for many of the study’s participants and therefore are in accordant with the literature on cancer and RTW which indicates that RTW is affected by work related factors, disease and treatment factors and person-related factors. Moreover, whether cancer patients are able to successfully RTW depends on having a controllable workload, flexible hours and positive social support from co-workers (Main et al., 2005; Pryce et al., 2007; Spelten et al., 2002).

The Demographic questionnaire received 14 responses, the highest number for this questionnaire across all three time points. Like the 6-month Demographic questionnaire, the 12-month version added additional questions asking if: 1) Participants had experienced a major change in their health since beginning the study; 2) If participants had experienced a relationship change since they began the study; 3) Whether participants had received services from BCCA Patient and Family Counselling; 4) Whether or not participants had received mental health services outside BCCA; and 5) Who had supported participants since his or her cancer diagnosis, almost all of which have been cited as important predictors in psychosocial and emotional adjustment to cancer (Corney et al., 1992; Goldberg & Cullen, 1985; Meyerowitz et al., 2008)
Slevin et al., 1996). Interpreting this result demands a certain amount of speculation. Out of the additional questions added, the one that provoked the most responses was who had supported the participants since his or her diagnosis. Since social support has been cited as a major factor in one’s ability to cope and adjust to cancer (Bloom, 1982; Cohen, 1988; Roberts et al., 1994) and post-treatment has been identified as a time that provokes anxiety and uncertainty (Mayfield, 1999), perhaps the 12-month follow-up represented a critical time whereby some participants became more aware of their social support networks given the cessation of treatment meant the loss of an important source of support, namely, his or her doctor(s). Because doctors have been cited as the most important source of social support for cancer patients (Akechi et al., 1998; Rose, 1990; Slevin et al., 1996) some participants may have been ‘mourning’ the loss of this support and thus became more aware of the diversity or lack of his or her support systems and perhaps the importance of more ‘stable’ and ‘available’ sources of social support.

The IIRS continued to show a marked decline and garnered only five responses at the 12-month follow-up. These findings somewhat contrary to the findings by Mah et al., (2011) who suggest that many post-treatment cancer survivors continue to experience long-term illness interference. While it is not possible to answer the question ‘why’ with any certainty, one could postulate this may have been in part due to the severity of one’s cancer, the variability in how one adapts to cancer (Meyerowitz et al., 2008; Rodrigue et al., 1994; Stanton et al., 2005), the cessation of treatment or perhaps, participants were beginning to re-focus his or her attention from their disease to regaining his or her pre-cancer lives such as RTW (Spelten et al., 2002). Additionally, as previously discussed, the decline in IIRS narratives could be due to the order in which the questionnaires were presented given that the PSSCAN garnered more illness related narratives than the IIRS. For those participants who indicated their illness was still affecting his
or her life, this could be in part due to research that concludes that some cancer types evoke more illness intrusiveness than others post treatment (Mah, Bezjak & Loblaw, 2011).

Like the IIRS, the PTGI also declined at the 12-month follow-up and received only one response. Once again, it is impossible to ascertain ‘why’ this occurred however a study on PTG following a cancer diagnosis by Carboon, Andeson, Pollard, Szer, and Seymour (2005) may provide some insight. The authors suggest that PTG may be related to disease severity. For instance, when an individual is focused on treatment and recovery, he or she may not be able to reflect on the big picture, and thus PTG may only occur when the treatment regime is complete and the immediate danger has dissipated. Furthermore, Linley and Joseph (2004) suggest that ‘adversarial growth’, the positive growth following trauma is temporal in nature and suggests that with the passage of time, comes more adversarial growth. As such, it is possible that the original study’s length did not provide enough time to truly assess PTG, a similar conclusion also reached by Carboon, Andeson, Pollard, Szer, and Seymour (2005). In that investigation, the authors conducted a study on PTG using the PTGI on 62 newly diagnosed cancer patients 36.8 days post-diagnosis and 183.7 days post treatment. The authors concluded that the limited time range might not have been sufficient to provide enough variance to observe temporal observations. Furthermore, the authors admit that although the study was longitudinal, their findings may be context dependent on the type of event and temporal proximity to assessment. Another explanation can be found in an investigation that assessed PTG and group interventions for individuals with cancer. In that study, Lechner and Antoni (2004) state that time since diagnosis was not associated with PTG and thus supports the idea that PTG is not necessarily a linear and accumulative process and may be subject to individual differences in how one changes over time (Frazier, Conlon, & Glaser, 2001).
Lastly, the Worries questionnaire received only three responses. Once again, this finding is difficult to interpret. One explanation could be that for those participants who provided narratives, his or her concern may have shifted from their disease as many of the narratives focused on the intrusiveness of other illnesses and injuries as well as issues concerning RTW. Another explanation could be that the participants had begun the transition from diagnosis and treatment to that of survivorship, a phase that is reportedly understudied (Stanton et al., 2005). Furthermore, it is also possible that the formatting and layout of this questionnaire may not have allowed sufficient space for written narratives.

5.2 Participant Characteristics

As previously discussed, the data for the participant characteristics were taken from the quantitative data received in the Demographic sections of the questionnaire packages at all three time points. In the current study, there were 86 participants, 57 females and 29 males. The age range for participants was 29 – 96 years of age and the participants within the 51-75 year age range provided the most narratives. The education obtained by this study’s participants also varied greatly. The least amount of education reported by one female with less than a grade 6 education and 31.40% of participants completed and/or graduated from a graduate or professional program. The household income for the study’s participants also varied. Eight participants had the smallest household income of less than $20,000 and the highest household income of $100,000 or more was reported by 28.40% of this study’s participants. The ethnicity of the participants was overwhelmingly Caucasian (89.41%), which is consistent with research on race, sex and age disparities in participation in cancer clinical trials (Murthy, Krumholz, & Gross, 2004) and almost half of the participants identified with an organized religion. In terms of marital status, 12 participants were single, 52 married or common-law, 13 were separated or
divorced and nine were widowed. Six females also reported that they were or had been in the past caregivers for adult children and aging parents and family close members and is consistent with evidence provided by Lee (1999) who reports that caregivers are primarily female. The overall health of participants was of interest. Thirty-four participants reported that they had suffered from a serious medical condition in the past while 71 participants reported the current cancer diagnosis was their first and for two participants, the current cancer was a recurrence of the same type of cancer and 10 participants reported that their cancer diagnosis was a second and different type of cancer.

5.3 What type(s) of information were participants trying to convey in their written narratives?

The overarching conclusion of the information participants were trying to convey in his or her unsolicited narratives was similar to similar the few qualitative studies I was able to find on unsolicited narratives (Clayton et al., 1999; Malinski & Litwin, 2007; Warms et al., 2005) in health research. Namely, the participants were yearning to engage in discourse with the research team. While seeing written comments in the margins of quantitative questionnaire packages is certainly not a new phenomenon, recognizing its usefulness the unsolicited narratives as a source of additional information is relatively new (Malinski & Litwin, 2007). With a diagnosis of cancer, the participants in this study involuntarily became authorities on living with cancer. Interestingly, as authorities in living with a new cancer diagnosis, it was clear that participants were eager to share their personal experiences. This finding is supported by research that suggests that when individuals are confronted by traumatic events (e.g., cancer diagnosis), there is an increased need to discuss the fallout of those events, which in turn, may lead to increased self-disclosure (Tedeschi & Calhoun, 2004). The narratives provided a platform by which they
were able to express themselves without perceived social barriers (Manne, 1998; Manne et al., 1999). This finding is clearly in line with Carlick and Biley, (2004) and Lepore et al., (2004) who suggest that some individuals may chose not to disclose their illness or feelings about his or her illness out of fear about how it may affect others.

As a whole, the unsolicited narratives of this study, irrespective of the participant’s motivation, allowed the participants to detail and record how cancer was affecting his or her lives. Moreover, the narratives also provide evidence that this was a mode by which they were able to document how cancer was affecting his or her life, which is homogenous with Hyden (1997) who maintains that narratives are a formidable mode of being able to express one’s illness and suffering.

The specific type of information that was offered in the narratives was diverse. Some participants made reference to how the question or questionnaire did not define or capture his or her experience or made no sense at all. For others, the narratives offered the participants the opportunity to add further description to a question as seen in the Descriptive responses as well as the opportunity to add GCs (Additive) when the questionnaire or specific question triggered a reaction which prompted them to offer a written narrative. Specific types of information included the participants thoughts and feelings on treatment types and related illnesses, interpersonal relationships and social support, describing the impact of additional non-cancer illnesses, loss and grief, employment, faith and/or spirituality, other life events, caregiving, finances, additional cancer diagnoses, how cancer was affecting his or her life, disclosure, daily activities, utilizing complimentary health medicine, cancer recurrence, fatigue, sexuality, living with uncertainty, sleep disturbances, memory loss, returning to work, and connectedness to the medical system. Participants also included specific dates that indicated when they were
diagnosed, when they were expected to begin treatment or scheduled for surgery as well as dates for other life events. Although it is focal to consider that the original study was social constructionist in nature, namely, the participants were responding to questions and statements provided by the research team, the types of information discussed by the participants in this study is consistent with findings from previous studies that examined the psychological adjustment to cancer (Grassi, Rosti, Lasalvia, & Marangolo, 1993; Harrison & Maguire, 1995; Linden et al., 2012; Mosher & Danoff-Burg, 2005; Thune-Boyle et al., 2006; Van’t Spiker et al., 1997; Watson, Greer, Pruyn, & Van Den Borne, 1990), cancer patient concerns (Ness et al., 2013) and illness intrusiveness (Devins, 2010; Devins et al., 2006).

5.4 What are the major themes that emerge from the data?

Analysis of the 213 unsolicited narratives were coded and then grouped into over-arching themes. In deciding order of popularity, the six major sub-themes that emerged from the data were: 1) Coping and Adjustment; 2) Diagnosis and Treatment; 3) Employment and RTW; 4) Social Support; 5) The Effects of Cancer; and 6) Other Life Events.

5.4.1. Coping and Adjustment. Coping and Adjustment was by far the theme that resonated with the participants the most. The narratives reveal that how participants were able to cope and adjust to his or her cancer diagnosis lays on a continuum. Specifically, some participants indicated they were struggling with coping and adjusting whilst others reported limited difficulty or, no problems at all. Once again, this finding is supported by the variability by which individuals cope with cancer (Meyerowitz et al., 2008; Rodrigue et al., 1994; Stanton et al., 2005). Furthermore, the participants also revealed that their cancer diagnosis was not his or her only stressor and is supported by literature that suggests that roughly 50% of a cancer
patient’s emotional turmoil can be attributed to issues unrelated to cancer (Weisman & Warden, 1972-1976; as reported by Goldberg & Cullen, 1985).

Consistent with Goldberg and Cullen (1985), many of the participants had difficulty coping and adjusting to his or her diagnosis. For instance one participant used sarcasm to describe how she felt which may indicate she was struggling to accept her diagnosis. The literature on the use of sarcasm and cancer is limited however several studies report participants using sarcasm in participant interviews (Jenkins, 2006; Jonsson, Aus, & Bertero, 2009; Step, Rose, Albert, Cheruvu, & Siminoff, 2009), which could suggest a sophisticated expression of anger (Kahn, 1989; as cited in Swaminath, 2006). Participants also commented on being anxious while waiting for diagnosis and treatment and is consistent with literature provided by Welch-McCaffrey, Hoffman, Leigh, Loescher, and Meyskens (1989).

Participants also revealed how his or her diagnosis resulted in various kinds of negative psychological reactions such as anger, depression, anxiety and hopelessness. These findings are consistent with several lines of investigation. For instance, a review paper on psychosocial adjustment to cancer by Goldberg and Cullen (1985) suggests that anger, anxiety and depression are important factors in how one adjusts to cancer while other lines of investigation provide evidence of the prevalence of anxiety and depression in diverse populations of cancer patients (Hann et al., 2002; Helgeson and Cohen, 1996; Linden et al., 2012; Massie, 2004; Van’t Spiker, Trijsburg, & Duivenvoorden, 1997). Additionally, participants also reported feeling helpless or a loss of control. These discoveries are consistent with like findings from previous investigations on the psychosocial variables such as age, type of coping strategy, depression and anxiety, which have been shown to be associated with mental adjustment to cancer (Grassi, Rosti, Lasalvia, &
Some participants also made reference to feelings of isolation and feeling alone, which is supported by research on cancer and social connections (Reynolds & Kaplan, 1990), psychosocial problems and cancer (Baker, Denniston, Smith, & West, 2005) and quality of life studies on patients with head and neck cancer (Jones, Lund, Howard, Greenberg, & McCarthy, 1992). Participants also commented on the lack of social support from friends, family and medical professionals, whom we can assume based on the literature, negatively affected how these participants were able to cope and adjust to his or her disease. These are important findings and further support literature that speaks to the importance of social support from doctors, family and friends (Akechi et al., 1998; Corney, Everett, & Howells, 1992; Slevin et al., 1996) as well as life partners (Manne, 1998; Meyerowitz et al., 2008) in one’s ability to cope with a cancer diagnosis. Relatedly, participants also revealed patterns of non-disclosure in his or her personal and professional lives. While we cannot ascertain why participants chose not to disclose his or her disease, research on non-disclosure suggests it is often impacted by the receipt of negative social support (Manne et al., 1999) and may depend on one’s social context (Lepore et al., 2004). Non-disclosure has also been cited as an important factor pertaining to cancer survivors’ RTW. Pryce et al., (2007) present evidence that disclosure is necessary for workplace adjustments when cancer survivors decided to RTW and further insist that non-supportive work environments are negatively associated with a successful RTW.

On the other hand, some participants described different experiences; ones that indicate he or she were coping and adjusting well to his or her cancer diagnosis. This finding is supported by several research studies in which the researchers conclude that not all cancer
patients experience a maladaptive reaction to his or her cancer diagnosis (Meyerowitz et al., 2008; Rodrigue et al., 1994; Stanton et al., 2005). For instance, some participant’s narratives were upbeat and cited that cancer was a minor inconvenience, or that they experienced no life disruptions or had a low-level cancer severity or were no longer affecting them anymore. While is impossible to know the severity of some of these patients’ illnesses, inference can be made that his or her cancer was non-life threatening. As such, these findings are supported by a study on the multidimensional determinants of cancer adjustment by Rodrigue et al., (1994) who explain that when illness is perceived as less serious, the lower patients perceive global distress and anxiety. Moreover, although some participants may have developed some initial anxiety at diagnosis, a meta-analysis on the psychological sequelae by Van’t Spiker et al., (1997) reports that anxiety decreases over time.

It is also possible that for some participants, his or her successful coping and adjustment may have been facilitated by his or her faith and/or spirituality given 40 of this study’s participants identified with a major religion. The literature suggests that religion and spirituality are commonly relied upon as a coping strategy in elderly medically patients (Koenig et al., 1995; Koenig et al., 1992) and cancer patients (Folkman, 1997). Moreover, religious coping is thought to improve one’s emotional health thus allowing patients to positively cope with stress associated with the onset of illness (Easton & Andrews, 2000). Moreover, a study examining spirituality, demographic, disease factors and adjustment to cancer reveals that greater levels of spirituality are associated with higher levels of psychological adjustment (Schnoll et al., 2000).

