

The Experience of Well-being in the Midst of Advanced Cancer

by

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of the Requirements for the Degree of

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## Abstract

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People with advanced cancer may have significant challenges to their physical, emotional, spiritual, and social well-being. However, some individuals are able to experience an overall sense of well-being in spite of these challenges. This study sought to understand the experience of well-being from the perspective of people with advanced cancer. Guided by interpretive descriptive methodology, eight participants were interviewed and the data were analyzed using the constant comparative approach. The participants took an active role in their well-being experience and described four main themes: view of self, the fluctuating nature of well-being, choices made to enhance well-being (including choosing supportive relationships, putting one's own needs first, treatments, focusing on the positive, and honoring the negative), and living in ambiguity. These findings have implications for nursing practice, nursing education, and health care organizations.

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## **Dedication**

This work is dedicated to the participants who were willing to give of themselves, to share what they have learned and how they have grown in the midst of their illness. I have been honored to bear witness to your tenacity and resilience. I will be forever changed because of you.

## Chapter 1 - Introduction

During a home care nursing shift, I was assigned to visit a client who had a progressive debilitating condition. As I read the chart, I found that she frequently spent weeks in the hospital receiving blood transfusions. The charting described her as very weak, frequently in pain, highly sensitive to bright light, and unable to swallow well. As a result, she spent much of her time lying down in semi-darkness and had to force herself to eat pureed food. She was described as a dancer and an artist who had traveled all over the world, but because of her illness, she was no longer able to do any of the things that previously brought her pleasure. I anticipated a depressing visit, where I would feel discouraged at the futility of her life and frustration that I could not do anything to change her situation.

As I entered her dimly lit living room I was struck by the beauty of the artifacts all around the room. There were splendid paintings hanging on every wall, adding vivid color to the shadows. I then sat on a footstool across from my patient. As I met her eyes, I encountered a serenity and joy that took me by surprise.

I quickly assessed her symptoms and planned for her next hospital admission. She said that it was exhausting to be repeatedly admitted to hospital and she wished she could be pain free. Then I forgot about paperwork and finishing my shift as I listened to her talk. Although she was unable to do any of her previous activities, she told me how thankful she was for her life experiences

and how she loved to remember the places she had visited. Her granddaughter was also a dancer, and she spoke of the pleasure she received from her frequent visits. She showed me pictures of herself as a young, healthy ballerina.

I was struck by how off the mark my expectations of meeting this woman were. I assumed she would be suffering in every aspect of her being, yet she seemed settled. I wanted to ask her, "Why aren't you depressed?" Instead, I asked, "Where do you find the strength to deal with everything you are going through?" She could not give me an answer.

As I drove back to my health unit, I wondered how someone whose illness had invaded her life could have such joy. Why wasn't she depressed? How did she have the tenacity to face her trials without allowing them to destroy her spirit? Where did her strength come from? As I pondered these questions, several other people came to mind who had faced the challenges of a life-threatening illness, but seemed to have well-being in the midst of it. In the weeks that followed, I discussed my observations and reflections with colleagues and found that they, too, had cared for people who stood out in their memory as being able to rise above serious illness with optimism and joy. Well-being in the midst of life-threatening illness did not seem to be isolated to this one person. I realized that an understanding of this phenomenon had potential implications for nursing practice, health care organizations, policy and program development, education, and research. Therefore, it warranted further exploration.

## Background

People who are diagnosed with advanced cancer experience significant challenges because of their illness (Yarbro, Frogge, & Goodman, 2005). Cancer treatment and disease may lead to a variety of physical symptoms such as nausea, fatigue, hair loss, body structural changes, bowel changes, loss of appetite, skin changes, and pain (Yarbro, Frogge, & Goodman, 2005). Physical symptoms have been shown to diminish well-being and have been correlated with depression and emotional distress (Chen & Chang, 2004; Lobchuk & Bokhari, 2008). As a result of physical changes, people may feel that their body is against them (Rydahl-Hansen, 2005).

Emotional suffering can also result from a diagnosis of advanced cancer and may lead to disruption in a person's sense of value to society (Zalenski & Raspa, 2006). Such feelings often lead people to evaluate their contribution to the world throughout their lifetime (Kuhl, 2003). Emotional suffering can also be caused by the challenge to retain a sense of identity in light of physical limitations (Zalenski & Raspa, 2006). An example would be a man who identifies himself as an athlete, and his illness prevents him from doing physical activity. This would increase the gap between his view of himself before and after the illness (Carter, MacLeod, Brander, & McPherson, 2004). When the perception of self is inconsistent, a person cannot feel "self-actualized" (Zalenski & Raspa, 2006). Self-actualization is described by Kuhl (2003) as being authentic and "living in the truth" (p. 229).

Of the losses that may occur because of advanced cancer, one of the most salient for people is loss of control over what is happening to them (Herth, 2000). Patients often state they do not have a clear understanding of their diagnosis, prognosis, or what they will experience as their disease progresses (Beckstrand, Callister, & Kirchhoff, 2006). The fear of the unknown and imagined scenarios of death can be overwhelming (Zalenski & Raspa, 2006). There is sometimes a spiritual crisis that occurs when a person discovers they have an untreatable illness and begins to contemplate their death (Kuhl, 2003). This crisis may be due to a fear of the afterlife, as reflected in a Gallup poll in 1997 (cited in Breitbart, 2004) which asked people to identify their greatest fear of dying. Fifty to sixty percent of respondents reported their greatest concern was of not being forgiven by God or of being separated from a higher power. The crisis may also arise from existential anguish as they question the reason for their illness (Taylor, 2000).

Challenges to social relationships can also occur when people are diagnosed with a life threatening illness such as advanced cancer. People may have a limited ability to give and receive affection because they are reluctant to be perceived as a burden, fear being unlovable because of physical changes, and may have a perception of not belonging (Chochinov, Krisjanson, Hack, Hassard, McClement, & Harlos, 2006; Downing, 1998; Kuhl, 2003; Zalenski & Raspa, 2006). Some people are concerned for their family, in the present time and after their anticipated death (Wayman & Gaydos, 2005). As a result of these

challenges, people sometimes feel very socially isolated (Blinderman & Cherny, 2005).

In spite of the potential for distress and suffering caused by the challenges of life-threatening illness, some people describe themselves as happy and satisfied with their lives (Sahlberg-Blom, Ternstedt, & Johansson, 2001); they are able to maintain social and spiritual well-being (McMillan & Weitzner, 2000). Blinderman and Cherny (2005) interviewed people with advanced cancer and found that while they had considerable existential concerns, many were not in distress. The researchers attributed this finding to the early timing of palliative care, effective coping strategies, social support, and religious beliefs.

Kendall (2006) asked nurses what they admired about patients with life-threatening illness. The nurses described people who inspired them because of their courage, determination, and tenacity as they struggled to maintain physical functioning with a fighting spirit. In contrast to those who fight and struggle, another study by Block (2001) found there are also people who have a calm acceptance of their prognosis and are perfectly content with the thought of coming to the end of their lives. Some people find that, while their circumstances are very difficult, they discover or develop an inner strength to effectively cope (Kendall; Lipsman, Skanda, Kimmelman, & Bernstein, 2007); they are able to learn from and see positive benefits from their illness, saying it has caused them to grow in ways they would not have done otherwise (Block, 2001; Lipsman et al., 2007). Some research suggests that people see their illness as an

opportunity to learn about themselves and grow in their relationships with others (Block). In short, people with cancer may experience well-being even in the midst of advanced disease.

### **Statement of the Problem**

The phenomenon of well-being during life-threatening illness has been observed by clinicians and been the focus of study by researchers. However, this phenomenon is not well understood from the point of view of people experiencing it. Mount and colleagues argue that well-being can only be understood as a subjective assessment of self (Mount, Boston, & Cohen, 2007). However, there is limited research which elicits individual subjective experience. Kiefer (2008) notes that many tools have been used to measure the concept of well-being, but agrees with Cohen and Mount (1992) that the questions asked do not fully capture the complexity of the concept. There is a need to understand how people define well-being for themselves and what they perceive to be the antecedents to their own well-being (Cohen & Leis, 2002). As Kiefer states, “although the current research environment has emphasized the importance of well-being, little emphasis has been placed on this concept from the individual’s point of view or perspective. The definition of well-being is usually assumed or lacking in clarity.” (Kiefer, 2008, p. 249)

### **Purpose of the Study**

The overall purpose of this study was to gain a better understanding of how people with advanced cancer experience well-being in spite of significant

challenges. The research question guiding this study was: “*What is the experience of well-being in the midst of advanced cancer?*”

### **Definition of Terms**

For the purpose of this study, the following terms were defined:

*Advanced cancer* is “a disease in which there is little chance of cure and in which the aim of treatment is usually to achieve palliation” (Redmond, 1998, p. 31). This definition was chosen over “terminal cancer” or “incurable cancer” because the latter terms are not often used at the British Columbia Cancer Agency (BCCA) (where recruitment occurred) and may have had negative connotations for both health care providers and patients. In discussion with health care providers at BCCA, “advanced” seemed to be the most acceptable and frequently used term to describe cancer that will likely lead to death.