Several participants also displayed positive attitudes towards his or her disease while others expressed acceptance. These findings are consistent with the notion of having a fighting spirit, such as having a positive attitude towards one’s illness, being able to perceive illness as a
challenge, and accepting responsibility for one’s own recovery (Akechi et al., 1998; Grassi et al., 1993). Participants also made numerous references to being well supported by family, friends, spouses and medical professionals, which is consistent with the literature, that having a good social support network is associated with successful coping and adjustment (Akechi et al., 1998; Goldberg & Cullen, 1985; Slevin et al., 1996). Moreover, many participants acknowledged the importance that support from medical professionals while others cited that medical professionals had a profound effect on his or her ability to successfully cope with his or her disease. These findings are supported by literature that asserts that doctors may be the most important source of patient support (Akechi et al., 1998; Rose, 1990; Slevin et al., 1996).

In addition, some participants also admitted to using denial as a coping strategy. At face value, this coping strategy may appear to be maladaptive, however one study suggests that using denial in the short-term may facilitate a good short-term adaptive response (Watson, Greer, Blake, & Shrapnell, 1984). Still, for others, faith and/or spirituality were a factor in his or her ability to cope with their disease. Support for these findings is found in numerous investigations that examined the relationship between religious coping and successful adjustment to cancer (Koenig et al., 1995; Koenig et al., 1992; Nairn & Merluzzi, 2003; Thune-Boyle et al., 2006).

Another important finding was how many participants successfully coped and adjusted to the physical changes that occurred as a result cancer and its treatment. Many participants spoke to temporary challenges and/or offered narratives that spoke to one’s ability to be creative in tackling those challenges. This finding is in contrast to the literature on illness intrusiveness (Devins, 2010; Devins et al., 2006) and a review article by Welch-McCaffrey et al., (1989) who cite multiple studies that solely speak to the difficulties of adjusting to “physical compromise” of the relationship between the physical and psychosocial of the cancer experience (p. 518). For
these reasons, this finding is better supported by investigations that speak to the variability of how one responds to a cancer diagnosis (Meyerowitz et al., 2008; Rodrigue et al., 1994; Stanton et al., 2005).

Furthermore, for some participants, the current cancer was not their first cancer. These participants’ narratives revealed a fighting spirit, which indicates they were somehow adjusting and coping relatively well given many cited their previous experience had already changed their lives. While a systematic review on psychological coping styles and cancer recurrence yielded inconsistent findings with respect to fighting spirit and helplessness/hopelessness (Petticrew, Bell, & Hunter, 2002), this finding is better supported by the possibility that these participants had experienced some kind of posttraumatic growth (Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004) or adversarial growth (Linley & Joseph, 2004) as a result of his or her previous experience with cancer or other serious illnesses.

Examination of the narratives also revealed that participants not only adjusted to his or her cancer experience, but also grew personally as a result. Some participants cited enjoying new activities, enjoying closer personal relationships and developing a greater appreciation for others, and life in general as well as changing one’s life’s priorities. These findings are well supported the literature on PTG (Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004) and PTG and cancer (Manne et al., 2004; Weiss, 2009).

5.4.1.1. Sex Differences. The first observation on differences between the sexes was that although responses were seen for both males and females, females wrote the majority of the narratives. There were also marked sex differences with respect to how the sexes coped and adjusted to his or her disease. In terms of challenges with coping and adjusting, females were the only ones to overtly report psychological distress such as depression, anxiety, loss of control
and anger. This discovery is consistent with investigations that report females with cancer are more prone to depression than males with cancer (Kadan-Lottick, Vanderwerker, Block, Zhang, & Prigerson, 2005; Massie, 2004) and depending on cancer type, anxiety and depression has been shown to be two to three times higher than for females (Linden et al., 2012). Males on the other hand were the only ones to report that diagnosis was a difficult time and that the reality of their diagnosis had not sunk in yet. One interpretation of this finding is that these males were relatively young (57 years-old and 46 years-old) and thus may have been surprised to discover they had cancer, which is supported by literature that suggests ‘younger’ patients have more difficulty adjusting to cancer than ‘older’ patients (Harrison & McGuire, 1995; Schroevers, Ranchor & Sanderman, 2004). Another possible explanation is that these male’s support networks may have been too small (Greimel et al., 1998; Harrison et al., 1995) or perhaps they may have experienced a lack of social support, which negatively affects one’s ability to cope and adjust to cancer (Goldberg & Cullen, 1985; Mererowitz et al., 2008). A third possibility is that these males may have been more anxious depending on the severity of their disease (Rodrigue et al., 1994). Furthermore, females also were the only ones to admit that other life events (excluding additional illnesses) were more stressful than their disease which is consistent with findings that women’s lives are more stressful than male’s lives (Matud, 2004).

In addition, females were also the only ones to report that the current cancer was not their first cancer diagnosis. Many of these participants described how their previous cancer was a learning experience that prepared them for their current diagnosis. These findings are buttressed by investigations that PTG is more common in females than males (Vishnesvsky, Cann, Calhoun, Tedechi, & Demakis, 2010).
In terms of adaptive coping and styles, males were more prone to rely on problem-focused coping whereas females relied heavily on emotion-focused coping. For example, one male stated his need for social isolation due to a compromised immune system and was able to use Skype for meetings while another male who ultimately lost his battle with cancer shared that his lifestyle was not affected by cancer because he was no longer doing demanding things. Both of these narratives illustrate that a problem existed until an alternate solution was found. These findings are consistent with the literature on gender differences and coping styles, which suggest that male and female coping styles are distinctive from one another in prostate and breast cancer patients (Kiss & Meryn, 2001) as well as coping strategies and gender differences throughout the lifespan (Melendez, Mayordomo, Sancho, & Tomas, 2012). In addition, females were more prone to discuss the impact of both negative and positive experiences in their social support networks, and when they did, their responses were typically more emotive and descriptive. These findings are consistent with evidence provided by Matud, (2004) who suggests that females are more emotional and tend to rely on emotion focused coping whereas males are typically more emotionally inhibited.

At this point, it is important to re-state that the in no way were the absence of emotive responses by the males in this study taken to mean that males do not have feelings or were not emotionally affected by their disease. What it does suggest is that males and females differ in how they “…think, feel, and behave.” (Kiss & Meryn, 2001; p. 1055). This conclusion is supported by research on gender role socialization and how society influences the construction of gender via values, beliefs and stereotypes (Addis & Mahalik, 2003). Good, Thompson and Braithwaite (2005) report that gender role socialization is a by-product of how society expects men to behave. Furthermore the authors state that males learn how society expects them to
behave in childhood and when boys break social norms of what it means to be male (such as crying), young boys are humiliated and shamed, which in turn, affect their male identity or self-concept. For these reasons, it is understandable why males in general may resist being overly emotional and more specifically, why the males in this study may have been less emotive in their responses.

5.4.2. Diagnosis & Treatment. The diagnosis of cancer and ensuing cancer treatment was the second most responded to theme.

The time of diagnosis presented a range of emotions for several participants. Many of the participant’s narratives described difficulty coping and adjusting to his or her diagnosis and early days of treatment that is consistent with the squeal of negative psychological reactions reported by Goldberg and Cullen (1985) and Stanton and Snider (1993). For one male participant, he acknowledged he hadn’t had enough time for his diagnosis to sink in and another participant stated she had accepted her diagnosis well, thus further evidence for the variability by which individuals cope with a cancer diagnosis (Meyerowitz et al., 2008; Rodrigue et al., 1994; Stanton et al., 2005). For three females, participation in this study was not their first cancer experience.

The participant’s narratives also described treatment type, treatment planning, the availability of treatment and the effects of treatment. The most cited mode of treatment was surgery alone (23) and the remaining nine narratives made reference to surgery in combination with one to four different treatment modalities, with surgery, radiation, chemotherapy and medication cited by one participant.

A major theme throughout the narratives on diagnosis and treatment was waiting to plan or begin treatment. Many of the narratives clearly illustrate that wading into the abyss of what his or cancer would bring provoked anxiety of the unknown. This finding is consistent with
Breitbart’s (1995) notion of “Reactive anxiety”, (p. 52) in which the author proclaims that most cancer patients experience anxiety at various points of the illness trajectory. Specifically, the author emphasizes how waiting for diagnosis, diagnostic tests and surgery can impede a patient’s normal functioning, impact their interpersonal relationships and possibly compromise understanding and compliance with treatment regimes. Further evidence is provided by Welch-McCaffrey, (1985) who emphasizes that anxiety at diagnosis is often exaggerated by patients having to wait during testing and then waiting for results from those tests. It is also noteworthy to acknowledge that for one participant treatment was not available in her hometown and thus highlights the discrepancies in the availability of treatment options between urban and rural communities and is well described by (Desch et al., 1992). Another participant also commented on the need for regular 3-month check-ups over a two-year period, indicating that for her, the cancer experience was not complete. Although this participant’s narrative did not disclose feelings of anxiety, it is possible that anxiety may persist given the extended time needed for constant check-ups. For others, the narratives were more upbeat and reflected gratitude for the speed of treatment.

The narratives penned on the effects of one’s cancer treatment provided a rich description on his or her individual experience. A few participants commented on how treatment resulted in immediate improvements in health, the discovery of additional non-cancer related illnesses and how cancer had no negative effects. Conversely, the lion’s share of narratives made reference to the negative aspects of treatment. Some participants made reference to temporary recovery from treatment; yet others provided more descriptive narratives on how treatment negatively affected him or her physically and are supported by the literature on illness intrusiveness (Devins, 2010;
Devins et al., 2006) and that treatment regimes are more troublesome than the disease itself (Ashbury, Findlay, Reynolds, & McKerracher, 1998).

5.4.2.1. Sex Differences. In terms of the number of narratives written about diagnosis and treatment, females scribed the majority. Ten females also commented on the type of cancer and a male penned only one. Females also scribed almost all of the narratives with respect to their feelings at diagnosis and included feelings a loss of control, anger, anxiety and feeling distraught. Support for these findings can be found in several investigations that present evidence that females have higher rates of depression and anxiety (Kadan-Lottick et al., 2005; Linden et al., 2012; Massie, 2004) and are more prone to use emotion focused coping (Kiss & Meryn, 2001; Matud, 2004). Interestingly, only one male spoke about the difficulty of diagnosis although he did not state how he felt about his disease, but rather how he felt about the lack of support and direction from his doctor(s). This finding confirms that doctors are one of the most important sources of support (Akechi et al., 1998; Slevin et al., 1996). Taken together, these findings are congruous with research that concludes cancer patients experience the most distress just after diagnosis (Costanzo, Ryff, & Singer, 2009; Stanton & Snider, 1993).

5.4.3. Employment & RTW. Employment and RTW was the third most responded to theme for the participants in this study. As previously described, the narratives for this theme increased incrementally over the course of the study, which, may have been in response to the inclusion of the RTW questionnaires added at the 12-month follow-up.

The most cited sub-theme within this theme was those narratives that addressed medical leave and/or time off from work. The participants varied with respect to whether they were off completely during treatment or whether they worked part-time or continued full time. For those who were off completely, finances were a concern for those who had to take time off without
pay. This finding is supported by a qualitative study on RTW and cancer survivors by Main et al., (2005) who report that participants felt obligated to continue working for financial reasons. Participants at the 6-month follow-up were more apt to describe currently taking a break from their employment whilst narratives at the 12-month follow-up indicated that many participants had RTW or were planning to RTW.

Additionally, the narratives also revealed that some participants were unable to continue working because treatment was not available in their hometown or that for some reason they were forced to find new employment or that their RTW was disrupted due to cancer recurrence. Still, for others, some participants indicated they were unable to meet previous work demands, went back too early or retired due to fatigue and is supported by similar evidence found in study on cancer survivorship and RTW (Pryce et al., 2007). The narratives also described changes in employment were made pre-cancer or how medical appointments were disrupting their ability to work. With respect to the latter, Pryce et al., (2007) state that having time off with pay to attend medical appointments is a factor in continuing to work during treatment. Lastly, non-disclosure in the workplace was also a concern and has been found to be a major factor in being able to continue work during treatment. More specifically, when employees disclose his or her illness and continue to work during treatment, employers are more apt to provide more workplace adjustments than employees who did not continue to word during treatment (Pryce et al., 2007).

5.4.3.1. Sex Differences. The first observation that can be made between males and females is that females penned almost all of the Employment and RTW narratives. For this reason it is impractical to suggest differences between the sexes with respect to RTW. In the current study, when males did make a comment they focused on medical leave and/or time off and employment status. Distinct within the male narratives was males reporting they had to find
a new job to return to, non-disclosure in the workplace and how early retirement instigated lifestyle changes prior to being diagnosed. These findings are consistent with investigations on disclosure namely, that reveal one’s decision to disclose is or her illness depends on social context (Lepore et al., 2004) and that RTW is not associated with gender (Spelten et al., 2002).

5.4.4. Social Support. Social support was also an important theme for the participants in this study and is supported by literature that suggests that social support is a major determinant in one’s ability to positively cope and adjust to a cancer diagnosis (Bloom, 1982; Cohen, 1988; Goldberg & Cullen, 1985; Roberts et al., 1994). Specifically, research on social support and cancer patients has revealed that social support is associated with lowered distress, fewer psychological disturbances and heightened physical recovery (Bloom, 1982; Cohen, 1988; Roberts et al., 1994). Furthermore, the narratives also reveal that the timing of social support is an important consideration. Jacobson, (1986) points out that a stressor (such as cancer) has three distinct phases: 1) a crisis phase; 2) a transition phase; and 3) a deficit phase. The author argues that emotional support may be the most important during the crisis phase (e.g., dealing with a new cancer diagnosis) whereas information is most needed during the transition phase when individuals begin to cope and instrumental support may be most helpful during the deficit phase when one’s resources cannot meet the demands of the stressor.

References to social support were sparse at Baseline and then increased dramatically at the 6-month follow-up and were consistent thereafter. This finding may be in part due to the fact that the participants were recruited shortly after diagnosis and thus, may have still been in shock and not ready to rally or tap into his or her support networks. Supporting evidence for this postulation is supported by Helgeson & Cohen (1996) who report that emotional support during the acute phase of the illness trajectory is believed to be the most important in one’s ability to
adapt during times of significant stress. This conclusion is also consistent with Jacobson (1986) who concludes that during the crisis phase (e.g., being diagnosed with cancer or the treatment phase of cancer trajectory), emotional support may be the most important.

The sub-themes that emerged were sources of social support, feelings about social support, timing of social support, social support needs and non-disclosure. The narratives also revealed that participants received emotional, informational and instrumental support. It is noteworthy to add that of the three types of support, emotional support was cited the most, followed by informational support and lastly, instrumental support. These findings are supported by several investigations on social support and cancer namely Corney, Everett, and Howells (1992), Helgeson and Cohen (1996), Slevin et al., (1996). Contrary to the literature that men prefer informational support (Greimel et al., 1998) the males in this study made more references to emotional support than informational support.

The majority of participants demonstrated that they were well supported, and that support was derived from a variety of sources. This finding is in accordance with investigations that report the support networks of cancer patients are diverse (Greimel et al., 1998; Harrison, McGuire, & Pitceathly, 1995). In descending order, social support was received the most from: medical professionals, family, friends and external sources such as support groups and alternate medicine. (With respect to the latter, two female participants mentioned they had received additional support from outside organizations, Inspire Health and Friends for Life. Interestingly, both organizations cite an integrated cancer care approach but one is manifestly more accessible than the other. While both organizations are non profit and are funded by private donations, to reap the benefits of Inspire Health, individuals must become a member which can cost anywhere from $225 to $450 depending on the membership type whilst Friends for Life is completely free
of charge.) These findings are confirmed by an investigation by Slevin et al., (1996) who report that cancer patients believe that the support they receive from doctors is the most important. Further support for this finding is seen in Akechi et al., (1998) who assert that support from doctors may be one of the most effective sources of social support. In addition, write the authors, the emotional support patients receive from their doctors is equally as important as the emotional support from family. Furthermore, a study on adult patients’ desire for support from family friends and medical professionals by Rose (1990) reports patients that felt the most vulnerable often relied on medical professionals for support. The author postulates that patients may seek support from medical professionals due to possible burn out from traditional sources of support such as family and friends.

Whilst most participants indicated they were supported, others indicated there was a lack of social support. For example, the female participant who repeatedly mentions her anger and the death of her brother, Gerard (*) at Baseline and the 12-month follow-up and the participant who stated she was not supported by her husband. These miniature case studies are supported by findings by Helgeson and Cohen (1996) who suggest that a lack of emotional support can be detrimental for cancer patients when need exceeds availability, especially from family and friends. While it is impossible to establish solely based of these narratives whether these participants may have been depressed, the written narratives indicate they may have been depressed, at least to some degree. As such, findings by Hann et al., (2002) support the notion that a lack of support has been linked to depression in cancer patients. Furthermore, several participants also stated social support from family, friends and doctors was not always available. This finding is congruent with Meyerowitz et al., (2008) who assert that perceived social support is an important predictor of positive adjustment. Additional findings from this study suggest that
social support was not wanted and is congruent with evidence that desire for social support may vary with the type of support (Helgeson & Cohen, 1996) and the timing by which support is desired and received (Jacobson, 1986).

Lastly, several participants identified his or her social support needs which included wanting seeking services from a Psychologist or Counsellor, CBT therapy, while a couple of participants indicated they sought additional support from either church groups, EFAP programs or support groups organized by BCCA staff.

5.4.4.1 Sex Differences. The first observation that can be made was that the females of this study appeared to have a more diverse social support system than males (e.g., medical professionals, family, friends, alternate medicine, church groups, BCCA support groups) whilst the support network for males was considerably smaller (medical professionals, family friends and paid help). This finding is consistent with the literature that suggests that females have larger support networks than males (Greimel et al., 1998; Harrison et al., 1995). In terms of lack of social support from family and friends, the females in this study were virtually only ones to overtly state they experienced a lack of support. By extension, this finding is supported by Greimel et al., (1998) who suggest that female’s preferred coping preference is to seek support from family. There was also an additional finding for the one male that commented on a lack of support from medical professionals. While it is impossible to know whether this participant was looking for emotional, instrumental or informational support, inference suggests that he may have been looking for informational support based his narrative, “…you are virtually left alone to wonder what happens after a doctor tells you that you have cancer.”

5.4.5. The Effects of Cancer. The effects of being diagnosed with cancer were numerous for the participants in this study. The narratives confirm that cancer had an impact on
family and spousal relationships, participant’s lifestyle and may also affect participant’s finances.

5.4.5.1. Family & Marital Relationships. The participants of this study were keen to discuss how cancer had affected their interpersonal relationships with spouses, family and friends. The literature on how cancer affects family and spousal relationships is sparse unless a particular type of cancer is identified (Lewis, 2006; 1986). The two studies by Lewis (2006; 1986) examined impact of cancer and the family and suggest that families also experience the calamity and impact of cancer. Findings from these studies reveal that this was also true for some participants who cited difficulty with children and a worried husband. With respect to the latter, several investigators support this finding. In a study that examined the concerns of adult cancer patients’ family members, (Wright & Dyck, 1984), the authors report four main concerns identified by family members, namely, 1) problems associated with disease symptoms, 2) fear of the future, 3) waiting, and 4) barriers obtaining information. Additional research also suggests that cancer patients and their spouses experience comparable psychological adaptation (Cassileth et al., 1985; Plum et al., 1977 as cited in Ell et al., 1988) or that spouses may be more distressed than the patient (Carlson et al., 2000; Gotay, 1984; Lichtman, 1986 as cited in Ell et al., 1988).

In addition, participants also revealed tensions with his or her spouse. Although it is impossible to know with absolute certainty whether these difficulties were a result of the cancer experience or pre-existing marital difficulties, the context of the responses allows for some inference and suggests that the marital strain existed prior to the participant’s diagnosis. In sum, these findings are consistent with the literature on how cancer can negatively affect family and spouses. However, these findings do not exemplify the majority of narratives, namely, the positive effect cancer had on family relationships.
Overall, participants reported that there was a marked improvement in his or her relationships with family, and especially with his or her spouse. Although it is impossible to answer the question ‘why’ this occurred, it is possible that some of these participants had well functioning family and marital relationships which based on the narratives, appeared to buffer the impact of his or her diagnosis. These findings are consistent with literature that suggests that high quality family communication and high marital quality facilitates effective adjustment to cancer (Gotcher, 1993; Rodrigue & Park, 1996) and greater satisfaction with one’s marriage is associated with fewer symptoms of depression, anxiety and fewer illness-instigated family problems (Rodrigue & Park, 1996). Furthermore, participants also made reference to how cancer resulted in positive changes in marital relationships. This finding is consistent with a study examining 34 couples and the impact of testicular cancer and marital relationships 4 years post-treatment (Gritz, Wellisch, Siau & Wang, 1990). Specifically, the authors write that most “…relationships were strengthened and couples emerged more tightly bonded” as a result of the cancer experience.

5.4.5.1.1. Sex Differences. The vast majority of narratives written about the effect cancer had on family and marital relationships were written by females and were mostly positive and offered more description. Several types of research support this finding. For example, the literature on PTG proposes that individuals who experience a traumatic event (such as cancer) can experience transformations in interpersonal relationships (Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004). Furthermore, research on cancer and marital satisfaction emphasizes that when females are well supported by their husbands, females experience less distress (Manne, 1998) and may explain for some of the accolades written about the participant’s husbands. Research also suggests that females also have larger support networks (Hann et al.,
2002) and therefore might be reaping the benefits of having more support. By extension, one might infer that for some of these females, their extended support networks may be having an overall positive effect on perceived support and ultimately influence how they are feeling about their support networks.

5.4.5.2. Health. The narratives also demonstrate how cancer was affecting the participant’s overall health and thus, are consistent with the literature on illness intrusiveness (Devins, 2010; Devins et al., 2006). Moreover, females penned all of the narratives. The vast majority of narratives revealed that to some degree, cancer was negatively affecting their overall health at one time or another. Conversely, one participant shared that her cancer diagnosis resulted in discovering an additional, un-related cancer illness. These findings taken together are consistent with several lines of previous research. For example, in a study on symptom reporting in a German sample, Ladwig, Marten-Mittag, Formanek, and Dammann (2000) state that females report more morbidities and more symptoms such as body changes in health. In another study on gender differences in reporting physical and somatoform symptoms, the authors reveal that females report 50% more physical symptoms than their male counterparts and further assert that symptom reporting was independent of psychological functioning.

5.4.5.3. Lifestyle. The questions that asked participants about how cancer was affecting his or her lifestyle provoked many participants to offer written narratives that revealed cancer was having a substantial and negative effect. The narratives revealed there was a broad range in terms of how participants were affected and included changes in his or her recreational activities as well as the length of time these activities were disrupted. These findings are supported by research on the effects of illness intrusiveness (Devins, 2010; Devins et al., 2006; Devins, 1994) and that physical symptoms of treatment are the first to be reported (Griffin et al., 1996). Given
the number of participants who shared his or her experiences with the side effects of treatment, I concur with Welch-McCaffrey, Hoffman, Leigh, Loescher, and Meyskens, (1989), who emphasize the importance of educating cancer patients about the psychosocial stress provoked by physical limitations and related changes that many cancer treatments produce.

Conversely, some participants described a different experience. For example, some participants stated that cancer had not affected his or her life or was not affecting his or her life as much anymore while others were determined not to let cancer interfere with his or her life. It should be noted that the possibility exists that some participants may have been engaging in denial and possibly may have experienced maladaptive reactions to his or her disease however, investigator triangulation (also known as interrater reliability) suggests this was not the case. These narratives confirm that not all cancer patients have maladaptive reactions to his or her disease (Meyerowitz et al., 2008; Rodrigue et al., 1994; Stanton et al., 2005). Additionally, participants also commented on how cancer caused them to develop new interests, which is consistent with the literature on PTG (Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004) or that lifestyle changes had occurred prior to his or her diagnosis.

5.4.5.3.1. Sex Differences. Although both males and females shared that cancer was having a negative impact on his or her lifestyle, males were more apt to report on physical challenges that impeded their mobility and capacity to engage in active recreation and daily activities whilst females were more prone to describe the length of time their disease prevented them from carrying out their usual activities. These discoveries are supported by a study on gender differences in cancer outcomes. In that investigation, the authors state that compared to females, men report significantly more cancer-related deficiencies as well as more impediments in activity and daily activities (Greimel et al., 1998).
Examination of the narratives also revealed that females were the only ones to report that cancer had positively changed their lifestyle by way of the development of new interests. Furthermore, females also discussed how a previous cancer diagnosis had already caused them to make lifestyle changes. Support for these findings can be found in the PTG literature. For example, in a meta-analysis on gender differences and PTG, the authors observe that PTG is more common in females than males (Vishnesvsky, Cann, Calhoun, Tedechi, & Demakis, 2010).

Furthermore, the PTG literature suggests that in response to a traumatic event (such as cancer) individuals may change his or her life’s priorities and may also cause some individuals to embark on a new life path and can also lead to the development of new interests (Tedeschi & Calhoun, 2004; Tedeschi & Calhoun, 1996).

**5.4.6. Other Life Events.** Analysis of the narratives revealed that in addition to one’s cancer diagnosis, the participants in this study also had to contend with additional non-cancer related stressors. These stressors included additional chronic illnesses such as COPD, asthma and arthritis and physical disabilities that limited one’s physical mobility. Moreover, because many of the participants commented on how non-cancer related illnesses were affecting his or her life in a study on how one adjusts to cancer, it is clear that these additional chronic illnesses were affecting the participants enough to make a comment and thus is supported by investigations on illness intrusiveness (Devins, 2010; Devins et al., 2006). Furthermore, participants also reported they were also dealing with short-term physical injuries such as broken bones and sprains that impeded their physical abilities as well as bad colds. Participants also made reference to various types of interpersonal stressors, caregiving for close family members, the loss of a loved one and various other life events. In sum, all of these additional stressors are
consistent with findings that suggest almost half of the distress cancer patients face is not due to his or her disease (Weisman & Warden, 1972-1976; as reported in Goldberg & Cullen, 1985).

5.4.6.1. Sex Differences. The narratives revealed that there were differences between the sexes with respect to Other Life Events. While both males and females reported they also suffered from chronic illnesses, males reported more respiratory illnesses while females reported illnesses such as osteoporosis and arthritis. Males and females also discussed short-term illnesses, although males overwhelmingly reported more injury related illnesses that impeded their mobility and active recreation. This finding is loosely supported by literature on sex differences that describe how males and females fare in terms of cancer outcomes. Specifically, Greimel, Padilla and Grant (1998) insist that males describe significantly more cancer related deficiencies and more restrictions in physical prowess than females. As such, by extension, we can assume that males reporting more additional illnesses that impede their physical ability are loosely supported by the literature.

The narratives also revealed that females reported difficulties with interpersonal relationships. Furthermore, females were the only ones to state they were caregivers. While most did not state caregiving was a burden, a review paper on the health of women caregivers by Lee (1999) presents evidence that the majority of family caregivers are females. Furthermore, the author asserts that caregiving duties can impact subjective wellbeing and thus is a risk factor for the development of serious illness. It is important to note that I am not suggesting that caregiving duties caused the development of these women’s cancers. I am however, drawing the parallel that it is possible that the additional stress of caregiving has the potential to impact disease trajectory based on evidence presented by McEwen (2004) who states that chronic stress
suppresses immune system functioning and according to Reiche et al., (2004), chronic stress may be responsible for the increased progression of some types of cancers.

5.5 Do the narratives provide evidence that participants experienced positive psychological adjustment/improvement over time?

A review of the literature suggests that there are a multitude of factors that affect one’s ability to cope and adjust to cancer. These include personal characteristics, coping style, social support, gender, age, relationship status, and education, faith and/or spirituality, (Akechi et al., 1998; Harrison & Maguire, 1995; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992).

For the participants in this study, many of the above mentioned variables were revealed in his or her narratives. Furthermore, how the study participants were able to cope and adjust to his or her cancer diagnosis fluctuated over the course of the study.

Baseline narratives indicate that only a few participants disclosed how he or she was coping and adjusting. For those few who did, some reported having a difficult time coping and adjusting to their cancer diagnosis citing anger, disbelief and anxiety. This finding is also supported by the number of responses found in both the IIRS (36) and the Demographic questionnaires (7) as well as those narratives that alluded to a lack of social support from family, spouses and medical professionals. Conversely, successful coping and adjustment appeared to be a result of accepting his or her diagnosis. This may be in part due to the positive social support received and by the possibility that some participants were engaging in intrusive rumination (a predictor of PTG) as evidenced by the 18 narratives found in the PTGI.

Conversely, the 6-month follow-up was ripe with narratives that revealed the struggles of coping and adjusting to cancer. Specifically, the PSSCAN garnered 32 responses and the Demographic questionnaire received 10, many of which alluded to difficulties with coping and
adjusting such as disbelief, denial, and loss of control, depression and a reduced sense of resilience. Moreover, some participant’s narratives indicated he or she was not receiving the social support he or she desired. On the other hand, this was also a time that some participants began to show signs of successful coping and adjusting, many of which were seen in the PTGI, which received 19 responses. For example, participants cited positive moods, acceptance, lack of worry and how a previous cancer diagnosis was helpful in his or her adjustment. In addition, many participants commented how the receipt of positive social support positively affected his or her adjustment.