The term *well-being* has been conceptualized in various ways in the literature. For example, it has been defined as “a positive evaluation of one’s life associated with positive feelings” (Kiefer, 2008, p. 248). For the purposes of this study, people who are experiencing well-being are those who “still [have] health issues, and grief and life challenges, but they [describe themselves as] whole and well” (Wayman & Gaydos, 2005, p. 269). This definition acknowledges that people with advanced cancer do have challenges, as previously discussed. Importantly, the emphasis of this definition is on the subjective experience of well-being, rather than on objective measures or assumptions of what well-being means.

## **Assumptions and Beliefs**

As I will discuss further in chapter 3, I began this study with strong assumptions and beliefs that have been challenged by my experience of conducting this research. Specifically, I entered the study believing that most people experience well-being because of a belief in a higher power, or having a strong sense of spirituality. I also assumed that people experienced emotional or spiritual well-being by somehow transcending their physical distress.

I assumed that being aware of a diagnosis of advanced cancer meant the participants would be expecting to die from their illness and actively preparing for their death. I also assumed that the adversity of a life-threatening illness would be perceived as different from other adversities in life and would require new skills and strategies to cope with it. All of these assumptions and beliefs were challenged in the course of doing this study.

## **Potential Significance**

Being diagnosed with advanced cancer is often seen as a devastating circumstance. Findings of this study have the potential to challenge current conceptualizations. This study has potential application for nursing practice and for nursing and health care research. If the experience of people with advanced cancer who experience well-being can be better understood, further research may be done to find ways nurses and other health care providers can support people to maintain their well-being or to develop it when they are struggling. This improved understanding could be incorporated into nursing education programs

as well. This study also has potential implications for health care organizations and policy and program development. In health care for people with life-threatening illness, the goal of care is quality of life and enhancing well-being (Cohen & Mount, 1992). Therefore, an understanding of how people with advanced cancer are able to experience well-being could inform the way health care is provided to this population and could inform the development of programs and policies directed toward enhancing well-being in the advanced cancer population.

In addition to these pragmatic applications there is another less tangible but significant potential benefit: The health care providers I have spoken with as well as my read of the literature suggest that many providers are inspired by their interactions with people who experience well-being in the midst of life-threatening illness (Block, 2001; Kendall, 2006). Dissemination of the findings of this study may lead to a more wide-spread sense of hope amongst health care professionals in the human spirit to thrive in the midst of very challenging circumstances.

### **Organization for the Remainder of the Thesis**

Having laid out the background and purpose for my study, defined my terms and assumptions and beliefs, in chapter 2, I review previous studies about well-being in advanced cancer and related themes. In chapter 3, I outline the methods and methodology of my research. In chapter 4, I present the findings as they have been interpreted, in keeping with the methodology of interpretive

description. In chapter 5, I discuss the findings in light of current knowledge, describe my understandings as a result of this research, and suggest implications for nursing practice, education, leadership and research.

## Chapter 2 – Review of the Literature

The purpose of a literature review is to establish what is already known about a topic (Patton, 2002) and to ascertain the need for the proposed research in light of what is known and not yet known (Thorne, 2008). Interpretive description is intended to produce knowledge that is applicable to nursing practice and other health care disciplines. Therefore, before embarking on a new study, one should demonstrate that there is a phenomenon observed clinically which is not well understood, and that further understanding would impact practice (Thorne, 2008). As mentioned in chapter 1, I have observed people in my nursing practice who seem to be experiencing well-being in the midst of a life-threatening illness. My observation has been confirmed by many health care providers in palliative care and cancer treatment settings. Although well-being has been observed, neither I nor my colleagues had a clear understanding of the phenomenon. Thus, Thorne's first criterion has been met in terms of a clinically observed phenomenon. Next, I needed to review the existing literature to determine the state of knowledge in nursing and health research. Once what is known about a phenomenon has been established, Thorne recommends creating a "theoretical scaffolding" (Thorne, 2008, p. 54), which serves to outline the themes from current literature, as well as the researcher's own theoretical stance from clinical experience and their particular discipline.

In this chapter, I will describe how I searched the literature, the themes that arose about how people with life-threatening illness, specifically advanced cancer, experience well-being, present the theoretical scaffolding that supported

decisions about data collection and analysis, and discuss the need for my study in light of what is already known.

### **Search of the Literature**

I searched the CINAHL, Medline and PsychArticles databases using the following terms: “quality of life,” “coping,” “positive attitude,” “healing,” “well-being,” and “wellness” as linked to the terms “dying,” “life-threatening illness,” “advanced cancer,” “terminal cancer,” and “palliative”. I examined studies which sought to understand what contributes to well-being or similar phenomena in people with life-threatening illnesses. “Well-being” was not always the term used, but similar phrases or terms were found in studies focused on “positive outlook,” “quality of life,” and “coping”. I consistently refer to the phenomenon of interest as “well-being” in order to maintain clarity throughout this review. The two overall themes found in the literature were: (1) Well-being in one or more dimensions of self (physical, emotional, social, and spiritual) and (2) Approach to life and illness.

### **Well-being in Dimensions of Self**

Advanced cancer, as a life-threatening illness, is “an assault on the whole person - physical, psychological, social, and spiritual” (Mount, Boston, & Cohen, 2007, p. 372) and, “the dying experience affects all dimensions of an individual” (Prince-Paul, 2008, p. 365). It could be predicted, then, that people with advanced cancer would experience suffering holistically. For example, if they had severe physical symptoms, they would also experience distress emotionally,

socially, and spiritually. However, as Mount, Boston, and Cohen (2007) observed in their phenomenological study, some people with significant pain or other physical symptoms may not be suffering overall, and conversely, others without any physical symptoms may “suffer terribly” (p. 372).

Other researchers have also found that well-being in one or more dimensions of self can result in overall well-being in spite of suffering in one dimension. As Cohen and Mount (1992) suggest: “It would appear that considerable suffering in one domain [dimension] may be overridden by an enhanced sense of personal meaning in another, resulting in a net increase in quality of life, in spite of the co-existing suffering” (p. 41). In the following sections, I describe studies in terms of the dimension explored by the researchers: physical, emotional, social, and spiritual. The association between the dimension of interest and overall well-being will be discussed.

### **Physical well-being.**

The presence, number, and severity of physical symptoms has been associated with poor emotional (Chen & Chang, 2004; Lloyd-Williams, Dennis, & Taylor, 2004; Lobchuk & Bokhari, 2008) and social well-being (Steginga, Lynch, Hawkes, Dunn, & Aitken, 2009) in people with life-threatening illness. Chen and Chang (2004), using the Hospital Anxiety and Depression Scale (HADS) for participants with advanced cancer, found that physical symptoms were significantly associated with anxiety and/or depression. In addition, participants with multiple symptoms had higher rates of depression than those with only one

symptom. Lloyd-Williams, Dennis, and Taylor (2004) were testing a verbal screening tool for depression with participants from a palliative cancer clinic. While the researchers found that the new screening tool was not effective for identifying depression, they did confirm that physical symptoms were associated with depression when it was diagnosed by interviews with a psychiatrist.

Tuesnissen, de Graeff, Voest, and de Haes (2007) used the HADS, the Edmonton Symptom Assessment System (ESAS), and a single “yes/no” question to determine if people hospitalized with advanced cancer were anxious and/or depressed. They assessed physical symptoms of the participants using ESAS and a semi-structured interview. In contrast to other studies, these researchers found that physical symptoms were not significantly associated with emotional distress. The authors hypothesized that the difference between their findings and those of other researchers may be due to their participant group, who had lower functional status and were closer to death than participants in the majority of other studies. The participants in Chen and Chang’s study (2004) had a high mean functional status and were earlier in the disease trajectory and Lloyd-Williams, Dennis, and Taylor’s (2004) participants were mobile with little assistance. Tuesnissen, de Graeff, Voest, and de Haes postulated that the association between depressed mood and symptom severity may decrease as disease progresses. This may be the case and would require further research. However, other studies have shown that for some people, well-being in other dimensions of their lives (emotional, social, or spiritual) enables them to

experience a general sense of well-being despite physical symptoms or decreased functional abilities.

### **Emotional well-being.**

People with advanced cancer may experience diminished emotional well-being due to the physical effects of their disease (Beckstrand, Callister, & Kirchhoff, 2006; Kuhl, 2003; Zalenski & Raspa, 2006), fear about anticipated physical symptoms (Kuhl, 2003), or a perception of uncertainty (Beckstrand, Callister, & Kirchhoff, 2006; Heyland, Dodek, Rocker, Groll, Gafni, Pichora, et al., 2006). However, this may not always be the case. Many people seem to be able to see positive aspects of their illness even when they are aware they will likely die from it. They may find that, while their circumstances are very difficult, they discover or develop an inner strength to effectively cope (Kendall, 2006; Lipsman, Skanda, Kimmelman, & Bernstein, 2007). Sahlberg-Blom, Ternstedt, and Johansson (2001) used the EORTC QLQ-C30 (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire) and a psychosocial well-being questionnaire to assess the quality of life of 47 cancer patients in their last month of life. Although the participants' physical functioning was much lower than the general population on the EORTC QLQ-C30, they had similar emotional functioning to people without cancer on the same questionnaire. As well, on the other psychosocial well-being questionnaire, about one-third of participants rated themselves as "happy" or "somewhat happy" (p. 555), and half were "satisfied" or "somewhat satisfied" (p. 555) overall.