Similarly, the 12-month follow-up revealed that time seemed to have a positive effect on the participant’s ability to cope and adjust to their diagnosis. Specifically, there was a marked decrease in the amount and tone of emotional distress in the written narratives. This is evidenced by the marked decrease of responses to the IIRS, which was highest at Baseline (36), declined to 21 at the 6-month follow-up and received only five responses at the 12-month follow-up. Specifically, participants commented on positive moods, acceptance of his or her disease and revealed he or she had developed new interests and were making plans to RTW, although a few participants continued to cite anger and denial. Interestingly, the social support narratives at the 12-month follow-up were more diverse than Baseline or the 6-month follow-up. While some participants stated they were not receiving the support he or she desired, other participants continued to be grateful for social support and others recognized a need for professional mental health services. This finding supports the notion that the receipt of social support is only part of the equation in how individuals adjust to cancer given the influence of psychosocial factors such as gender, age, cancer type and severity have on one’s ability to cope and adjust to his or her disease (Kiss & Meryn, 2001; Linden, et al., 2012; Mosher & Danoff-Burg, 2005).
The findings from the current study are consistent with an 8-year longitudinal study that investigated newly diagnosed cancer patients with various types of cancer at three months, 15 months and 8 years post-diagnosis (Schroevers, Ranchor, & Sanderman, 2006). Although the Baseline measurements are dissimilar (our study’s Baseline was generally within a couple of weeks versus three months), the authors report that participants experienced the most distress at three months and dissipated sharply at the 15-month follow-up. Similarly, in the current study, participants reported the most distress at 6-months and declined sharply at the 12-month follow-up.

Evidence also suggests that age plays a role in one’s ability to cope and adjust to cancer (Harrison & Maguire, 1995; Mosher & Danoff-Burg, 2005). Schroevers et al., (2004) also report on how age influences long-term adjustment (three months, 15 months and 8 years post-diagnosis) of 155 cancer survivors. In that study, the authors suggest that psychological functioning was most impaired at three months for those survivors 65 years and younger compared to similarly aged matched controls. Furthermore, the authors point out that depressive symptoms in the long term were similar to aged matched controls, although younger survivors were more inclined to report thinking about cancer and a search for meaning with respect to his or her cancer experience (Schroevers et al., 2004). These findings are consistent with the current study, namely, the age group that experienced the most difficulty were those participants between the ages of 51 and 75. A weak comparison can also be made to the current study with a cross sectional study of the influence of age on psychological adjustment of 520 cancer patients 8 weeks post-diagnosis (Harrison & Maguire, 1995). The authors report that younger patients have a more difficult time adjusting to a cancer diagnosis although this is somewhat difficult to
interpret and relate to the current sample given the authors provide only age range (18-75) and age means (51.5 and 53.4) for males and females, respectively.

In sum, the 213 unsolicited narratives provide anecdotal evidence to support the conclusion that generally speaking, that many of the 86 participants demonstrated positive psychological adjustment from the time of diagnosis to the 12-month follow-up.

5.6 Significance of the Research

The current study sought to understand the 213 unsolicited narratives found written in the margins of a quantitative study examining the psychological adjustment of 86 newly diagnosed cancer patients. The significance of this research is four fold, namely, 1) The use of unsolicited narratives as data; 2) The use of QD; 3) Contributions to understanding patients’ adjustment to cancer; and 4) How quantitative investigation fails to fully capture the totality of individual experiences.

5.6.1. Unsolicited Narratives as Data. As previously discussed, the use of unsolicited narratives as data in empirical research, is a fairly new development. This finding is supported by a systematic review on the use of unsolicited narratives in research by O’Brien and Clark (2010) who identified a mere 18 published, peer reviewed papers (nine unpublished [internet narratives], eight published [print] and one that used both genres) from 1997 to 2009. A common feature of the studies cited in this thesis on the use of unsolicited narratives as data (Clayton et al., 1999; Malinski & Litwin, 2007; Robinson, 2001; Warms et al., 2005) all support the belief that unsolicited narratives are a rich source of information. Specifically, Clayton et al., (1999) concluded that their investigation enhanced their understanding of individuals living with chronic illness. A similar conclusion was reached by Malinski and Litwin (2007); the authors maintain that using unsolicited comments is useful in identifying additional information about
men’s concerns regarding quality of life after prostate cancer. Relatedly, the investigation by Warms et al., (2005) insists that unsolicited narratives of individuals with spinal cord injury adds value and extends understanding to traditional quantitative survey methods. Robinson (2001) on the other hand, emphasizes the importance of unsolicited narratives found on the Internet data as a rich source of data.

Taken together, these studies support the salience of the current investigation’s attempt to explore and understand how 86 cancer patients chronicled his or her adjustment to cancer via the analysis of unsolicited narratives and the themes identified that promoted or hindered his or her adjustment to cancer.

5.6.2. The Use of Qualitative Description. In the methods section of this thesis, I sought to describe why QD was used for this study over other well-known and better supported qualitative methods. My decision was largely based on my inability to confirm the meaning of the narratives and as such, staying close to the data with as little inference as possible was a primary consideration. Furthermore, the plethora of many qualitative methods require the researcher to adopt a philosophical stance that buttresses how the research will be carried out and the meanings derived from it. Given I sought to describe the experiences of the participants who offered unsolicited narratives with as little inference as possible, while capturing the critical elements of the participant’s experiences, QD was the best choice. For these reasons, I agree with Sandelowski (2000) that QD is a valuable method of inquiry given my decision was based on the appropriateness of the method with the end goal of allowing the narratives to speak for themselves. As such, I was cognizant of not trying to fit a square peg into a round hole, which would have compromised scientific rigor.
Furthermore, QD is rooted in the cannon of existing knowledge and how it linked to previous investigations by others in the field (Neergaard et al., 2009). Additional support for using QD in health research has been identified by Neergaard et al., (2009) who suggest that QD is a useful method in medical research and mixed method designs. Further support for using QD is described by Sullivan-Bolyai et al., (2005) who suggest that this method is particularly relevant to “…assessing, developing and refining interventions with vulnerable populations.” (p. 127). Moreover, the authors cite that QD may be more useful over other methods in its ability to identify health care concerns and provide direction on how to improve health care based on needs identified by the patient. For these reasons, I believe that this study adds to the existing literature on how using QD is unique in its ability to draw upon those theoretical orientations that best support analyzing and reporting the data without making the well described mistake of incorrectly reporting methods and techniques that fail to address the uniqueness of the data (Sandelowski, 2000).

5.6.3. Contributions to Understanding Patients’ Adjustment to Cancer. The current study is unlike many quantitative and qualitative studies that seek to investigate a new phenomenon or look for a cause and effect relationship between variables. Instead, this study was primarily descriptive in nature in its use of unsolicited narratives to describe what was most important to the participants who provided unsolicited narratives. To accomplish this, it is important to remember that this study was had elements of social constructionism. Specifically, the original study provided a vehicle by which it asked participants to think about his or her cancer (e.g., the specific questionnaires chosen for the original study) in ways that have been previously identified as important in how cancer patients cope and adapt to a cancer diagnosis. While the findings of the current study do not offer much novel insight, they provide further
support for previous investigations that focus on coping and adjustment, diagnosis and treatment, employment and RTW, the importance of social support, the effects of cancer on interpersonal relationships, how cancer may affect finances, mood and health and the impact of other life events have when dealing with a new cancer diagnosis. In sum, this investigation highlighted a broad spectrum of cancer patient’s concerns (similar to those reported by Ness et al., 2013) as they embarked on the unexpected journey that cancer dictates.

5.6.4. How Quantitative Investigations Fails to Fully Capture the Totality of Individual Experiences. It has been well noted that traditional quantitative research is unique in its ability to garner vast amounts of information from a large number of participants and is valued for its efficiently and usefulness (Clayton et al., 1999) as well as its ability to generalize results (Warms et al., 2005). Taken together, the 213 unsolicited narratives in this study as well as the studies cited that used unsolicited narratives as data, provide undeniable evidence that pure quantitative studies have innate limitations.

Specifically, Clayton et al., (1999) argue that traditional survey questionnaires with closed-response formats limit the amount of information participants can provide. Moreover, the authors argue, researchers create the questions within the surveys and thereby minimize the amount and quality of information that participants are able to provide. This conclusion is well supported in the current study given the range of experiences and the amount of detail about those experiences that were provided by participants. One can only speculate the additional information that might have been gleamed had the original study provided a vehicle by which participants were provided an opportunity and invited to share what was uniquely important to them as individuals. As a result, the experiences of those participants who did not add their personal narratives were lost. Furthermore, any personal meaning making that might have
resulted by narrating his or her stories was limited to those who chose to add additional narratives. As such, we as researchers must ask ourselves, *how much information have we let slip through our fingers by not offering participants the opportunity to offer his or her thoughts or by failing to address the unsolicited narratives found in traditional quantitative measures?*

### 5.7 Recommendations for Research

In light of evidence provided, the results from the current study suggest several recommendations for future research. The first and most obvious argument is a call for the increased use of mixed method research designs, an idea that is also supported by Neergaard et al., (2009) and Moffatt et al., (2006). Moreover, Moffatt et al., (2006) emphasize that using a mixed method design using both quantitative and qualitative designs in health research produces a greater yield of information than either method by itself. To accomplish this, researchers might consider the simple addition of a few lines to the end of a traditional quantitative survey that invites participants the opportunity to add context or additional information about his or her experiences. Additionally, researchers could gain even more information by interviewing participants individually for more specific types of information or perhaps, using a group format to explore general similarities and differences among males and females or even the psychological effects that different types of cancers can incite (Linden et al., 2012; Massie, 2004).

Second, quantitative researchers should consider accepting responsibility for the value that unsolicited narratives offer and thus should be used in future studies given that each participant is a *person* with a *unique* story to tell, a conclusion also supported by Clayton et al., (1999) and Warms et al., (2005). It seems wholly inappropriate that researchers ask participants...
for their time and energy to answer questions they deem important and dismiss the value-laden information that can be discovered by exploring and analyzing unsolicited narratives.

Third, since using unsolicited narratives as data is still in its infancy, I concur with the recommendations made by O’Brien & Clark (2010; 2011). Specifically, it is imperative that researchers begin to use a common language in an attempt to build a strong foundation by which future researchers are able to build and improve upon what has already been done. Moreover, if the use of unsolicited narratives as data becomes more common, there needs to be a consensus on how this type information and subsequent research is evaluated.

Fourth, with respect to questionnaire surveys that have been reliably validated, it is not enough that test developers rest on his or her laurels and adopt the stance that there is no room for improvement. While additional analysis of the various ways participants responded to particular questions is beyond the scope of this thesis, it is important that researchers and test developers examine unsolicited narratives when provided. Specifically, investigators might consider analyzing the range and/or similarities and/or differences that exist in unsolicited narratives and ask themselves, is this cause to re-examine the measures?

It is noteworthy that several participants answered questions on the PSSCAN and the IIRS in the opposite direction of what the question was asking (e.g., question was asking about how one’s illness was negatively affecting some aspect of his or her life and participants responded in the positive). For instance, several participants found the PSSCAN question, “Have you lost your life partner in the past few years?” ambiguous. At face value, it appears that life partner could be referring to marriage, common-law or intimate partner however, several participants cited non-intimate relationships such as brother, friend and mother. This finding is important given this question may potentially exclude participants who don’t have an intimate
*life partner* but may consider other types of relationships equally as important. Moreover, investigators ought to be on the lookout for responses that elicit more information that was asked or responses indicating that the question was not fully understood. For this reason, test developers might periodically consider test refinement based on planned participant feedback in an attempt to avoid incorrect reporting on the part of participants and researchers alike.

### 5.8 Recommendations for Clinical Practice

The current study was based on analyzing the unsolicited narratives of 86 cancer patients and used QD to summarize and report the results. Given QD has been reported to be rooted in existing literature (Neergaard et al., 2009), the question remains, *what* have we learned from this investigation that would *improve* clinical practice?

There were several findings in this study that provoke thoughts on how to improve clinical practice. The first speaks to how the sexes differed in terms of psychological adjustment to cancer. For example, mental health professionals working in clinical practice need to be aware of how the sexes differ in the development of anxiety and depression in conjunction with a cancer diagnosis (Kadan-Lottick et al., 2005; Linden et al., 2012; Massie, 2004) and how this may differ in terms of the type of cancer and disease stage (Linden et al., 2012). It is also imperative that mental health professionals understand how the sexes differ in terms of coping styles (Kiss & Meryn, 2001; Melendez et al., 2012). Specifically, mental health professionals would be well advised to consider the salience of incorporating gender specific and individually tailored cancer support services given 1) males are thought to share information whereas females prefer to share emotion (Kiss & Meryn, 2001) and 2) females generally cope with a cancer diagnosis better than males (Volkers, 1999) and are reported to have better outcomes compared to males (Greimel et al., 1998).
One example of a gender specific intervention for male cancer patients is provided by Adamsen, Rasmussen and Pedersen (2001). In that study, the authors investigated how a group intervention program that combined physical activity and information exchange affected men’s sense of well being and their ability to successfully cope with the physical and psychological challenges of living with cancer. Findings from that study suggest that the men demonstrated improved wellbeing, increased energy and self-confidence. According to the authors, this was in part due to the solidarity among group members, which facilitated their willingness to share personal experiences, thoughts and feelings. These findings are especially important because of the impact of male stereotypes that may prevent males from emotional expression (Addis & Mahalik, 2003; Good, Thompson & Braithwaite, 2005) and the fact that males have smaller social support networks compared to females (Greimel et al., 1998; Harrison et al., 1995). For these reasons, cancer group interventions specifically tailored for males may be one vehicle by which males may feel more comfortable sharing their experiences because of the camaraderie that develops by sharing similar experiences, which in turn, can also increase the size of their support networks. Furthermore, research on the benefits of group participation states that participants often experience more personal gains when the group encourages participants to engage with the group in ways that challenge the participant’s usual ways of relating and experiencing (Kivlighan & Goldfine, 1991).

Second, 20.4% of the original study’s sample provided unsolicited narratives. From this, we can conclude that interventions that offer a narrative component may be beneficial in assisting some cancer patients with coping and adjusting to his or her cancer diagnosis. As Hyden (1997) suggests, narratives are an important mode by which one is able to express his or her suffering. The latter is an important consideration given Zakowski et al., (2004) report that
emotional expression is a crucial component of many cancer interventions. Furthermore, engaging in the process of writing one’s illness narratives provides an opportunity to discuss one’s experience without negative social support (Manne et al., 1999) or potential social barriers (Manne, 1998; Manne et al., 1999) or fear how it may affect others (Carlick & Biley, 2004; Lepore et al., 2004).

Third, mental health professionals need to be aware that one’s gender may influence the types of support that cancer patients may need and the timing for which those supports are most effective (Jacobson, 1986). According to Mayfield (1999) one specific area that has not received much attention is the desire for support after the cessation of cancer treatment (a theme also identified by two participants). The author argues that post-treatment provokes anxiety and uncertainty. For this reason, medical and mental health professionals as well as policy makers need be aware that the support needs of many cancer patients may extend beyond post-treatment and into the survivorship phase. Relatedly, cancer does not only affect the patient, but also affects those around them. For this reason, ensuring that additional supports are available for spouses, family and friends are recommended, a conclusion also supported by (Northhouse, 1988).