Zalenski and Raspa (2006) postulate that people who are dying will experience well-being if they have reached the highest level of needs achievement in Maslow's hierarchy (Maslow, 1970). Maslow's pyramid of human needs starts with physiologic needs and progresses in ascending order to needs of safety, love / belonging, esteem and finishing with self-actualization. Zalenski and Raspa applied their theory to one palliative care patient who they used as an exemplar. They found that once his needs on the lower levels of the hierarchy were met, he was able to progress to meeting needs on the higher levels. In conclusion, they stated; "a person who is able to meet the range of human needs described in the pyramid could be considered healed despite the absence of a cure for terminal illness" (p. 1126).

### **Social well-being.**

Although many studies have reported that life-threatening illness poses a significant challenge to social relationships (Blinderman & Cherny, 2005; Chochinov et al., 2006; Downing, 1998; Kuhl, 2003; Wayman & Gaydos, 2005; Zalenski & Raspa, 2006), other studies have found that social relationships have been maintained (McMillan & Weitzner, 2000) or strengthened at end-of-life (Prince-Paul, 2008). Furthermore, Lobchuk and Bokhari (2008) found that while depression was associated with physical symptoms, the experience of these symptoms seemed to be mitigated by the presence of empathic social support.

McMillan and Weitzner (2000) did a secondary analysis of data from a previous study (McMillan & Weitzner, 1998) which used the Hospice Quality of

Life Index (HQLI) with 231 people with advanced cancer. The HQLI asks the participants to rate their well-being from 0 (severe problem) to 10 (no problem) for 28 potential problem areas. The secondary data analysis revealed that the participants had the lowest scores for functional well-being and the highest scores for social/spiritual well-being. The researchers concluded that people are able to maintain satisfactory relationships with family and friends as well as with God despite functional decline and physical symptoms.

Prince-Paul (2008) conducted a qualitative study interviewing eight terminally ill patients to understand the meaning of social relationships at the end of life. Although relationships were challenged by changes in role function and physical decline, the participants reported that their connection to others was strengthened overall. The knowledge that they were dying increased the value they placed on relationships. Relationships that were previously strained had moments of healing and reconnection. Participants expressed a need to be surrounded by family and friends, stating that participating in social activities gave them a purpose and a feeling of belonging. Another theme that arose was the need to give back to others in acts of gratitude. The participants all expressed a strong desire to express their love and to feel connected to their loved ones.

### **Spiritual well-being.**

A diagnosis of life-threatening illness may lead to a spiritual crisis and diminished spiritual well-being (Breitbart, 2004; Kuhl, 2003; Taylor, 2000).

Alternatively, spirituality may be a source of well-being for people who use spiritual practices to find meaning and purpose (Baldacchino and Draper, 2001). Spirituality may or may not be linked to religion, but usually includes a connection to a transcendent higher power (Sand, Olsson & Strang, 2008).

Spiritual well-being was associated with physical and psychological well being of 95 advanced cancer patients in a study by Laubmeier, Zakowski, and Bair (2004), which used a questionnaire developed for the study to measure “perceived life threat” (p. 50). The researchers also used the Spiritual Well-being Scale, the Brief Symptom Inventory, and the Functional Assessment of Cancer Therapy-General Scale. Laubmeier et al. found that high levels of spiritual well-being were associated with less overall distress and symptom severity regardless of how life-threatening the participants perceived their illness to be. Similarly, Meraviglia (2004) surveyed 60 adults with lung cancer using the Life-Attitude Profile-Revised, Adapted Prayer Scale, Index of Well-Being, Symptom Distress Scale, and a cancer characteristics questionnaire. She found that spirituality, meaning in life, and prayer had a positive effect on psychological well-being and overall well-being. Moreover, prayer was associated with lower symptom distress.

Tatsumura, Maskarinec, Shumay, and Kakai (2003), used semi-structured interviews with 143 cancer survivors to determine the role of spiritual resources in their illness experience. Connection to God was found to serve many purposes for participants; some stated that God had healed them of their cancer

while others said that prayer and daily connection with God helped them make treatment decisions, bear emotional pain, and have inner peace. It seemed to be the connection to something beyond the physical that helped the participants to cope with their illness:

Somehow, if you rely on a power source beyond yourself, you can bear a lot more things. Whether it is physical pain or whether it is emotional pain, like worrying, you know you are able to just let go and let God worry about it. (p. 67)

In summary, the literature reviewed has provided support to the claim that well-being in one or more aspect of self can enable people with advanced cancer to experience well-being overall even when distressed in another dimension. However, the majority of these studies used quantitative methodologies, a limitation that will be further discussed. The two qualitative studies I reviewed focused on the effect of only one domain as it related to over-all well-being. Prince- Paul (2008) sought to understand social well-being, while Tatsumura et al. (2003) explored spiritual well-being.

### **Approach to Life and Illness**

The way people approach their illness may reflect how they have reacted to adversities in previous times of their lives. Many studies have found that a positive view of oneself and past successful coping enhances well-being in life-threatening illness (Block, 2001; Lethborg, Aranda, Bloch, & Kissane, 2006; Lipsman, Skanda, Kimmelman, & Bernstein, 2007; Mount, Boston, & Cohen,

2007; Ramfelt, Severinsson, & Lutzen, 2002; Reb, 2007). According to Coyle (2006), people with a pattern of maintaining control of their lives and having an optimistic philosophy towards difficulty may be better equipped to maintain well-being with a diagnosis of advanced cancer. The next studies to be presented explored the effect of a “take charge” approach or a “positive” outlook and how this influenced well-being in life-threatening illness.

### **Taking charge.**

Loss of control has been identified as one of the most salient concerns of people with life-threatening illness (Cohen & Leis, 2002; Reb, 2007). It makes sense, then, that people who are able to maintain some control have enhanced well-being (Carter, MacLeod, Brander & McPherson, 2004; Coyle, 2006; Reb, 2007). Carter, MacLeod, Brander, and McPherson (2004) interviewed 10 people living with terminal cancer to ascertain what their priorities were. This research group had noted that standard assessment tools may have limited ability to capture the holistic nature of people’s experience. Using grounded theory, they asked open-ended questions rather than asking about themes that had been determined beforehand. Following data analysis, “taking charge” (p. 614) emerged as the most dominant theme. The participants were actively engaged in their dying process and needed to be in control of the entire experience, from management of their symptoms to developing their own philosophy of living in the face of death.

Reb (2007) also used grounded theory to explore the ways that 20 women who had been diagnosed with advanced ovarian cancer transformed a “death sentence” (p. E70) into hope. Reb found that the participants went through three phases of transformation: shock, aftershock, and rebuilding. In each phase, they used strategies to maintain control. They controlled the nature and amount of information they received from health care providers, who would form their support network, how their symptoms would be managed, and what goals they would attempt to achieve. This sense of control was identified by the participants as crucial to their ability to hope. One participant stated, “Hope is just a realistic expectation of things getting better. That’s what I gotta have...I want to be able to control living” (p. E75).

Henselmans, Sanderman, Helgeson, de Vries, Smink, and Ranchor (2010), using questionnaires and face-to-face interviews, found that a strong sense of control over illness was related to capacity for adaptation for women with breast cancer. The participants stated that their sense of control was enhanced by “maintaining a positive attitude, accepting treatment, and adopting a healthy lifestyle” (p. 525). Furthermore, the people who reported feeling in control over their illness also had a strong sense of control over their lives as a whole. The researchers stated that people with a sense of control over their illness are better able to adapt their life to accommodate the challenges associated with illness.

In Coyle's (2006) exploratory study, seven people with advanced cancer were interviewed using a semi-structured format. Similar to Reb (2007), Coyle also found that the participants were all actively engaged in maintaining control by designing their own support system, finding meaning, creating legacy, making lifestyle choices, and choosing treatments. Some participants believed in their ability to control their illness even to the point of curing themselves, as one participant stated, "my mind permitted me to get [advanced cancer] and my mind could cure [the cancer]. I had to change my lifestyle." (p. 269). Coyle's participants described their efforts to maintain control as the "hard work of living in the face of death" (p. 266).

#### **Attitude / outlook.**

There is a common discourse in North American media that a positive attitude towards cancer improves survival and well-being (Henselmans, Sanderman, Helgeson, Vries, Smink, & Ranchor, 2010; O'Brien & Moorey, 2010). Some describe positive attitude with military or combat language by referring to a person's "battle against [cancer]" or their "fighting spirit" (O'Brien & Moorey, 2010. p. 1239). O'Brien and Moorey (2010) did a literature review of quantitative studies that used a variety of tools to identify themes related to successful adjustment to advanced cancer. Although the authors stated that there were methodological issues with each of the eight studies reviewed, they were able to make a few tentative conclusions. They speculated that positive attitude is associated with better emotional adjustment to advanced cancer. In

contrast to fighting terminology, O'Brien and Moorey used the term "positive attitude" (p. 1247) to describe people who have optimism about survival, belief in their ability to affect the disease, and determination to adjust to their illness.

An optimistic outlook has been attributed to improved well-being in people with life-threatening illness. In a correlational study to determine the relationship between treatment-specific optimism (the belief that a specific treatment will cure one's illness) and depressive symptoms with advanced cancer patients, Cohen, de Moor, and Amato (2001) found that optimism was associated with fewer depressive symptoms. The authors extrapolated that when people have optimism about the effectiveness of their treatment, they may adjust better to their illness, even if they are aware that the treatment is not likely to cure them, than those who are pessimistic. Furthermore, they state that a generalized optimistic view of the world may also be associated with better emotional adjustment to advanced illness.

Winterling, Wasteson, Sidenvall, Sidenvall, Glimelius, Sjoden, et al (2006) used the HADS questionnaire and the Life Orientation Test to explore the relationship between optimism and psychological distress. Participants who felt they could live a good life with advanced cancer had less depression and anxiety and were more optimistic. Furthermore, participants who scored as being highly optimistic had less psychological distress. Similarly, Petersen, Clark, Novotny, Kung, Sloan, Patten, et al (2008) found that optimism may help to diminish the psychological stress from a cancer diagnosis, and found that participants with a

pessimistic style scored significantly lower on mental health and quality of life measures.

Cohen and Leis (2002) recognized that many studies with advanced cancer patients have used measurement instruments to quantify participants' quality of life. Although quality of life is defined in many different ways in other studies, these researchers defined it as "subjective well-being." (p. 48) They stated that it is important to use qualitative methods to ask people with advanced cancer what they see as crucial to their own well-being. The researchers interviewed 60 participants and asked them what was important to their quality of life. After analysis, they reported five determinants of quality of life: the participant's physical, psychological and cognitive functioning, quality of the care they received, their physical environment, social relationships, and "outlook" (p. 55). They conceptualized outlook as a domain that included existential well-being, spirituality, hope, coping, and being able to find joy in life. Outlook had a significant impact on the participants' quality of life, regardless of their physical circumstances. The researchers found that people with similar physical concerns could describe their quality of life as "terrible or quite good, depending on the person's outlook" (p. 55). Participants said that their quality of life was enhanced by a positive outlook that involved being able to find pleasure in the simple things of life, accepting the life-limiting nature of their illness, focusing on others, being "settled spiritually" (p. 55), and finding meaning. Similarly, when Thomsen, Rydahl-Hansen, and Wagner (2010) did a literature review of factors relevant to coping with advanced cancer, they found that creating meaning and "positive

reframing” (p. 3418) of negative aspects of illness were important for well-being. They also reported that some studies had described participants as being able to be “lifted out of the suffering” (p. 3418) by experiencing joy and pleasure.

The studies reviewed provided possible ways that people with advanced cancer are able to experience well-being. Well-being in one or more dimension seems to enhance over-all well-being or at least diminish distress in another dimension. Furthermore, the approach people take to their life and the way they see the world seems to impact their ability to experience well-being in serious illness.

### **Theoretical Scaffolding**

Following the literature review, I built “theoretical scaffolding” (Thorne, 2008, p. 54), which served as a foundation on which to build the rest of the study. I addressed both parts of the scaffolding identified by Thorne (2008): In chapter 1, I outlined my assumptions, beliefs and theoretical position. In this chapter (chapter 2) I have reviewed the literature to gain an understanding of the current state of knowledge related to well-being in life-threatening illness. Nursing, as an applied discipline, needs to situate what is known in a clinical context before data collection and when applying research findings to practice (Thorne 2008). To that end, I first reflected on my and other health care providers’ clinical experience as well as my review of available literature. Then, I created the following fore structure:

I expected that participants may attribute their ability to experience overall *well-being* to the following themes:

- The *ability to transcend suffering* in one dimension of self (physical, emotional, social and/or spiritual) through well-being in another dimension.
- Their *approach to life and illness*, including:
  - Taking charge
  - Outlook / attitude

### **Need for the Study**

Most of the studies I found in my search of the literature used surveys and standardized measurement tools to identify factors contributing to well-being. While the data reported in quantitative studies is certainly valuable, these methodologies do not allow for participants to describe their experience in their own words, which would be helpful to understand their experience more fully. Mount, Boston, and Cohen (2007) state that well-being can only be understood as a subjective assessment of self, yet there is limited research which elicits individual subjective experience. Kiefer (2008) notes that many tools have been used to measure well-being, but agrees with Cohen and Mount (1992) that the questions on standardized questionnaires may not fully capture the complexity of the concept. Sahlberg-Blom, Terestedt, and Johansson (2001) found that some participants scored low on quality of life questionnaires, yet they experienced

happiness and satisfaction on a psychosocial questionnaire. This implies that quantitative measurement instruments may not capture the respondents' full experience of well-being (Cohen & Leis, 2002)

Of the seven qualitative studies I did find related to well-being in advanced cancer, two focused on only one aspect of well-being (Prince-Paul, 2008; Tatsumura, Maskarinec, Shumay, & Kakai, 2003) Also, Tatsumura et al. (2003) interviewed cancer survivors as opposed to people living with advanced cancer. Two studies used grounded theory methodology (Carter, MacLeod, Brander, & McPherson, 2004; Reb, 2007), which seeks to create theoretical concepts rather than describe and interpret experience. One study was focused specifically on perceptions of personal control over cancer rather than well-being (Henselmans, Sanderman, Helgeson, de Vries, Smink, & Ranchor, 2010).

The two remaining qualitative studies I reviewed both used an open-ended interview format with the explicit purpose of understanding the experience of people with advanced cancer (Cohen & Leis, 2002; Coyle, 2006). These studies have been described in the previous sections and have added to the current state of knowledge about well-being with advanced cancer. However, Coyle (2006) purposively selected participants who had expressed a desire for a hastened death and had only seven participants. Cohen and Leis (2002) had 60 participants with advanced cancer, from three Canadian cities. Thus, their findings may be somewhat transferable to the context I recruited from. Yet, the participants in my study were all still receiving care in a cancer treatment facility

while Cohen and Leis recruited half from home care and half from palliative care units. Furthermore, their primary research question was, “what is important to your quality of life?” (p. 50). It is possible that the participants had completed quality of life questionnaires during their treatment and their answers to this question may have been influenced by preconceived notions about what constitutes quality of life.

It has been documented in the literature and observed clinically that well-being is experienced by some people with life-threatening illness. Therefore, it does not seem that research is needed to determine if such a phenomenon exists. Rather, what is required is a more in-depth understanding of the phenomenon from the perspective of people experiencing it. There is a need to further understand how people with advanced cancer understand their experience of well-being, including what may contribute to or diminish that experience (Cohen & Leis, 2002). In chapter 3 I present the methodology and methods I used to explore the experience of well-being with the participants.

### **Chapter 3 –Methods**

The purpose of this study was to understand how people with advanced cancer experience well-being. I chose the methods and methodology from the basis of a constructivist paradigm with the following goals in mind; to understand the participants' experience of well-being from their own perspective and to provide opportunity for the researcher and participants to co-create a conceptualization of well-being in the midst of advanced cancer. In this chapter, I first describe the constructivist paradigm. Then, I provide a brief summary of interpretive description methodology followed by the methods I used for recruitment, data collection, and data analysis. Finally, I report the measures I took to enhance the rigor of my findings.

#### **Paradigm**

This study was shaped by a constructivist paradigm. Patton (2002) describes constructivism as a perspective of values and beliefs that is concerned with how people create reality, what their perceived truths are, and how their behaviors reflect their understanding of the world. The following philosophical perspectives based in constructivism informed my methodology selection, data generation, and data analysis.

#### **Axiology.**

Axiology refers to what is considered to be of value within a certain paradigm (Munhall, 2007). Constructivism values individual experience and perception, which is in line with my own values. Consequently, I approached

participants with an attitude of curiosity and respect for their individual interpretations. Each individual was seen as having a unique, highly relevant perspective. For all of the interviews, I opened with a question like, “how do you think you have been able to have well-being at this time in your life?” and then allowed the participant to answer without very much prompting. I interrupted only to clarify the details of what I was hearing or to paraphrase and check that I understood their intent. This open-ended interview style gave the participants the opportunity to talk about what came first to their mind, and to emphasize what they saw as important.

### **Epistemology.**

Epistemology refers to what is considered knowledge. From a constructivist perspective, knowledge is co-created through transactions between people and within contexts (Guba & Lincoln, 2005). In this study I attempted to work with participants to develop a shared understanding of their experience. For example, one participant said she had changed because of having cancer; she said she had “become the person I think I always was.” I replied that it sounded like she was not a different person; just free to be herself and she confirmed that is what she meant. This example shows how a shared understanding is separate from each individual and could not have been created by either of us alone. Another example was with Linda, who described her life as “bittersweet” near the beginning of the interview. The two of us both used the terms “bitter” and “sweet” as language with a shared meaning to refer to aspects

of her life throughout the interview. By the conclusion of the interview, we had created a concept of “bitter sweetness” that was new for both of us.