Fourth, the results from this investigation confirm previous findings on the importance of social support’s ability to assist cancer patients with coping and adjusting to his or her cancer diagnosis (Akechi et al., 1998; Corney et al., 1992; Goldberg and Cullen 1985; Manne, 1998; (Manne et al., 1999; Meyerowitz et al., 2008; Slevin et al., 1996). For this reason, mental health professionals would be well advised to assist cancer patients in both identifying positive sources of social support and identifying ways to increase patient’s social support networks to prevent the possibility of social support burn out.
Fifth, mental health professionals need to be aware that cancer patients are often dealing with more stress than just their cancer diagnosis (Weisman & Warden 1972-1976 as cited in Goldberg & Cullen, 1985). As such, mental health professionals might consider focusing their work with cancer patients in identifying ways to reduce their overall stress load given the negative effects stress can have on the body and possibly disease progression (Reiche et al., 2004).

Sixth, medical and mental health professionals should be aware that how he or she engages with cancer patients may affect his or her willingness to disclose concerns about one’s illness. This conclusion is supported by Maguire et al., (1996) who report that directive questions that focus on psychological features and empathetic statements promote greater disclosure in cancer patients. Conversely, the authors point out, using leading questions that focus on clarifying illness resulted in advice giving and reassurance, which stunted cancer patient’s willingness to disclose. Moreover, since doctors have been described as being out of touch with identifying the support needs of his or her patients (Sollner et al., 2001), training medical professionals and medical students with interviewing skills that facilitate a more holistic understanding of his or her patients may be a major step towards bridging the gap between merely taking medical information and understanding the totality of the individual.

Lastly, it is noteworthy that only one out of this study’s 86 participants mentioned support groups offered at BCCA. This finding is important because it leads one to wonder whether the Patient and Family Counselling Service at BCCA or BCCA cancer support groups are doing enough to promote their in-house support services. This might be particularly important for those individuals who are in need of support but are unaware of support services or individuals who are contemplating accessing services or those individuals whose PSSCAN
scores are not severe enough to warrant BCCA counsellors to make contact and may potentially fall through the cracks.

5.9 Limitations

There were several limitations to this study. The first and most obvious was that this study was based on unsolicited narratives so there was no control over who, how and when the participants chose to respond. Second, because this study is rooted in unsolicited written narratives of cancer patients, it is impractical if not impossible to check the meanings of the written narratives. This is in part due to the lapse in time from the original investigation, which may certainly cloud participant’s memories and perspectives over the two years since the original study was completed. Additionally, it is possible that some of the original study participants have died, either from cancer or other causes. Third, it is important to acknowledge the disproportionality of males to females in the current study. For this reason, many of the narratives written by males were given more weight in order to highlight those responses that were unique to males and to illustrate how their responses differed from their female counterparts. Fourth, because most narratives were hand written, it is possible that the research assistants that transcribed and entered the data had difficulty interpreting the handwriting, which may have lead to incorrect interpretations of what was written. Fifth, many narratives were made without reference to a particular question which sometimes required more inference in interpreting the narrative. Sixth, whilst several participant’s narratives alluded to being depressed or having marital difficulties, it is impossible to know if these impairments may reflect a pre-diagnosis condition or situation. Seventh, the qualitative software, Atlas.ti 7 was entirely self-taught. As the analysis progressed, it became clear that how the data was originally entered into the software and failing to master such a powerful tool prevented precise analysis in some
cases. As such, there is a possibility that a ‘small’ margin of error exists in the results. Eighth, statistical analysis revealed some minor discrepancies with respect to the total sample in several analyses. These discrepancies might be explained by the differential weighing of cases. It is a normal expectation in longitudinal research that there will be a certain rate of attrition, which ultimately affects data analysis due to missing data, and the variability of sample sizes. Lastly, the conclusion that this study’s participants appeared to show improvements in his or her attempt to cope and adjust to their cancer diagnosis is solely based on the written narratives and has not been verified via the quantitative data collected in the original study.

Conclusion

This study sought to answer five research questions based on 213 unsolicited comments written in the margins of quantitative questionnaires packages. Based on the narratives, there were many ways the narratives could have been analyzed and an equal amount of questions that could have been asked. What seemed salient however was to understand: 1) Which questions and questionnaires were participant’s responding to? 2) What are the participant characteristics of those who provided unsolicited narratives?; 3) What are the major themes that emerged from the data?; 4) Do sex differences exist within the major themes and how males and females responded?; and 5) Did the participants demonstrate psychological adjustment or psychological improvement over time?

Over the course of the study, almost all of the questionnaires at all three time points triggered 86 participants to offer a written narrative. The questionnaire that received the most responses was the IIRS. The second was the PSSCAN, followed by the PTGI, Demographics, the RTW questionnaire and lastly, the Worries questionnaire. Furthermore, over the course of the study, the responses for each questionnaire fluctuated with the IIRS garnering the most
responses at Baseline, and the PSSCAN at both the 6-month and 12-month follow-ups. Moreover, within the questionnaires, participants also gravitated to certain questions over others in terms of the number of responses each received. The questions and statements that incited the most responses focused on 1) How many days one’s health kept participants from usual activities, self care, work or recreation (PSSCAN); 2) Learning how wonderful people are as a result of their disease (PTGI); 3) How much one’s illness and/or treatment interfered with his or her health (IIRS); 4) Employment status (Demographics); 5) Who had supported participants since being diagnosed with cancer (Demographics); 6) How much time was taken off work due to his or her diagnosis (RTW); and 7) Fear of cancer recurrence (Worries).

The participant characteristics obtained from the Demographic questionnaires allowed this investigator to gain a better understanding of who the participants were, beyond his or her narratives. As a whole, the participants were mostly female, Caucasian, and 60.5% were married or common law. Furthermore, 67.4% of the participants fell within the 51-75 year age group and 86.0% of the participants completed or partially completed post secondary educations or graduate and/or professional programs. The household income of the 81 participants who responded ranged from 22.2% (N = 18) reporting a household income less than $40,000 to 28% (N = 23) reporting incomes over $100,000. In addition, 47.7% of the participants indicated they identified themselves with a major faith and/or religion. In addition, 39.5% of the participants indicated they had previously suffered a serious medical condition. Lastly, comparisons of the Demographic data for this study’s participants and those from the original study reveal that the participants of this study were not unique and thus were largely representative of the total sample in the original investigation. For this reason, we can infer that the experiences shared by those
who wrote in the margins of his or her questionnaires were experiences also shared by those participants who did not.

The major themes that emerged from the narratives were chiefly influenced by the questionnaires and specific questions within them. Analysis of the narratives indicates some themes generated more narratives than others. This finding could be due to many factors including but limited to the timing of when the questionnaire was added, the placement of each questionnaire within each of the questionnaire packages and certainly the personal experience of the participant. In descending order of popularity (defined as the most responses) the themes that emerged were: Coping and Adjustment, Diagnosis and Treatment, Employment and RTW, Social Support and the Effects of Cancer and Other Life Events.

While there were overall similarities between males and females in terms of the written narratives, there were also marked differences. The first and obvious sex difference can be seen in the 1.97:1 ratio based on 59 females and 29 males who offered unsolicited narratives. In terms of responding, males were more inclined to offer information without much emotive content whereas females were more apt to focus on their feelings and emotions as well as offer information and did so with longer and more detailed responses. With respect to describing one’s psychological reaction to cancer, females were the only ones to divulge their personal experiences with such as anxiety, depression and feeling a loss of control. Furthermore, females were the only ones to report on the difficulty of waiting for diagnosis and treatment whereas males were more inclined to offer descriptive information on the side effects of treatment. Religious coping was predominantly a female coping style although two males reported being spiritual. In terms of how other illnesses were more debilitating than one’s cancer diagnosis and how one’s disease affected his or her physical ability, males responded more than females.
Another difference between the sexes was found in the diversity and importance of social support networks, with females reporting more than their male counterparts. Females also made more reference to how their own previous cancer or experience with another’s cancer had prepared them for their current diagnosis. In addition, females overwhelmingly responded more to the RTW questionnaires than males and were also the only ones to report caregiving to others.

The unsolicited narratives of the 86 participants provided powerful and moving stories about how these individuals embarked on the journey known as cancer, a journey that they had no control over, and appeared for many to be life-altering experience. The participants in this study not only agreed to participate in the original study but also went beyond what was originally asked of them by providing personal highlights and struggles in his or her attempt to make sense of their experiences. In doing so, the participants of this study privileged us with personal insights into his or her experiences with coping and adjusting to cancer, overcoming illness intrusiveness and the personal growth as a result of the cancer experience. Whether this was done out of a sense of altruism or personal need, we will never know. What we do know is these participants inadvertently added to the existing literature on how individuals cope with cancer diagnosis, and for this we are eternally grateful.
Table 1

*Cancer Survivor’s Concerns (Ness et al., 2013)*

<table>
<thead>
<tr>
<th>Concerns by Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of recurrence</td>
</tr>
<tr>
<td>Finance and fatigue</td>
</tr>
<tr>
<td>Long-term effects of treatment, peripheral neuropathy and sexuality</td>
</tr>
<tr>
<td>Medical debt, hot flashes, osteoporosis and bone health</td>
</tr>
<tr>
<td>Living with uncertainty, health insurance, hair and skin issues, loss of physical strength</td>
</tr>
<tr>
<td>Sleep disturbance, memory and concentration and bowel or bladder issues</td>
</tr>
<tr>
<td>Intimacy, managing emotions, developing a new sense of normal, mobility, weight changes and pain</td>
</tr>
<tr>
<td>Returning to work, managing stress and lymphedema</td>
</tr>
<tr>
<td>End of life concerns, isolation, body changes, well-being, nausea and vomiting and connectedness to the medical system</td>
</tr>
<tr>
<td>Caregiving duties, poor appetite, daily activities, finding support outlets, changes in relationships with family, friends and spouse, contact with primary MD, and who to call when medical issues arise</td>
</tr>
<tr>
<td>Coping with grief and loss, trouble swallowing and utilizing complementary and alternative medical treatment</td>
</tr>
<tr>
<td>Disclosure to family and friends, fertility, utilizing counselling services and looking for the bright side</td>
</tr>
<tr>
<td>Religious or spiritual distress, loss of faith and spiritual or religious support</td>
</tr>
</tbody>
</table>
Table 2

Comparison of Age & Gender

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Males</th>
<th>Males in Original Study</th>
<th>Females</th>
<th>Females in Original Study</th>
<th>Total</th>
<th>Total Original Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>21-50</td>
<td>6 (20.7)</td>
<td>18 (9.0)</td>
<td>13 (22.8)</td>
<td>64 (22.2)</td>
<td>19 (22.1)</td>
<td>82 (18.7)</td>
</tr>
<tr>
<td>51-75</td>
<td>21 (72.4)</td>
<td>163 (81.5)</td>
<td>37 (64.9)</td>
<td>148 (62.2)</td>
<td>58 (67.4)</td>
<td>311 (71.0)</td>
</tr>
<tr>
<td>76-96</td>
<td>2 (6.9)</td>
<td>19 (9.5)</td>
<td>7 (12.2)</td>
<td>26 (10.9)</td>
<td>9 (10.5)</td>
<td>45 (10.3)</td>
</tr>
<tr>
<td>Mean Age</td>
<td>61.52</td>
<td>61.68</td>
<td>58.93</td>
<td>57.88</td>
<td>58.80</td>
<td>60.74</td>
</tr>
</tbody>
</table>

Note: There is an overrepresentation of 17 participants in the total sample of males and females.
### Table 3

**Education Level by Gender**

<table>
<thead>
<tr>
<th></th>
<th>Males with Narrative (n=29)</th>
<th>Males without Narrative (n=94)</th>
<th>Females with Narrative (n=57)</th>
<th>Females without Narrative (n=185)</th>
<th>Total Sample with Narrative (n=86)</th>
<th>Total Sample (n=444)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 6 or less</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>1 (1.8)</td>
<td>1 (0.8)</td>
<td>1 (1.16)</td>
<td>2 (0.5)</td>
</tr>
<tr>
<td>Grades 7 – 12 without graduating high school</td>
<td>4 (13.8)</td>
<td>22 (12.7)</td>
<td>3 (5.3)</td>
<td>13 (7.0)</td>
<td>7 (8.1)</td>
<td>42 (9.5)</td>
</tr>
<tr>
<td>Graduated High School or High School Equivalent</td>
<td>0 (0.0)</td>
<td>32 (18.5)</td>
<td>4 (7.0)</td>
<td>34 (18.4)</td>
<td>4 (4.7)</td>
<td>70 (15.8)</td>
</tr>
<tr>
<td>Partial Post-Secondary Education</td>
<td>6 (20.7)</td>
<td>33 (19.1)</td>
<td>9 (15.8)</td>
<td>37 (20.0)</td>
<td>15 (17.4)</td>
<td>85 (19.1)</td>
</tr>
<tr>
<td>Graduated 2-year Post Secondary Education</td>
<td>1 (3.5)</td>
<td>9 (5.2)</td>
<td>10 (17.5)</td>
<td>18 (9.7)</td>
<td>11 (12.8)</td>
<td>38 (8.6)</td>
</tr>
<tr>
<td>Graduated 4-year Post Secondary Education</td>
<td>6 (20.7)</td>
<td>20 (11.6)</td>
<td>10 (17.5)</td>
<td>25 (13.5)</td>
<td>16 (18.6)</td>
<td>61 (13.7)</td>
</tr>
<tr>
<td>Partial Graduate/Professional Program Completed</td>
<td>0 (0.0)</td>
<td>10 (5.8)</td>
<td>5 (8.8)</td>
<td>10 (5.4)</td>
<td>5 (5.8)</td>
<td>25 (5.6)</td>
</tr>
<tr>
<td>Graduate/Professional Program</td>
<td>12 (41.4)</td>
<td>47 (27.2)</td>
<td>15 (26.3)</td>
<td>47 (25.4)</td>
<td>27 (31.4)</td>
<td>121 (27.3)</td>
</tr>
</tbody>
</table>

Note: There is an overrepresentation of 23 participants in total sample.
Table 4

*Household Income*

<table>
<thead>
<tr>
<th></th>
<th>Narrative = Yes (n=81)</th>
<th>Total Sample (n=429)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n(%)</td>
<td>n(%)</td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>8 (9.9)</td>
<td>33 (7.7)</td>
</tr>
<tr>
<td>$20,000 – $39,000</td>
<td>10 (12.4)</td>
<td>82 (19.1)</td>
</tr>
<tr>
<td>$40,000 – $59,000</td>
<td>15 (18.5)</td>
<td>77 (17.9)</td>
</tr>
<tr>
<td>$60,000 – $79,000</td>
<td>16 (19.8)</td>
<td>83 (19.3)</td>
</tr>
<tr>
<td>$80,000 – $99,000</td>
<td>9 (11.1)</td>
<td>48 (11.2)</td>
</tr>
<tr>
<td>$100,000 or more</td>
<td>23 (28.4)</td>
<td>106 (24.7)</td>
</tr>
<tr>
<td>Total</td>
<td>81</td>
<td>429</td>
</tr>
</tbody>
</table>