### **Ontology.**

Ontology refers to what is considered to be reality. From a constructivist perspective reality is seen as being subjective and relative (Patton, 2002). There are multiple, equally valid possible interpretations of reality; therefore, truth lies within individual subjective interpretation. This is in line with my approach of seeking to understand the subjective experience of participants using open-ended questions. I also practiced reflexivity to be aware of the potential impact my own pre-conceived interpretations of reality had on the research findings. My process of reflexivity will be discussed further in the section on trustworthiness later in this chapter

### **Methodology**

Methodology refers to how one acquires knowledge. The methodology for this study was interpretive description, developed by Thorne (2008) as a way to investigate phenomenon that have been observed by nurses clinically and apply research findings to practice. Guba and Lincoln (2005) describe a constructivist methodology as one which uses an interpretation of words and language (hermeneutics) together with an arrival at the truth by exchange of different ideas (dialectics). Thorne’s philosophical underpinnings are congruent with the constructivist view that reality and meaning are shaped through interaction with self, others, and the world. She describes the purpose of her methodology as

seeking to understand subjective consciousness together with the context within which one lives.

One purpose of interpretive description is to gain better understandings of health and illness from the perspective of those who are living the experiences. This purpose is shared by many qualitative methodologies. However, interpretive description is distinct from methodologies that are solely descriptive because the researcher interprets data to form “tentative truth claims” (Thorne, Reimer Kirkham & O’Flynn-Magee, 2004, p.7). These claims are based on analysis of common patterns and themes found in subjective descriptions of a phenomenon, with the assumption that general knowledge about that phenomenon can be applied to particular people and situations in nursing practice (Thorne, Reimer Kirkham & MacDonald-Emes, 1997). Researchers using interpretive description do not attempt to make factual claims or to state universal truths. Rather, they link concepts together in a framework that will inform clinical nursing practice (Thorne, Reimer Kirkham & O’Flynn-Magee, 2004). Thorne (2008) notes that there are countless phenomena observed in clinical nursing practice which require better understanding through interpretive analysis:

We desperately need new knowledge pertaining to the subjective, experiential, tacit, and patterned aspects of human health experience – not so that we can advance theorizing, but so that we have sufficient

contextual understanding to guide future decisions that will apply evidence to the lives of real people (p. 36).

This methodology was developed as nurse researchers sought a way to go beyond the descriptive approaches commonly found in qualitative inquiry (Thorne, 2008). Nursing is an interpretive and relational discipline which requires knowledge that is applicable to practice (Thorne, Reimer Kirkham & MacDonald-Emes, 1997). The potential for this research to inform health care providers' practice has been discussed in chapters 1 and 2 and will be expanded in chapter 5.

Thorne, Reimer Kirkham and O'Flynn-Magee (2004) recognize that interpretive description has philosophical underpinnings aligned with naturalistic inquiry and constructivism in respect to the nature of reality (ontology) and ways of knowing (epistemology). Reality is seen as contextual and subjective, so there are multiple valid realities dependent on individual perspectives. Knowledge generation is a reciprocal process between the participant and researcher, and, as such, necessitates an equal balance of power between the two (Mills, Bonner, & Francis, 2006). The object of inquiry and the inquirer influence each other, becoming indistinguishable from each other (Lincoln & Guba, 1985; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004) and "the knower and the known are inseparable" (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, p. 5). Since no one theory could possibly encompass every possible reality, what is known must come from the co-constructed meaning generated during the interaction between

the researcher and the participant (Mills, Bonner, & Francis, 2006). The researcher acts as an interpreter, rather than simply a disengaged recorder of data (Thorne, 2008).

The process of interpretive description involves questioning that is informed by assimilation of existing knowledge, followed by critical and reflective examination of interview data (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). The goal of this methodology is to configure data into themes and patterns that characterize the phenomenon being studied, while accounting for variation in different individuals and contexts (Thorne, 2008). The product is a new conceptual understanding of a clinically observed phenomenon that is credible, meaningful, and has potential to affect health care providers' practice (Thorne, 2008; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004).

## **Methods**

### **Sampling.**

For my study, purposive sampling was used to select participants based on their manifestation of the phenomenon of interest. The intent of purposive sampling is to gain rich insight into the phenomenon rather than to create a sample that is representative of a population (Patton, 2002). Therefore, the sample consisted of people who described themselves as experiencing well-being and who were aware that their disease was advanced (see inclusion criteria below). I did not attempt to recruit for variety in gender, age, or other

demographic criteria due to the small number of potential participants that were recruited (to be addressed as a limitation).

### **Criteria for inclusion.**

Participants for this study were diagnosed with advanced cancer, defined as “a disease in which there is little chance of cure and in which the aim of treatment is usually to achieve palliation” (Redmond, 1998, p. 31). This diagnosis and intent of treatment was known to the health care providers who assisted with recruitment (see below) and to the potential participants. The health care providers were instructed to assess potential participants’ awareness of the diagnosis in the following way (See Appendix A and B):

The patient must have made reference to the advanced nature of their disease, either by referring to their own death as an expected outcome or by stating that they see their illness as being very serious.

The invitation pamphlet (Appendix C) clearly stated that the study was aimed at people with advanced cancer. Due to the nature of the interview questions, which required the participant to describe subjective experience using introspection, participants needed to be able to communicate verbally in English. The participants were all adults.

### **Recruitment.**

Members of the Pain and Symptom, Palliative Care inter-professional team as well as Patient and Family Counselors at the Vancouver Island Center of

the BC Cancer Agency were asked to assist with recruitment of potential participants who were known to them as a current patient or as a participant in a supportive services group. The health care providers were given instructions, a script for invitation, and a brochure to hand to the potential participants (Appendix A, B, and C). Originally, the pain and symptom team was asked to consider their patients' responses to a question about well-being on the Edmonton Symptom Assessment System (ESAS), which is a screening tool they use routinely in their clinic. However, they stated that most people who came to their clinic scored as having poor well-being on the ESAS tool. They ended up inviting only one participant who they thought might fit the criteria for inclusion. This participant stated she initially did not think she would be suitable for the study, but she said her health care provider perceived her as having the qualities described on the invitation pamphlet: "coping well," "inner strength," and "positive outlook." Upon reflection, she realized she did have those qualities. However, this departure from the recruitment procedure is a potential limitation as this participant may not have recognized herself as someone with well-being without the health care provider's encouragement. The patient and family counselors invited members of a support group for women with metastatic breast cancer, clients of a therapeutic touch clinic, and patients they saw for individual counseling. In the end, all but one participant was recruited by the patient and family counseling department. This will be further discussed in the section on limitations.

It was important for the potential participants to identify themselves as people who were experiencing well-being, so the recruitment pamphlet was worded to elicit their own reflection (Appendix C). The front page of the pamphlet asked the reader if any of the following terms could be used to describe them: “coping well,” “inner strength,” and “positive outlook.” I used three terms with the intent of providing at least one concept that resonated with potential participants. Instructions were written on the pamphlet and in the health care provider’s script for participants either to call me or give verbal permission to their health care provider to release their contact information to me, and I would call them.

### **Description of participants.**

A total of eight participants were recruited and interviewed. Six participants were referred by patient and family counselors and one referred himself after reading the invitation pamphlet in the Patient and Family Counseling waiting room. Only one participant was recruited through the Pain and Symptom Management clinic. There were six women and two men, ranging in age from 32 to 69 years old. There were four participants with breast cancer, two with bowel cancer, and one with lung. All of them had numerous sites of metastases and four were receiving chemotherapy at the time of the interviews. All but one participant had current physical symptoms from their cancer including fatigue, pain, nausea, decreased mobility, and shortness of breath. They were all able to walk independently and transport themselves to the cancer centre. Four

participants had post-secondary education and three were either employed or volunteered in a health care area.

### **Data collection.**

The data were collected in single interviews with me that took place in a private room at the Vancouver Island Cancer Centre or in the participants' homes, as decided by the participant. Each interview was about one and a half hour long. They were semi-structured, with open-ended questions designed to elicit the participants' conceptualization of well-being and their experience of the phenomenon (Appendix D). With each interview, I asked slightly different questions in order to test the emerging commonalities and differences between participants' responses. For example, in the first four interviews, a theme of the need to maintain control seemed to be emerging. I then asked subsequent participants if they felt this need as well. Similarly, when I noticed that the first few participants described their perceived success in past difficulties as important to their well being, I asked questions about the next participants' past difficulties, strategies they had developed, and if these strategies were useful in dealing with serious illness as well.

After each interview, I recorded my initial thoughts about possible themes from that interview, especially what stood out as being important to that participant. I also recorded my reflections about what feelings were arising for me, how my assumptions had been challenged, and questions I might ask in the

next interviews. These personal reflections and the interviews were audio recorded, then transcribed verbatim by a transcriptionist.

### **Data analysis.**

The purpose of interpretive description is to provide the health care providers with new insights and ways of thinking about a phenomenon (Thorne, 2008). "Interpretive description is always a meaning-making activity" (Thorne, 2008, p. 175) that provides new insight into a clinically observed phenomenon.

The process of data analysis is a fluid and non-linear one: "the mechanisms of interpretation...depend far less on coding, sorting and organizing than they do on the process of intellectual inquiry" (Thorne, 2008, p. 13). Thorne repeatedly encourages researchers to avoid coding too early in the analysis process. Rather, she suggests keeping all possibilities of thematic linkages open while comparing various different ways of structuring the data. Analysis involves an ongoing immersion in the raw data to understand the participants' experiences within their context (Thorne, 2008). It is an inductive reasoning process where the researcher identifies which data pieces are important, groups and sorts them and considers relationships between the pieces (Thorne, 2008).