Note: There is an overrepresentation of 8 participants in the total sample.
Table 5

Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>Narrative = Yes</th>
<th>Total Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=85)</td>
<td>(n=443)</td>
</tr>
<tr>
<td></td>
<td>n(%)</td>
<td>n(%)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>76 (89.4)</td>
<td>390 (88.0)</td>
</tr>
<tr>
<td>Asian</td>
<td>3 (3.5)</td>
<td>32 (7.2)</td>
</tr>
<tr>
<td>First Nations</td>
<td>2 (2.4)</td>
<td>5 (1.1)</td>
</tr>
<tr>
<td>African</td>
<td>1 (1.2)</td>
<td>2 (0.5)</td>
</tr>
<tr>
<td>East Indian</td>
<td>0 (0.0)</td>
<td>5 (1.1)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1 (1.2)</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (2.4)</td>
<td>8 (1.8)</td>
</tr>
<tr>
<td>Total</td>
<td>85</td>
<td>443</td>
</tr>
</tbody>
</table>

Note: There is an overrepresentation of 22 participants in the total sample.
Table 6

**Spirituality**

<table>
<thead>
<tr>
<th></th>
<th>Spirituality in Current Study (n=40)</th>
<th>Spirituality in Total Sample (n=200)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spirituality</td>
<td>n(%)</td>
<td>n(%)</td>
</tr>
<tr>
<td>Christian</td>
<td>11 (27.5)</td>
<td>47 (23.5)</td>
</tr>
<tr>
<td>Catholic</td>
<td>5 (12.5)</td>
<td>48 (24.0)</td>
</tr>
<tr>
<td>Islam (Muslim)</td>
<td>1 (2.5)</td>
<td>5 (2.5)</td>
</tr>
<tr>
<td>Hinduism</td>
<td>1 (2.5)</td>
<td>1 (0.5)</td>
</tr>
<tr>
<td>Unitarian</td>
<td>2 (5.0)</td>
<td>3 (1.5)</td>
</tr>
<tr>
<td>Protestant</td>
<td>3 (7.5)</td>
<td>21 (10.5)</td>
</tr>
<tr>
<td>Anglican</td>
<td>3 (3.6)</td>
<td>18 (9.0)</td>
</tr>
<tr>
<td>Lutheran</td>
<td>1 (2.5)</td>
<td>2 (1.0)</td>
</tr>
<tr>
<td>Pentecostal</td>
<td>1 (2.5)</td>
<td>3 (1.5)</td>
</tr>
<tr>
<td>United</td>
<td>5 (6.0)</td>
<td>15 (7.5)</td>
</tr>
<tr>
<td>Baptist</td>
<td>1 (2.5)</td>
<td>6 (3.0)</td>
</tr>
<tr>
<td>Buddhist</td>
<td>0 (0.0)</td>
<td>2 (1.0)</td>
</tr>
<tr>
<td>Judaism</td>
<td>0 (0.0)</td>
<td>2 (1.0)</td>
</tr>
<tr>
<td>Sikhism</td>
<td>0 (0.0)</td>
<td>2 (1.0)</td>
</tr>
<tr>
<td>Lakota</td>
<td>0 (0.0)</td>
<td>1 (0.5)</td>
</tr>
<tr>
<td>Presbyterian</td>
<td>0 (0.0)</td>
<td>5 (2.5)</td>
</tr>
<tr>
<td>Methodist</td>
<td>0 (0.0)</td>
<td>1 (0.5)</td>
</tr>
<tr>
<td>Jehovah’s Witness</td>
<td>0 (0.0)</td>
<td>1 (0.5)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (7.5)</td>
<td>11 (5.5)</td>
</tr>
<tr>
<td>Total</td>
<td>40 (46.50)</td>
<td>200 (47.5)</td>
</tr>
</tbody>
</table>
Table 7

Marital Status

<table>
<thead>
<tr>
<th></th>
<th>Current Study (n=86)</th>
<th>Original Sample (n=443)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n(%)</td>
<td>n(%)</td>
</tr>
<tr>
<td>Single</td>
<td>12 (14.0)</td>
<td>45 (10.2)</td>
</tr>
<tr>
<td>Married or</td>
<td>52 (60.5)</td>
<td>303 (68.4)</td>
</tr>
<tr>
<td>Common Law</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separated or</td>
<td>13 (15.1)</td>
<td>65 (14.7)</td>
</tr>
<tr>
<td>Divorced</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>9 (10.5)</td>
<td>30 (6.8)</td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>443</td>
</tr>
</tbody>
</table>

Note: There is an overrepresentation of 22 participants in the original sample.
### Table 8

**PSSCAN Frequency of Questions & Responses at the 6-month & 12-month Follow-up**

<table>
<thead>
<tr>
<th>Question</th>
<th>6 months</th>
<th>12 months</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you live alone?</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>When you need help, can you count on anybody to help you with daily tasks like grocery shopping, cooking, and giving you a ride?</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Have you lost your life partner within the past few years?</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Can you count on anyone to provide you with emotional support?</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>To what extent do you want and need emotional support?</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?</td>
<td>6</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Now thinking about level of stress, depression, and problems with emotions, for how many days during the past 30 days was your mood not good?</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>During the past 30 days, for how many days did poor physical or emotional health keep you from doing your usual activities, such as self-care, work or recreation?</td>
<td>8</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>During the past week I have felt that my heart races and I tremble.</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>During the past week I have felt that I cannot control anything.</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>During the past week I have lost interest in things I usually cared for or enjoyed.</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>During the past week I have felt nervous and shaky inside.</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>During the past week I have felt tense and can’t relax.</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>During the past week I have felt restless and find it difficult to sit still.</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>I have had 2 years or more in my life when I felt depressed or sad most days even if I felt OK sometimes.</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>General Comment</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Total Comments</td>
<td>39</td>
<td>21</td>
<td>60</td>
</tr>
</tbody>
</table>

Note: Baseline was completed at BCCA during participant’s initial visit to BCCA and thus has no responses.
Table 9

*Post Traumatic Growth Inventory Frequency of Responses at Baseline, 6 months & 12 months*

<table>
<thead>
<tr>
<th>Phrases</th>
<th>Baseline</th>
<th>6 months</th>
<th>12 months</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I changed my priorities about what is important in life.</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>I have a greater appreciation for the value of my life.</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>I have a better understanding of spiritual matters.</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>I more clearly see that I can count on people in times of trouble.</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>I established a new path for my life.</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>I am more willing to express my emotions.</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>New opportunities are available which wouldn’t have been otherwise.</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>I have a stronger religious faith.</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>I learned a great deal about how wonderful people are.</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>General Comments</td>
<td>13</td>
<td>12</td>
<td>1</td>
<td>26</td>
</tr>
<tr>
<td>Total Comments</td>
<td>18</td>
<td>19</td>
<td>1</td>
<td>38</td>
</tr>
</tbody>
</table>
Table 10

Illness Intrusiveness Scale Frequency of Responses: Baseline, 6 months & 12 months

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>6 months</th>
<th>12 months</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much does illness and/or treatment interfere with your health?</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your diet?</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your work?</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your active recreation?</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your passive recreation?</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your financial situation?</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your relationship with your spouse?</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your sex life?</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your family relations?</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your other social relations?</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your self-expression/self/improvement?</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your religious expression?</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>How much does illness and/or treatment interfere with your community and civic involvement?</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>General Comments</td>
<td>5</td>
<td>4</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td>21</td>
<td>5</td>
<td>62</td>
</tr>
</tbody>
</table>
Table 11

**Demographics**

<table>
<thead>
<tr>
<th>Question</th>
<th>Baseline</th>
<th>6 months</th>
<th>12 months</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you a caregiver of a person that resides with you and has health problems? * +</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Employment Status * +</td>
<td>2</td>
<td>6</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Which version of the PSSCAN questionnaire have you completed? *</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Are you a religious person? If yes, which religion? *</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Is the current cancer your first cancer, a recurrence of the same cancer, or a second and different type of cancer? *</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>What type of treatment have you received or are currently undergoing? + °</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>In the last year, have you received services from a psychiatrist, psychologist or counsellor outside of the BC Cancer Agency? °</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Has your relationship changed since you began the study? °</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Who has supported you since your cancer diagnosis? °</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Did a major change in your health occur since you began the study? °</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>General Comments</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>10</td>
<td>15</td>
<td>33</td>
</tr>
</tbody>
</table>

Note: Inclusion of questions per time point: * denotes Baseline, + denotes 6 month and °denotes 12 month inclusion.
Table 12

*RTW Questionnaires (RTW & RTW A)*

<table>
<thead>
<tr>
<th>Question</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you work prior to your diagnosis? If ‘yes’ what kind of job did you have?</td>
<td>1</td>
</tr>
<tr>
<td>Provided that you were working at the time of your cancer diagnosis, did you continue to work during active treatment (chemotherapy and/or radiation)? *</td>
<td>2</td>
</tr>
<tr>
<td>If you were working at the time of your cancer diagnosis, have you returned to work since? * v</td>
<td>1</td>
</tr>
<tr>
<td>How many months did you take off from the diagnosis of cancer until you went back to work? * v</td>
<td>6</td>
</tr>
<tr>
<td>Do you feel you can meet the demands of your job? If ‘no’ what do you think is the reason? * v</td>
<td>2</td>
</tr>
<tr>
<td>For how many months were you on sick leave after your cancer diagnosis? *</td>
<td>1</td>
</tr>
<tr>
<td>Which type of employment do you have right now?</td>
<td>1</td>
</tr>
<tr>
<td>What is the extent of your work? *</td>
<td>1</td>
</tr>
<tr>
<td>Did your position change when you returned to work?</td>
<td>1</td>
</tr>
<tr>
<td>To what degree have you been able to resume activities such as volunteering or hobbies? *</td>
<td>1</td>
</tr>
<tr>
<td>Have you developed new interests or activities as a result of having gone through the cancer experience? *</td>
<td>2</td>
</tr>
<tr>
<td>The physical demands of work are now more of a burden then they used to be.</td>
<td>1</td>
</tr>
<tr>
<td>My colleagues are considerate of my disease. +</td>
<td>1</td>
</tr>
<tr>
<td>My supervisor is considerate of my disease. +</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
</tr>
</tbody>
</table>

Note: RTW denoted by *. RTW A denoted by +. Question 3 in RTW A was a multi-layered question and is denoted by v. RTW B had no comments.
Table 13

*Frequency & Type of Narrative Across all Three Time Points*

<table>
<thead>
<tr>
<th></th>
<th>Additive</th>
<th>Descriptive</th>
<th>Clarifying</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>19</td>
<td>40</td>
<td>0</td>
<td>59</td>
</tr>
<tr>
<td>6 month</td>
<td>18</td>
<td>63</td>
<td>3</td>
<td>84</td>
</tr>
<tr>
<td>12 month</td>
<td>18</td>
<td>52</td>
<td>0</td>
<td>70</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>155</td>
<td>3</td>
<td>213</td>
</tr>
</tbody>
</table>
Table 14

*Frequency of Reported Treatment Type*

<table>
<thead>
<tr>
<th>Type of Treatment</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy</td>
<td>6</td>
</tr>
<tr>
<td>Radiation</td>
<td>2</td>
</tr>
<tr>
<td>Radiation &amp; Chemotherapy</td>
<td>1</td>
</tr>
<tr>
<td>Surgery</td>
<td>23</td>
</tr>
<tr>
<td>Surgery + unknown*</td>
<td>1</td>
</tr>
<tr>
<td>Surgery &amp; Chemotherapy</td>
<td>2</td>
</tr>
<tr>
<td>Surgery &amp; Radiation</td>
<td>3</td>
</tr>
<tr>
<td>Surgery, Chemotherapy &amp; Medication</td>
<td>1</td>
</tr>
<tr>
<td>Surgery, Radiation &amp; Chemotherapy</td>
<td>1</td>
</tr>
<tr>
<td>Surgery, Radiation, Chemotherapy &amp; Medication</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
</tr>
</tbody>
</table>

Note: *Participant did not specify second type of treatment.*
Table 15

*Differences in Responding by Sex and Age Group*

<table>
<thead>
<tr>
<th></th>
<th>Descriptive</th>
<th>Additive</th>
<th>Clarifying</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males Aged 25 – 50</td>
<td>9</td>
<td>2</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Females Aged 25 – 50</td>
<td>22</td>
<td>4</td>
<td>0</td>
<td>26</td>
</tr>
<tr>
<td>Males Aged 51 – 75</td>
<td>22</td>
<td>14</td>
<td>0</td>
<td>36</td>
</tr>
<tr>
<td>Females Aged 51 – 75</td>
<td>90</td>
<td>25</td>
<td>3</td>
<td>118</td>
</tr>
<tr>
<td>Males Aged 76 – 96</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Females Aged 75 – 96</td>
<td>10</td>
<td>8</td>
<td>0</td>
<td>18</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>155</strong></td>
<td><strong>55</strong></td>
<td><strong>3</strong></td>
<td><strong>213</strong></td>
</tr>
</tbody>
</table>
Table 16

*Sex Differences in Types ofResponding at 3 Time Points*

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
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Figure 1

Response by Questionnaire at 3 Time Points
References


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Appendices

Appendix A First Contact Information Sheet

THE UNIVERSITY OF BRITISH COLUMBIA

Department of Psychology, 2136 West Mall
Vancouver, B.C., Canada V6T 1Z4

BC Cancer Agency – Patient and Family Counseling Services

Dear Potential Research Participants

Patient and Family Counseling Services here at the BC Cancer Agency are conducting a questionnaire study on how the mood of individuals who receive services at the BC Cancer Agency change over time. If you choose to participate in the study, it involves no extra visit to the cancer centre, just completion of brief questionnaires at home. Given that you likely have a full day ahead of you, we don’t want to provide too much detail here. If you already know that you are not interested, please leave the sheet bland and return to the receptionist. Note that even if you do give your name and phone number below, you are not already agreeing to participate in the study. It simply means that a research assistant may give you a call in 1-2 weeks to describe the study. You can choose not to participate at any time. Thank you!

I am willing to be contacted later for a description of the study and my name and contact information is inserted below:

Name: ______________________________ Phone number: ____________________
What is the best time of day to reach you by phone? Time of day: ____________________
PI Signature

Dr. Wolfgang Linden
Principle Study Investigator
Appendix B First Contact Recruitment Telephone Script

First Contact Phone Script – Tracking patient adjustment when in BCCA care

“Hello, may I speak to ________? Hi, this is _________ [first name] calling from UBC. I am calling in reference to your recent visit to the BC Cancer Agency. You may remember that you completed a salmon coloured form indicating that you might be interested in participating in an ongoing study through the BC Cancer Agency and the Department of Psychology at UBC.

First, have you recently received a phone call from the BC Cancer Patient and Family Counselling offering you access to their services?

IF YES, skip down to below line

Okay, so what our study is trying to assess is the level of psychological distress of new cancer patients over the course of one year. You total time commitment would be approximately 45 minutes. We would begin by sending you two consent forms to fill out. One would be for your personal records, and the second you would send back to us in an enclosed stamped envelope along with an enclosed questionnaire package that takes approximately 15 minutes to complete. We would then repeat this process in 6 months and one final time 12 months from now.

Lastly, should you be interested, we would also ask that you provide us with your provincial MSP health number. The reason why this is important is that it allows us to merge the study data collected from your questionnaires with other data on your medical status with the Cancer Agency Information System that would provide a comprehensive analysis of your health status. This kind of analysis is quite typical for empirical studies. After the information has been entered, it is IMPORTANT FOR YOU TO KNOW that our data files will be completely stripped of any indentifying information and with be completely anonymous.

“So, that’s all there is to it. Do you think that you’d be willing to participate in our study?

“that’s great. At this point I’ll collect some further contact information from you so I can send out your consent form and first questionnaire package

What is you mailing address?........What is your MSP number?

You should receive a letter-sized brown envelope within a week with the consent form and questionnaire package. Please do not forget to sign the consent form and enclose it with the completed questionnaire package when you mail it back to us. In addition, we will provide you with an information sheet that outlines everything we have gone over along with our contact number in the event that you have any questions.
Okay, on the day of your first consultation at BC Cancer, you indicated on a questionnaire that you found your current health problems to be very stressful. This is the reason that the staff at Patient and Family Counselling has offered you their services. Individuals with cancer diagnoses sometimes need professional support to deal with their diagnosis and treatment, but it’s quite often unclear which type of person benefits most from which type of intervention. So, we are trying to collect this information by having a wide variety of people, like yourself, fill out two brief questionnaires a total of two times over the course of six months. Basically, BCCA counselors want to find out how to give those who may need support the best support possible.

Should you be interested in participating, your total time commitment would be approximately 30 minutes. We do it all through the mail. We would begin by sending you two consent forms to fill out. One would be for your personal records, and the second you would send back to us in an enclosed stamped envelope along with an enclosed questionnaire package that takes approximately 15 minutes to complete. We would then repeat this process again in 6 months from now.

The only other things I should mention is that we would also ask that you provide us with your provincial MSP health number. The reason why this is important is that it allows us to merge the study data collected from your questionnaires with other data on your medical status with the Cancer Agency Information System that would provide a comprehensive analysis of your health status. This kind of analysis is quite typical for empirical studies. After the information has been entered, it is IMPORTANT FOR YOU TO KNOW that our data files will be completely stripped of any indentifying information and with be completely anonymous.

“So, that’s all there is to it. Do you think that you’d be willing to participate in our study?

In that case, all I need from you now is your mailing address and your CareCard number.

You should receive a letter-sized brown envelope within a week with the consent form and questionnaire package. Please do not forget to sign the consent form and enclose it with the completed questionnaire package when you mail it back to us. In addition, we will provide you with an information sheet that outlines everything we have gone over along with our contact number in the event that you have any questions.
SUBJECT INFORMATION AND CONSENT FORM

Title: "Tracking patient adjustment when in BC Cancer Agency Care"

BCCA Principal Investigator: Dr. Wolfgang Linden

This research has been funded by the Canadian Institutes of Health Research (CIHR).

Background: You are invited to participate in this study because you are about to go through treatment at the BC Cancer Agency. We want to learn more about what it is like, at an emotional level, to go through this process.

Purpose of the Study: This study is a questionnaire study where you will be asked to complete the same brief set of questionnaires a total of three times, over a period of one year. Why is this study being done? The process of being diagnosed with cancer and going through lengthy, often aversive treatments is very emotionally demanding. This is generally made worse because the treatment success can not be perfectly predicted. Nevertheless, many research participants diagnosed with cancer show admirable resilience and seem to cope well with these burdens. Remarkably, we do not know very much about how individuals with cancer change in their mood over time and which psychological and disease specific factors account for such changes in psychological well-being. It is possible that certain individuals improve quickly without much help and that others seem to do well initially but then find it difficult to adjust. We believe that it is important to fully understand this process so that patients can be re-assessed at the right times; BCCA counselors want to prevent those who might need help from “falling through the cracks”. We need to know when to assess and service providers want to be sensitive to the most difficult stages in the process of completing cancer treatments and the later adjustment in the post-treatment phase. We are trying to learn about this process by having a wide variety of people like yourself complete two brief questionnaires.

Who can participate in this study? You may participate in this study if you are about to begin a treatment program with the BC Cancer Agency, Vancouver Centre. We will contact you at the information desk on the main floor to ask you whether you are willing to participate in this study. At that time point you will not have seen a doctor and have agreed upon treatment at BCCA.

Who should not participate in this study? You are not a suitable participant if you are not of legal age (less than 19 years) and/or have difficulty reading and completing questionnaires in English.

Procedure: Taking part in this study takes about 45 minutes in total. The same test is given three times, taking 15 minutes each time. You are asked to respond to brief questionnaires now, 6 months later, and then again after another 6 months. There is no need to come to the BC Cancer Agency for another visit.
because all questionnaire completion can be done by mail. You will be contacted in 6 and 12 months by mail and asked to fill out a questionnaire, to be returned in a pre-addressed, postage-paid envelope. In the event that a significant number of patients do not send back the questionnaires, you may receive a reminder phone call from a research assistant. In order to avoid having to ask you a long list of questions about your physical health, we ask that you give us permission to access your electronic medical chart on one occasion so that we can extract data from the chart. Once we have obtained your health data, we will remove all identifying information.

Benefits and Risks: You may learn how your well-being changes over time and what reasons for these changes may be and help the researchers learn how counseling services can be offered in the most efficient way possible. Participation in this study does not involve a known risk to your health and will not have an impact on the quality, timing or type of treatments that you may receive.

Confidentiality: Your confidentiality will be respected and all information is confidential. Findings may be published in scientific journals but there is no identification of you personally in any of these papers or reports. Information collected on you will be given a code number and maintained in a locked filing cabinet; only the investigators and the staff involved in this study will have access. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected. All information associated with this study will be kept behind locked doors or in secure computer files.

Research records and medical records identifying you may be inspected by representatives of Health Canada and the UBC BCCA Research Ethics Board for the purpose of monitoring the research. However, no records that identify you will be allowed to leave the study centre.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected. All information about you is confidential. Findings may be published in scientific journals but there is no identification of you personally in any of these papers or reports. Information collected on you will be given a code number and maintained in a locked filing cabinet; only the investigators and the staff involved in this study will have access. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected. All information associated with this study will be kept behind locked doors or in secure computer files.

Research records and medical records identifying you may be inspected by representatives of Health Canada and the UBC BCCA Research Ethics Board for the purpose of monitoring the research. However, no records that identify you will be allowed to leave the study centre.

Compensation: You will not be paid for participating in this study.

Rights and Responsibilities: You have read the above information and you have had a chance to ask any questions about the study and your involvement. You understand what you are asked to do and what will happen when you take part in this study. You understand that you can withdraw at any time. If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line at the UBC Office of Research Services at the University of British Columbia. You freely choose to take part in this study.

Contact Information

You understand that if you have any questions or desire further information with respect to this study you can contact one of the study team members, who are:

Dr. Wolfgang Linden, Department of Psychology, University of British Columbia Clinical Psychologist, Professor at UBC and a researcher at the BC Cancer Agency.

Or, Gina MacKenzie, Professional Practice Leader, BC Cancer Agency

Or Dr. Andrea Vodermaier, Research Fellow, University of British Columbia
Subject Consent

I understand that participation in this study is entirely voluntary. I authorize access to my medical record as described in this consent form. I may choose not to participate or withdraw from the study at any time and I will continue to be offered the best available medical care. I understand that I may ask questions about the study in the future.

I will receive a signed copy of this consent form for my own records.

I consent to be a participant in this study.

___________________       __________________________
Subject signature       Printed name

___________________       __________________________
Witness signature       Printed name

___________________       __________________________
Signature of Person Obtaining consent       Printed name       Study role

All copies of the consent form must be signed.
Dear Sir or Madam,

Thank you for taking a moment to speak with one of our research assistants regarding participation in our study. Your commitment to advancing current knowledge about patient well-being during cancer treatment is greatly appreciated. As indicated during our conversation, your participation will involve filling out a brief questionnaire three times over a 12-month period. These questionnaire packages will ask questions relating to your emotional well-being and will take approximately 20 minutes to complete.

To facilitate your participation, we have enclosed two consent forms; one for your personal records, and one to be filled out and sent back to us along with the completed questionnaire package. To ensure an accurate assessment at the beginning of your treatment, we suggest that these two items be completed in a timely fashion that is convenient for you. Once complete, please send both the signed consent form and completed questionnaire package back to us in the enclosed self-addressed stamped envelope.

To ensure that your identity will be kept anonymous, you have been given a research ID code. Please do not put your name on any of the questionnaires.

Please carefully read the instructions for each questionnaire. If you have any questions about completing these questionnaires, please contact Candace or Duncan at the Behavioural Cardiology Lab at the University of British Columbia. Thank you for your time and participation.

Sincerely,

Dr. Andrea Vodermaier, Research Fellow
Dr. Wolfgang Linden, Principal Investigator
Appendix E 6-month Introduction Letter

THE UNIVERSITY OF BRITISH COLUMBIA

BC Cancer Agency
Care & Research
An agency of the Provincial Health Services Authority

Department of Psychology
2136 West Mall
Vancouver, B.C., Canada V6T 1Z4

Research Code:

Study: Emotional Well-Being during Cancer Treatment

Dear Sir or Madam,

Thank you for completing and returning the first questionnaire package. If you recall, our study is examining which type of individual with cancer benefits most from which type of intervention and professional support. We are examining these issues at 6 and 12-month intervals from your initial appointment at BCCA. As such, our records indicate that you are due for your 6-month follow-up.

Given our study protocol has specific time points for measurement, the results you provide via the answers on your questionnaires will be most effective if they are completed and returned to us in the shortest time possible from the time you initially receive them in the mail. As such, please find enclosed a questionnaire package that will ask questions relating to your emotional well-being, health, and demographics. These questionnaires take approximately 20 minutes to complete. To ensure that your identity is kept anonymous, you have been given a research ID code. Please do not put your name on any of the questionnaires.

Once you have completed the questionnaire package, please mail the entire questionnaire package in the enclosed self-addressed stamped envelope. Please carefully read the instructions for each questionnaire. If you have any questions about completing these questionnaires, please contact Candace or Duncan at the Behavioural Cardiology Lab at the University of British Columbia.

Including yourself, we have almost reached our goal of recruiting 500 participants for our study. What a marvelous gift you are giving to others by participating and taking the time to share your experience, thoughts and feelings! That being said, our research team appreciates your time and commitment in participating in our study. As a token of our appreciation, please find enclosed a computer mouse mad with the UBC logo. This particular model was chosen due to the ease of which it is to keep clean from dirt.
and germs as well as its sleek design, which makes it the perfect mouse pad for a backpack or brief case.

Our research time looks forward to your continued participation and wishes you all the best!

Thank you for your time.

Sincerely,

Dr. Andrea Vodermaier, Research Fellow
Dr. Wolfgang Linden, Principal Investigator
Appendix F 12-month Follow-up Introduction Letter

THE UNIVERSITY OF BRITISH COLUMBIA

Department of Psychology
2136 West Mall
Vancouver, B.C., Canada V6T 1Z4

Research Code:

Study: Emotional Well-Being during Cancer Treatment

Dear Sir or Madam,

Thank you for completing and returning your six-month follow-up questionnaire. Our research team appreciates your continued time and commitment in participating in our study.

As you may recall, our study is examining which type of individual with cancer benefits most from which type of intervention and professional support. We are examining these issues at baseline, six and twelve month intervals. As such, our records indicate that you are due for your final assessment; the twelve-month follow-up.

Please find enclosed the last questionnaire package. You will notice that this questionnaire is slightly different from the first two that you completed and sent back to us. After recruiting over 600 participants for this study, we began to question how your cancer diagnosis and treatment might affect your ability to RTW (for those previously in the workforce) or your ability to resume previous activities or hobbies. As such, this questionnaire package continues to look at our original questions relating to your emotional well-being and health, but also includes some brief questions on returning to work and/or regular activities. These questionnaires take approximately 20 - 25 minutes to complete.

To ensure that your identity will be kept anonymous, you have been given a research ID code. Please do not put your name on any of the questionnaires.

Once you have completed the questionnaire package, please mail the entire questionnaire package in the enclosed self-addressed stamped envelope.
Please carefully read the instructions for each questionnaire. If you have any questions about completing these questionnaires, please contact Candace or Duncan at the Behavioural Cardiology Lab at the University of British Columbia.

One last note before we say goodbye. Many of you have naturally expressed interest in the results of this study. Given that full data analysis will not begin until December 2011 when the last of our participants have completed their twelve-month follow-up, results will not be available until the spring of 2012. For those of you interested in those results, please refer to our lab website and click on the ‘Current projects’ or ‘Publications’ tab at the top of the page.

Thank you for your time and commitment!

Sincerely,

Dr. Andrea Vodermaier, Research Fellow
Dr. Wolfgang Linden, Principal Investigator
Appendix G Baseline Demographic Form

DEMOGRAPHICS

Place a ✓ in the appropriate field

AGE: __________

GENDER: 
(1) ______ Female  (2) ______ Male

CURRENT MARITAL STATUS:
(1) ______ Single
(2) ______ Married or common-law
(3) ______ Separated or divorced
(4) ______ Widowed

EDUCATION LEVEL:  
(1) ______ Grade 6 or less
(2) ______ Grade 7-12, without graduating HS
(3) ______ Graduated HS or HS equivalent
(4) ______ Partial Post-Secondary Education
(5) ______ Graduated 2-yr Post-Secondary Program
(6) ______ Graduated 4-yr Post-Secondary Program
(7) ______ Partial Graduate/Professional Program
(8) ______ Completed Graduate/Professional

EMPLOYMENT STATUS
(1) ______ Full-time employee
(2) ______ Part-time employee
(3) ______ Currently unemployed
(4) ______ Retired
(5) ______ Other: Specify: ____________________

HOUSEHOLD INCOME:
(1) ______ Less than $20,000
(2) ______ $20,000-$39,000
(3) ______ $40,000-$59,000
(4) ______ $60,000-$79,000
(5) ______ $80,000-$99,000
(6) ______ $100,000 or more

ETHNICITY:
(1) ______ Caucasian
(2) ______ Asian
(3) ______ First Nations
(4) ______ East Indian
(5) ______ African
(6) ______ Hispanic
(7) ______ Other: Specify: ____________________

Are you a RELIGIOUS person?  
(1) ______ YES  ➜ which religion? ____________  (2) ______ NO

Do you have any CHILDREN under the age of 7 years? 
YES________ ➜ how many?__________  NO______
Are you the CAREGIVER of a person that resides with you?
YES_____ → how many?___________  NO____

Is the current cancer:
(1) _____ your first cancer diagnosis?
(2) _____ a recurrence of the same cancer?
(3) _____ a second and different type of cancer

Have you suffered from a SERIOUS MEDICAL CONDITION in the past apart from cancer?
YES______ if YES, what type of illness?__________________________________________  NO____

Do you have a FAMILY HISTORY of any first degree relatives with cancer?
YES______ if YES, did the disease progress?________________________________________  NO____

CURRENT MEDICATION: Please list below all the medications you are currently taking.
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

Thank you for your responses
Appendix H 6-month Demographic Form

DEMOGRAPHICS

You may recognize some of these questions from the baseline questionnaire you completed 6 months ago. Although it may seem repetitive, some of these questions are of interest to us given they are things that might have changed for you in the past 6 months. Thank you for taking the time to answer them once again.