Data for this study was collected and analyzed concurrently. Each interview was approached as an exploration into a unique individual's experience, but the questions were informed by the themes that were being formed from a combination of the literature review and the previous interviews. There was ongoing engagement with the data through constant comparative

analysis as conceptualizations of well-being were explored and tested throughout the process (Thorne, 2008).

The process of analysis was as follows: after each interview, I audio-recorded my initial impressions, both as a reflexive process and to document themes or ideas that had come to mind during the interview and upon immediate reflection. Throughout data analysis, I used the mind mapping technique of drawing a diagram with a central idea in the center and using arrows and lines to show relationships between ideas. As I listened to the recordings and read the transcripts entirely, I highlighted passages that seemed to be important or emphasized by the participant. I then re-read these passages and summarized the main idea of each, rather than coding line by line. I then made a mind-map for each participant to begin to see associations and themes within their interview. As I gathered more data, I made new mind-maps of each theme that seemed to be emerging. I kept a journal which contained the numerous mind-maps and different representations of the data and analysis. I used the mind-map format to explore various ways of configuring the data, and to draw tentative relationships and associations between themes and sub-themes. During data collection, I was continually shaping and re-shaping the maps of individual interviews and the collection of interviews as a whole. As I progressed through the interviews and data analysis, I created a large mind-map which included all of the themes and subthemes written on small pieces of paper that I could move around the map.

Once I had an idea of some possible themes, I used a combination of NVIVO and Microsoft Word to manage the data as I analyzed and coded the data. I coded passages ranging from 1-50 sentences. I identified many small themes and coded them within larger themes. For instance, I generated a larger theme of “focus on the positive” and within that theme, there were subthemes of: “focus on possibility of cure,” “don’t dwell on the negative,” “gifts from cancer,” “gifts from life,” “mind discipline – reframing,” and “living in the moment.”

### **Rigor**

Lincoln and Guba (1985) give four criteria which should be met to establish the trustworthiness of a qualitative study. These are credibility, transferability, dependability, and confirmability.

Credibility is the notion that the data reported reflects what the participant intended and that their reality is reported accurately (Lincoln & Guba, 1985). During the interviews, I paraphrased the participants’ description of their experience at one or two points in the interview to confirm my understanding. This test was also done with subsequent participants. For instance, I noticed that a theme of maintaining control was emerging in some of the early interviews. With subsequent interviews, I asked the participants if they had found that control over aspects of their lives had enhanced their well-being. They confirmed that while they may describe it differently, such as being “pro-active” or “making choices,” they found that this was true to their experience as well.

Transferability is the ability for the results to be applied to different contexts. In order for results to be transferable, the researcher must describe the context clearly so the reader can compare it to other contexts (Lincoln & Guba, 1985). Transferability is based on the idea that reality is dependent on context, which is in keeping with the constructivist paradigm. The participants of this study were all people with advanced cancer, most of whom had accessed the resources of the patient and family counseling department at the BC Cancer Agency. The context has been further described in the section entitled “description of participants.” The findings of this study may be tentatively applied to other people with advanced cancer, with similar demographic features. The findings should be only applied within the limitations of this study which will be described further.

Dependability is an evaluation of the reproducibility of the findings, that is, if more people with advanced cancer and well-being were interviewed, would similar themes emerge? This test was done using Thorne’s recommended “thoughtful clinician test” (Thorne, 2008, p. 85) and is described in a following section. Because interpretive description is intended for clinical application of findings, this test of dependability is based on clinicians’ perceptions of the phenomenon of interest as it has been manifested in the people they care for.

Confirmability is an evaluation of the effect of the researcher’s motivation, biases, and assumptions on the report and interpretation of data. I used reflexive

journaling throughout the research process as one method to enhance the trustworthiness of my findings.

Thorne, Reimer Kirkham, and O'Flynn-Magee (2004) suggest the following strategies to establish the trustworthiness of a researcher's findings: locating the findings within the framework of existing knowledge (as was described in chapter 2), concurrent data collection and constant comparative analysis (described previously), "tracking reflections" (Thorne, p. 109), and the "the thoughtful clinician test" (Thorne, 2008, p. 85). Thorne states that the reader should be able to follow the thought process of the researcher and to understand why he/she interpreted the data in a certain way. The researcher must be accountable and transparent throughout the process. To that end, I practiced reflexivity throughout the research process.

### **Reflexivity.**

The process of qualitative analysis should be highly reflective (Morse & Field, 1996; Thorne, 2008). Thorne notes that we are "hardwired for organizing and sorting what we see as meaningful even when we try to be open-minded" (p. 142) and may make subconscious or conscious judgments about what our participants say. Therefore, researchers must be aware that their role in interpreting meanings leads to the inability to be an objective observer (Munhall, 2007). Dowling (2006) describes reflexivity as a process that involves developing an awareness of the researcher's internal and external responses to the participants, the research topic, and the findings.

Throughout the research process, I kept a journal for reflection about how the research process affected me personally, including how my assumptions, values, and beliefs were being challenged. Before the first interview, I reflected on my assumptions and pre-conceived ideas from the literature review, my clinical experience, and my personal values and beliefs. I acknowledged that I needed to approach the interviews with an attitude of curiosity and not search for meanings that would confirm my own presumptions. Dowling (2006) encourages researchers to reflect upon the impact their assumptions may have on the findings of the research. Because I had quite strong assumptions and values, it was critical for me to be thoughtful about my influence on the data I chose to report and the emphasis I placed on individual participants' accounts (Thorne, 2008).

As outlined in chapter 1, I began this study assuming that the participants would attribute their well-being to spirituality. This assumption was based on my own experience of well-being during difficult circumstances and had also been shown in the literature to be a resource for many people dealing with life-threatening illness. Therefore, I was surprised when I began to notice that none of the participants directly referred to spirituality as a source of their well-being. I wrote in my journal about the disappointment I felt; I struggled morally because I did not want to report data that was incongruent with my own beliefs. However, I knew that for my findings to be credible and true to the participants' experience I had to report their experience accurately.

Another assumption I had was that people who were aware of a diagnosis of advanced cancer would be preparing for their death. Previously, my clinical experience with people with this diagnosis was as a home care nurse. The people I had seen in this clinical capacity were mostly nearer to death than the participants of this study. This assumption was challenged by every participant, as they all seemed to be living in ambiguity, which will be reported in chapter 4. I also assumed that life-threatening illness would be perceived differently from previous difficulties and would require new strategies to maintain well-being. In contrast, the participants seemed to deal with their illness in similar ways to how they had dealt with past difficulties, and drew on many of the same strategies.

Two examples of this reflexive process stand out: before the first interview I reminded myself that I had to be careful not to over-emphasize data that reinforced my own values and assumptions. The first participant was a woman who was an active member of a local church. During her interview, she described many ways of thinking and practices that were incongruent with my own faith. I had to resist the inclination to ask her how her faith community responded to the strategies she was using to maintain her well-being. Following that interview, I listened to the recording and read the transcript with the purpose of checking if I seemed to be leading her or expressing disapproval.

The second example was with a participant that I knew personally who died during the course of my study. I realized that whenever I read her transcript, my emotions colored my ability to interpret her words, and I was unable to listen

to her voice on the recording. Once I realized this, I took a break from data collection and analysis for a few weeks. Additionally, as I wrote up the findings, I observed that I was over-emphasizing her data because I was so determined to represent her experience accurately and honor her memory. I needed to find other ways to honor her and to allow myself to grieve her loss

### **Thoughtful clinician test.**

The “thoughtful clinician test” (Thorne, 2008, p. 85) means that experts in the field will find the claims of the analysis plausible in light of their own clinical practice. I presented a summary of the findings of my study to clinicians (a pharmacist, social worker, nurse, physician, and a dietician) from the Pain and Symptom team to determine if the themes were representative of what they have observed in practice. They confirmed each theme that I report in chapter 4.

### **Ethical Considerations**

The study proposal was approved by my thesis supervisor and committee members, and ethical approval was granted by the University of Victoria and the BC Cancer Agency/University of British Columbia ethic review boards. In the consent form, which was explained to participants before they signed it, the participants were made aware that they could withdraw from the study at any time without providing a reason for withdrawal. In addition, it was made clear to them at the point of invitation that their decision would not affect their treatment in any way.

**Potential for harm and benefit.**

The questions, by their personal nature, may have caused emotional distress. To address this risk, I planned to ask participants if they would like to postpone the interview or withdraw from the study if they appeared physically fatigued or emotionally distraught. The services of a patient and family counselor would be offered and contacted by the researcher or the participant as the participant desires. If the participant did not wish to speak with the BCCA counselor, contact information for other professionals outside of the cancer agency would also be given, such as the Victoria Hospice counselors or chaplain (if the participant is registered with Victoria Hospice) or community spiritual leaders. However, none of the participants seemed in distress nor did they ask to stop, postpone or withdraw from their involvement in the study. They all signed a consent form and received a copy (Appendix E).