Place a ✓ in the appropriate field

1. CURRENT MARITAL STATUS:  (1) Single
   (2) Married or common-law
   (3) Separated or divorced
   (4) Widowed

2. EMPLOYMENT STATUS  (1) Full-time employee
   (2) Part-time employee
   (3) Currently unemployed
   (4) Retired
   (5) Other: ___________________________

ff

3. Are you a CAREGIVER of a person that resides with you and has health problems?
   YES_____ → how many?_________ NO_____ 

4. CURRENT MEDICATION(S): Please list below all the medications you are currently taking.

   __________________________________________
   __________________________________________
   __________________________________________
   __________________________________________
   __________________________________________

5. What type of TREATMENT have you received or are currently undergoing for cancer?
   (1) Surgery
   (2) Drugs (Chemotherapy)
   (3) Radiation Therapy (Radiotherapy)
   (4) Other (alternative therapies, please specify)

   __________________________________________

6. Is your current therapy part of a CLINICAL TRIAL? YES_______ NO__________


Appendix I 12-month Demographic Form

Tracking Study: One Year Questionnaire

You may recognize some questions from the 6 month follow up questionnaire AND also notice added questions regarding RTW that are only useful to ask now at the end of the study. Completion is estimated to take about 10-15 minutes. You are of course not required to answer all the questions but we have learned that return-to-work is a very important topic for patients. By seeking answers here, we anticipate that the BC Cancer Agency will be able to provide better continuity of services once acute medical treatment ends.

Please place a ✓ in the appropriate field

1. CURRENT MEDICATION(S): Please list below all the medications you are currently taking.

______________________________
______________________________
______________________________
______________________________
______________________________

2. What type of TREATMENT have you received or are currently undergoing for cancer?

(1)______ Surgery (2)_______ Drugs (Chemotherapy)
(3)______ Radiation Therapy (4)_______ Hormonal therapy
(5) Other (alternative therapies, please specify):

________________________________________________________

3. Did a major change in your health occur since you began the study?

☐ No
☐ Yes, Recurrence of the tumor
    ☐ Localized tumor
    ☐ Distant, metastatic tumor
☐ Other disease: ________________________________

If ‘yes’, when? _______________ (month/year)
4. Has your relationship situation changed since you began the study?

- □ No
- □ Marriage/new common-law relationship
- □ Divorce/breakup
- □ Other: _________________________

If ‘yes’, when? _______________ (month/year)

5. Have you, during the last year, received services from the BC Cancer Agency Patient and Family Counseling?

   YES___________NO___________

6. Have you, during the last year, received services from a psychiatrist, psychologist or counselor outside of the BC Cancer Agency?

   YES___________NO___________

7. Who has supported you since your cancer diagnosis? (check ✓ all that apply)

   - Family ✓ Friends ✓ Online chat groups ✓ Religious group/church
   - Co-workers ✓ BC Cancer Agency support groups
Appendix J PSSCAN

*PSSCAN – Psychological Screening Tool

Please answer the following questions to help us learn more about your well being. A serious illness can affect the quality of your life in many ways. We may contact you to offer our counseling services based on the information you provide to us, or contact you regarding opportunities to participate in research.

Part A Please respond to each question with a simple "Yes" or "No" by making a circle around the appropriate answer or by circling a number. There are no right and wrong answers.

1. Do you live alone? YES NO
2. When you need help, can you count on anyone to help with daily tasks like grocery shopping, cooking, giving you a ride? YES NO
3. Do you have regular contact with friends or relatives? YES NO
4. Have you lost your life partner within the last few years? YES NO
5. Can you count on anyone to provide you with emotional support? YES NO
6. Do you feel that you want and need this kind of emotional support? No, not at all 0 1 2 3 4 5 6 7 8 9 10 Very much

Part B: Please circle the number that best describes how you feel:

7. Would you say that in general your health is:
   Very Poor 0 1 2 3 4 5 6 7 8 9 10 Excellent

8. Would you say that in general your quality of life is:
   Very Poor 0 1 2 3 4 5 6 7 8 9 10 Excellent

9. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? _________days
10. Now thinking about level of stress, depression, and problems with emotions, for how many days during the past 30 days was your mood not good? __________ days

11. During the past 30 days, for about how many days did poor physical or emotional health keep you from doing your usual activities, such as self-care, work, or recreation? __________ days

**Part C: Please place an ‘x’ in the box that best describes what you have experienced**

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<th>12. During the past week</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately so</th>
<th>Quite a bit</th>
<th>Very much so</th>
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<td>I have felt that my heart races and I tremble.</td>
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<th>Moderately so</th>
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<th>Very much so</th>
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<tbody>
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<td>I have felt that I cannot control anything.</td>
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<th>Moderately so</th>
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<th>Very much so</th>
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<tbody>
<tr>
<td>I have lost interest in things I usually cared for or enjoyed.</td>
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<th>Very much so</th>
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<td>I have felt nervous and shaky inside.</td>
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<th>Very much so</th>
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<tbody>
<tr>
<td>I have felt tense and can’t relax.</td>
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<th>Moderately so</th>
<th>Quite a bit</th>
<th>Very much so</th>
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<tbody>
<tr>
<td>My thoughts are repetitive and full of scary things.</td>
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<th>18. During the past week</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately so</th>
<th>Quite a bit</th>
<th>Very much so</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have felt restless and find it difficult to sit still.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>19. I have recently thought about taking my life.</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately so</th>
<th>Quite a bit</th>
<th>Very much so</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>20. In the past year, I have had 2 weeks or more during which I felt sad, blue, or depressed.</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately so</th>
<th>Quite a bit</th>
<th>Very much so</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>21. I have had 2 years or more in my life when I felt depressed or sad most days even if I felt o.k. sometimes.</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately so</th>
<th>Quite a bit</th>
<th>Very much so</th>
</tr>
</thead>
</table>

*Thank you for taking the time to respond to this form.*
Appendix K IIRS

**IIRS**

The following items ask about how much your illness and/or its treatment interfere with different aspects of your life. **PLEASE CIRCLE THE ONE NUMBER THAT BEST DESCRIBES YOUR CURRENT LIFE SITUATION.** If an item is not applicable, please circle the number one (1) to indicate that this aspect of your life is not affected very much. Please do not leave any item unanswered. Thank you.

**How much does your illness and/or its treatment interfere with your:**

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>HEALTH</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Very Much</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>2.</td>
<td>DIET (i.e., the things you eat and drink)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Very Much</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3.</td>
<td>WORK</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Very Much</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4.</td>
<td>ACTIVE RECREATION (e.g., sports)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Very Much</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5.</td>
<td>PASSIVE RECREATION (e.g., reading, listening to music)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Very Much</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6.</td>
<td>FINANCIAL SITUATION</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Very Much</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7.</td>
<td>RELATIONSHIP WITH YOUR SPOUSE (girlfriend or boyfriend if not married)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Very Much</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>8.</td>
<td>SEX LIFE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Very Much</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
How much does your illness and/or its treatment interfere with your:

9. **FAMILY RELATIONS**
   Not Very Much  1  2  3  4  5  6  7  Very Much

10. **OTHER SOCIAL RELATIONS**
    Not Very Much  1  2  3  4  5  6  7  Very Much

11. **SELF-EXPRESSION/SELF-IMPROVEMENT**
    Not Very Much  1  2  3  4  5  6  7  Very Much

12. **RELIGIOUS EXPRESSION**
    Not Very Much  1  2  3  4  5  6  7  Very Much

13. **COMMUNITY AND CIVIC INVOLVEMENT**
    Not Very Much  1  2  3  4  5  6  7  Very Much
Appendix L PTGI

PTGI

Instructions

Indicate for each of the following statements the degree to which the change reflected in the question is a result of your experience with cancer.

Please use the following scale:

0= I did NOT experience this change as a result of my experience with cancer.
1= I experienced this change to a VERY SMALL degree as a result of my experience with cancer.
2= I experienced this change to a SMALL degree as a result of my experience with cancer.
3= I experienced this change to a MODERATE degree as a result of my experience with cancer.
4= I experienced this change to a GREAT degree as a result of my experience with cancer.
5= I experienced this change to a VERY GREAT degree as a result of my experience with cancer.

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I changed my priorities about what is important in life.</td>
<td></td>
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<tr>
<td>2. I have a greater appreciation for the value of my own life.</td>
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<tr>
<td>3. I developed new interests.</td>
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<tr>
<td>4. I have a greater feeling of self-reliance.</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>5. I have a better understanding of spiritual matters.</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>6. I more clearly see that I can count on people in times of trouble</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>7. I established a new path for my life.</td>
<td></td>
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</tr>
<tr>
<td>8. I have a greater sense of closeness with others</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>9. I am more willing to express my emotions.</td>
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<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
10. I know better that I can handle difficulties.  

11. I am able to do better things with my life.  

12. I am better able to accept the way things work out.  

13. I can better appreciate each day.  

14. New opportunities are available which wouldn’t have been otherwise.  

15. I have more compassion for others.  

16. I put more effort into my relationships.  

17. I am more likely to try to change things which need changing  

18. I have a stronger religious faith.  

19. I discovered that I’m stronger than I thought I was.  

20. I learned a great deal about how wonderful people are.  

21. I better accept needing others.
Appendix M RTW

With the questions below we also want to learn about return-to-work for those patients who were in the workforce when they were diagnosed with cancer. As with earlier surveys, all your answers will be treated confidentially.

Not all questions below may be relevant for you and you may be asked to jump ahead to other questions.

W1: Did you work outside the home at the time of your diagnosis?

☐ Yes [If ‘yes’ Please continue with all the questions.]

☐ No [If ‘no’, you have completed the questionnaire, you can stop here, thank you!]

☐ Yes [Please continue.]
   If ‘yes’, what kind of job?

☐ Self-employed
☐ White-collar
☐ Blue-collar

☐ Full-time
☐ Part-time,
   If ‘part-time’, how many hours per week? __________

Do you feel you can meet the demands of your job?

☐ Yes
☐ No, If ‘no’, what do you think is the reason for it?
   __________________________________________________________________
   __________________________________________________________________

W2: Provided that you were working at the time of your cancer diagnosis, did you continue to work during active treatment (chemotherapy and/or radiation)?

☐ Yes, during chemotherapy
☐ Yes, during radiation
☐ Yes, both during chemotherapy AND radiation
☐ No
W3: If you were working at the time of your cancer diagnosis, have you returned to work since?

☐ Yes, if ‘yes’ then please continue with the remaining questions and fill out questionnaire A

☐ No, if you marked ‘no’, please answer the following question: What prevented you from returning to work?

________________________________________________________________

________________________________________________________________

If you have not returned to work, please fill out questionnaire B and you will have finished the survey. We thank you.

If ‘yes’, how many months did you take off from the diagnosis of cancer until you went back to work? __________ months

W4: How many months had you been on sick leave after your cancer diagnosis?

__________ months

W5: Which type of employment do you have?

☐ Self-employed
☐ White-collar
☐ Blue-collar

W6: What is the extent of your work?

☐ Full-time
☐ Part-time

If ‘part-time’, what are your weekly hours? __________ hours per week

W7: Did you change your position since you came back to work?

☐ Yes
☐ No

If ‘yes’, what type of change? [If appropriate, multiple answers are possible.]

☐ Change of work place or type of work
Promotion within company or job I like better
☐ Had to accept a less well paid position
☐ Had to accept a position I enjoy less

W8: What is your overall judgment regarding your RTW?

Please circle on this numbered scale where 0 means the situation at work improved, 3, that there was no change, and 6, that the situation at work became worse, which judgment is most appropriate to your situation.

Since I had returned to work
my work situation has
improved              not changed              worsened
0------1------2------3------4------5------6

W9: To what degree have you been able to resume activities like volunteering or hobbies?

☐ I completely went back to my previous level of activities.
☐ For the most part, I went back to my previous level of activities.
☐ To some extent I could go back to my previous levels of activities.
☐ For the most part, I had to give up my previous activities.

W10. Have you developed new interests or activities as a result of having gone through the cancer experience?

☐ Yes
☐ No

If yes, which ones

__________________________________________________________________________________________
__________________________________________________________________________________________
____
**RTW A:** Please answer the following questions regarding your work situation by circling the number that best describes what you have been thinking or feeling during the last four weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>do not agree/ not applicable</th>
<th>agree very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I really enjoy my work.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>2. My colleagues are considerate of my disease.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>3. I feel tired most days at work.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>4. I have to work because I need the money.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>5. My job supervisor tries to make things easier for me at the workplace.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>6. Being back at work helps me to recover.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>7. I have noticed difficulties with my memory at work.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>8. Working prevents me from getting caught up in my thoughts.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>9. My job supervisor is considerate of my disease.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>10. What I do outside my job is more important than my work.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>11. The physical demands of work are now more of a burden than they used to be.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>12. I have problems concentrating on my work tasks.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>13. I no longer feel needed at my workplace.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>14. Worry about my illness keeps me from working as well as I used to.</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
<tr>
<td>15. I feel comfortable sharing details</td>
<td>0----1----2----3----4----5----6</td>
<td></td>
</tr>
</tbody>
</table>
about my illness with my colleagues.

16. My job is varied and stimulating. 0-----1-----2-----3-----4-----5-----6

THANK YOU VERY MUCH!
Appendix N Worries

**Worries**

To what extent are you concerned about...

- **future diagnostic tests.**
  - [ ] not at all
  - [ ] a little bit
  - [ ] somewhat
  - [ ] very much

- **another type of cancer.**
  - [ ] not at all
  - [ ] a little bit
  - [ ] somewhat
  - [ ] very much

- **my cancer coming back.**
  - [ ] not at all
  - [ ] a little bit
  - [ ] somewhat
  - [ ] very much

- **dying.**
  - [ ] not at all
  - [ ] a little bit
  - [ ] somewhat
  - [ ] very much

- **my health.**
  - [ ] not at all
  - [ ] a little bit
  - [ ] somewhat
  - [ ] very much