The potential benefits as explained to the participants were opportunity for reflection on their life experiences, reinforcement of the factors that have supported their well-being, and validation of well-being as a resource for continued positive coping. Also, they would have the knowledge that their experience may help others who are facing advanced cancer to develop or maintain well-being.

**Confidentiality.**

Confidentiality was assured by using numerical identifiers on the audio tapes and written notes and by the transcriptionist signing a confidentiality

agreement. I assigned pseudonyms upon receipt of the transcribed interviews and used them in the report of findings in chapter 4. A cross-reference list was kept separate from the transcripts in a locked file cabinet that I have the only access to. I signed a confidentiality agreement on my hire to the BC Cancer Agency, which legally forbade me to access the participants' health information, although I had potential access to their electronic charts. Because I did not have direct contact with these patients as part of my employed role, I was not in a conflict of interest or an imbalance of power. The health care providers who recruited participants were not made aware of who consented to participate in the study, unless informed by the participants themselves. The cell phone number and email address given to potential participants in the information letter was only accessible to me, and both were password protected.

### **Limitations**

Aspects of this study that limit its applicability to others outside of the participants group are sample size, recruitment procedures, and wording of the pamphlet and interview questions.

#### **Sample size.**

The proposed sample size at the outset of this study was between 8 and 14. Eight participants were interviewed. There were a few possible reasons for this relatively small sample size. The recruitment period was during the summer months. The activities of the patient and family counseling department did not run in July and August and many health care providers were on holidays. The

pain and symptom management team were also inviting participants for another study being conducted by a member of their own team during the same time period, which may have taken precedence or been more at the forefront of their minds than my study. This team also reported that most of their patients seemed to be in too much distress to be invited.

The sample size of eight is a potential limitation; however, Thorne (2008) states that a study with the intent of understanding the nature of a phenomenon rather than to determine if it is experienced may use a relatively small sample size as long as the researcher acknowledges that even when similar themes are discussed by many participants in the study, one cannot claim generalizability (Thorne, 2008). That is, claims cannot be made that everyone experiencing the phenomenon in every context would describe the same themes. However, a meaningful description and interpretation from the lens of a health care professional can provide insight into patient experience. This insight potentially raises questions and concerns which, when considered by the professionals who provide care to these patients, can have a positive impact on their clinical practice (Thorne). I found that many similar themes arose early in the interview process and confirmed these themes with subsequent participants.

#### **Procedure for recruitment.**

Another potential limitation of this study is that all but one of the participants were members of a support group, patients of a support group facilitator, or clients of a therapeutic touch clinic. Many of the members of the

support group had similar language use around positive mental imagery, reframing, and mindfulness, which led me to wonder if these activities had been suggested to the group as helpful strategies to enhance well-being. Also, the clients of the therapeutic touch clinic seemed to use alternative therapies as a strategy to enhance their well-being, which might be a result of recruiting from this group rather than a characteristic of people experiencing well-being in general. It is impossible to know if participation in the therapeutic touch clinic and the support group actually caused them to experience well-being, or if similar findings would have emerged if participants had been recruited from the general patient population.

As previously stated, the members of the pain and symptom team decided not to invite patients that they perceived as being in too much distress to participate. This could have limited the inclusion of people who may have been experiencing well-being even while having significant symptoms. The pamphlets were not out in plain view, so invitation depended on the health care providers' judgment. As also mentioned previously, the participant recruited by this team may have been influenced by the health care provider's perception of her well-being.

### **Pamphlet content and interview questions.**

I received feedback from health care providers assisting with recruitment who said that "well-being" was too broad and people may not know what I was looking for. To increase the possibility of one of the concepts resonating with

potential participants, the invitation pamphlet included three concepts related to well-being. The wording may have limited the ability for the participants and researcher to co-create the concept of well-being during the interview, as was intended at the study's outset. The phrase "well-being" was chosen deliberately because of its ambiguity, openness to individual interpretation, and limited pre-conceived ideas of its meaning. The first question I asked was, "which phrase resonated most for you?" and few of the participants referred to "well-being." Many participants related more to the phrase "positive outlook" or "coping well." These observations and their impact on the findings will be discussed further in the following chapters.

## **Chapter 4 - Findings**

This research was originally inspired by the woman described in Chapter 1, who seemed to be experiencing well-being while in the midst of suffering. My one meeting with her prompted several years of reflection about the possibility of experiencing well-being while living with serious illness. Other people I had seen in my personal and professional life came to mind and conversations with colleagues reinforced my perception; they too had encountered some people who seemed to be able to “rise above” the challenges of their illness. A search of the literature also provided support for the existence of this phenomenon.

This purpose of this study was to gain an understanding of well-being from the perspective of people with advanced cancer. Each person interviewed had a unique way of conceptualizing their journey and yet commonalities existed in their descriptions. In this chapter the findings derived from the participants’ descriptions and my interpretations will be presented. There were four main themes that arose as a result of the data analysis. They were (1) view of self, (2) the fluctuating nature of well-being, (3) choices the participants made to enhance their well-being, and (4) living in ambiguity.

### **View of Self**

The participants seemed to have a strong belief in their ability to maintain well-being in spite of any difficulty. They took ownership over their experience of well-being and seemed confident that they could cope with “anything.” They saw themselves as capable because of their “take charge” personalities and

because they had survived many past difficulties. They were confident that the strategies they had used in the past would be effective to maintain well-being in their present illness as well. Belief in their own abilities was a resource they drew on in their work of maintaining well-being. Because they believed their efforts would make a difference, they were able to persevere in making the difficult choices that seemed to be necessary.

The participants viewed themselves in a positive way, and seemed to take pride in their ability to deal with difficult circumstances. When asked for one word to describe themselves, participants used words such as: “strong,” “flexible,” “positive,” “whole,” “independent,” “dependable,” “inspiring to others,” “resilient,” “resourceful,” “curious,” “accepting,” “fun,” “open,” “happy,” “friendly,” “trustworthy,” “intelligent,” and “a person with integrity.” Many had a sense of humor that emerged during the interviews and was referred to directly by some as a coping strategy. This positive self-view seemed to enhance their well-being because they believed in their ability to “deal with” past, present and future challenges, as Jennifer said:

[Well-being is] believing that things are going to be OK or that you can deal with things OK. Or things are going to be as OK as they're going to be but knowing that you can deal with them... taking that approach that you know we can deal with this, we can manage it, we can get through it.

Sharon talked about being able to have well-being now and in future difficulties because she could depend on herself and on the strategies she had developed:

So then if they take this drug away from me I am [not] going to go into, “I've got nothing.” ...I've got myself. I've got prayer. I've got my mind, all those kinds of things. So I must have those strengthened all the way through so that if the medical profession takes what they are giving me away that I don't go straight down into the pit.

The participants' belief in their ability to “cope” with present and future challenges seemed to be a reflection on the way they had dealt with difficulties in the past. When asked about how they have been able to experience well-being with advanced cancer, many participants spontaneously reflected on difficult life circumstances that they felt had prepared them for dealing with their illness, including estrangement from family members, abuse, losing a loved one to death or divorce, or experiences of being assaulted. While reflecting on these experiences, they realized they had developed successful strategies, such as meditation, support groups, or mental discipline to deal with past difficulties and they drew on these strategies to maintain well-being in the midst of the difficulties due to cancer.

Jason described an incident where he was walking through the snow and looked up to see a bobcat crouched in the bank in front of him. Although he was terrified, he yelled and ran towards it rather than away from it. This anecdote summed up the pattern of Jason's life as he told it. In spite of a lifetime of abuse, addiction, homelessness, and disability, he described himself as “fortunate” due to his willingness to face difficulty and ability to adapt to any situation:

It's just that I know that if I try and run away from this [cancer] it'll get me. But if I can continue to face whatever it is: my fears about cancer, or about anything...If I turn my back on it and don't confront myself with it, I'm gonna lose. So when a mad dog comes at me, I won't run away. I'll run at it, scared shitless, yes, but I'll do it because I've done it throughout my life.... it's just the way I approach my life....whenever there's a problem I don't ever get caught by it, I either climb over the wall or go around it and keep on going ... ..If something happens I couldn't run away from it. Man, I'd have been dead by now. I didn't know any other way of looking at life other than this...You gotta do what you gotta do and it isn't run.... I'm very fortunate. I created my own kind of luck. Everybody has a luck and it isn't necessarily lucky playing cards or anything else. My kind of luck is to be able to change direction quick and still succeed.

Carol also attributed her well-being to a willingness to be flexible,

I think the thing that has saved me is my ability to adapt and to make changes and...do whatever I have to do. To not be stuck in any particular mode. To be flexible. And to think of different ideas, ways to deal with things.

The participants described themselves in a positive way, and saw themselves as being able to affect well-being, which for some, seemed to be based on their past successes with difficulty. They viewed their personal attributes as a resource for well-being.

## **The Fluctuating Nature of Well-Being**

Although all of the participants stated they had an overall sense of well-being, many described well-being as something that “comes and goes” rather than a constant state. Linda expanded on her experience, alluding to a somewhat transitory sense of well-being as she described how she felt “right now,”

I’m coping well...and right now...there’s this intensity of gratitude that I’ve been having...that is quite remarkable actually and has turned into a bit of a journey for me of sorts.

Some participants said they waited to contact me after seeing the initial recruitment pamphlet because they did not feel they were experiencing well-being at that time or they needed to ask loved ones if they would “fit” the study. Carol described herself as someone who has a “positive attitude,” but it “comes and goes” and she “[has] to work at it.” Similarly, Sharon said, “even though you are experiencing general well-being there are times when you go up and you go down.” When invited to participate in the study, some potential participants told the health care providers who were inviting them that they would usually fit the criteria for the study, but were experiencing a “down” time and asked to be contacted in a few weeks, when they anticipated feeling a sense of well-being again. Most of them did not end up participating.

Some participants related a diminished well-being to times where they heard disappointing test results or when they received “bad news,” but after a

time of “sadness,” the participants seemed to be able to return to well-being by making deliberate choices, which will be presented in the following section.

Marissa described feeling sad temporarily then returning to well-being:

When I'm hit with a new piece of diagnosis or a new test that's kind of devastating...Sometimes I am sad at that time, sometimes I am sad afterwards, but through it all I seem to come back bubbling and hopeful and managing

Oftentimes, a sense of well-being was tied to laboratory test results. That is, if the test results were disappointing, some participants were less likely to feel a sense of well-being. Carol and Jason both used lab results to measure the success of their efforts to cure their cancer. They talked about the down times they experienced after receiving disappointing reports. Carol had made many life-style changes in an effort to cure her cancer. She rented out her apartment, gave up her job and moved in with her parents, who she perceived as being very supportive, and allowed them to care for her. She maintained a strict diet and focused her mental energy on lowering her tumor markers. Consequently, her well-being was challenged when her lab results showed the markers continued to increase despite her efforts:

All my blood tests are perfect. It's only my tumor marker so everything else in my body is working perfectly so ...what is it about that that I can't seem to get rid of it?...And you know, sometimes it's hard like if you get bad

news you know, to, to keep believing that you know, that I can accomplish what I think I can accomplish of getting rid of it.

Jason and Carol seemed to be able to return to well-being because of their enduring belief that they could survive cancer. They both stated that it was hard to hold onto their belief, but they somehow managed to. In contrast, when Linda received a test result showing her cancer was widespread, she had an “aha” moment. She said the “reality of the situation” hit her and she started to contemplate her death.

In addition to lab results, some participants’ well-being diminished with increasing symptom severity. Marissa recalled a time period when severe pain caused a significant decrease in her emotional well-being:

Two weeks ago ...I was in absolute agony and I was getting really angry at things that don’t normally make me angry.... it was really wicked.... when I was in pain, I got really angry and just...didn’t know how I was going to get through the next day you know. I didn’t recognize myself at all cause it was unrelenting I guess. ...it felt like it was wearing me down. I wasn’t sure how long I could take it for...I am not suicidal now but I got close to it when I was in pain, that pain I felt.

Marissa later described an encounter at the pain and symptom clinic that improved her well-being dramatically. She had begun to despair that she would never be pain free because she wanted to be able to drive and be alert during the day and did not think that was possible while taking medication for pain. The

pain and symptom management team began their interview with her by asking about her goals and priorities in terms of choosing medications. As a result, she felt confident that they would work with her to manage her pain and was hopeful that she could have her pain managed and still be as independent as possible.

Other participants also stated that their well-being was challenged by symptoms such as pain or fatigue, but, once these symptoms had been addressed, their sense of well-being returned. In contrast to the above examples and to Carol and Jason's experience with test results, Dave stated he experienced well-being because he hadn't had any side effects from cancer treatment or symptoms of his illness and because his recent test results were encouraging.

The participants said their sense of well-being fluctuated at times, especially when they received disappointing lab results or experienced distressing symptoms. They were proactive in their efforts to maintain well-being despite the challenges. For instance, they accessed health care resources to address their symptoms. Some participants, like Carol and Jason, seemed to cling to their belief that they would survive and forced their thoughts to focus on the positive, which will be further described. They also made lifestyle changes that they believed would enhance their health. These proactive efforts were described as "work" by several participants. Jennifer said she was like "an athlete in training." The participants took charge of their well-being because they believed their efforts would be effective, as was described in "View of self." The

work of maintaining well-being in the midst of the challenges of advanced cancer can be understood as a number of deliberate choices.

### **Choices Made to Enhance Well-being**

Many participants talked about the loss of control associated with having advanced cancer. Sharon said she felt that health care providers were initially in control of what happened to her in terms of treatment:

I think that's one of the difficulties that happens is that when you get to diagnosis you are given, a "we're gonna do this to you, we're gonna do that to you," so some certain control and power is taken away from you.

The participants also talked about the loss of control over their bodies, never knowing when a new symptom may arise. Jennifer said the uncertainty made it difficult to plan ahead:

You know that things can go wrong... all of a sudden something physically happens to you and it's just like I can't control it... you have to deal with it so that's your day all of a sudden. So you can't really plan in the way you used to.

In their efforts to maintain well-being, many participants dealt with the loss of control in some areas of their lives by focusing their efforts on areas they could control. They made intentional choices about relationships, self-care, and treatments.

### **Choosing supportive relationships.**

Some participants said that cancer gave them “permission” to care for themselves by being selective about which relationships to invest in and which to let go of. Nancy seemed to feel released as a result of “getting away” from some destructive sibling relationships. She said she became “the person I think I always was” and was now “free to be me.” Several participants deliberately chose to be surrounded by people who supported their individual approach to develop or maintain well-being. As Carol put it:

Right in the beginning I decided that I was going to be very selective about who I was going to have around me and that I was not having people around me that weren't being supportive and I needed to do that for my health. ... I have chosen to have people around me who are more positive and who are supportive and, and you know that makes a big difference. ...Well, for example, people who [I didn't find supportive or helpful were those who] maybe didn't agree with my treatment choices or, you know, they're opinionated but not knowledgeable. (Laughs) And you don't need that, right? So, they were...judging or being critical... if I felt stressful or stressed around them then that wasn't a good sign, cause I was trying to keep as much stress out of my life as possible, so....when you lay things out that way, things become pretty clear.

Many participants found that supportive relationships enhanced well-being. Jennifer described herself as being “surrounded by love” by her family

and friends. Nancy enhanced her well-being by spending time with her family and by participating in a support group. Others also found positive relationships within formalized support groups. Sharon stated she could be more open about her feelings with her support group than she ever had been with her friends and family. She felt she had to “be strong” for her loved ones but could cry in the support group and they would understand how she felt. Linda and Marissa joined a support group as a strategy they had used in the past when coping with difficult circumstance. Dave had made many lifestyle changes when he had a traumatic brain injury nine months prior to the interview, and continued on these changes upon receiving his cancer diagnosis six months later. He described himself as previously very isolated, but started reaching out to others a source of support for him. He also became very motivated to help others in similar situations because he could understand what they were going through. He actually moved to another city in order to live where there were more opportunities for joining support groups and volunteering. It seemed to give him a sense of purpose to help others,

I guess for the time before that I was playing internet bridge for 10-12 hours a day. Not much to show for myself. I haven't played bridge for probably six months. But [it's] not important anymore. I've got all sorts of things planned today to help people.

In addition to social relationships, many participants made active choices about relationships with health care providers. Interactions where the health care

provider was perceived to be insensitive to the participant's feelings or unsupportive were described as being difficult to "let go of" and were described in detail, often with tears. Many participants severed relationships with individual health care providers or made different treatment decisions as a result of these negative interactions. For example, Carol decided it was important for her to have a physician who was willing to communicate with her naturopath and who would support her choice to have alternative treatment instead of chemotherapy. To that end, she persisted for months to switch to an oncologist who met her needs. She said, "It's not that easy [to change oncologists]. But eventually I got the one I wanted who understands my approach and supports it."

Marissa described the ideal relationship between patients and health care providers as a co-operative "partnership." She felt respected by health care providers who asked about her priorities for care before offering solutions and then worked with her to meet her goals. This was a sharp contrast to a previous interaction with a physician who seemed dismissive of her efforts and did not ask her what she wanted:

I was meditating...I didn't want to grit my teeth...or be so nervous....she [the physician] came into the [waiting] room and said, "No more meditating, no more meditating" in a big loud voice right in front of everybody and I thought that was terrible. And then she said, "I have decided that you are going to have a whole body CT scan from your head to your feet." That kind of thing just gets my back up completely and I

decided that I wasn't going to have a CT scan...I think a doctor patient relationship ought to be a partnership and if it isn't a partnership it gets my back up... [she seemed to be] somebody who's not willing to look at it that way... basically I asked for a new [doctor].

Jennifer described an incident she had with a nurse who was inserting her PICC line for chemotherapy. After telling the nurse that she was afraid, she felt "brushed off" and devalued. She seemed hurt by the insensitivity of the interaction and referred to it several times during the interview.

It was the health care practitioner...and her approach...The procedure itself is quite scary for me. ...I was so used to people (Pause, Crying) being sensitive to people's needs. And this one [nurse] just wasn't. So ...that's the one experience ...that ...I've hung onto. ...I was panicking a bit when she's starting to put the PICC line in and I mentioned that to her and she just sort of brushed it off ...when my assumption would have been or my previous experience would have been at least acknowledging that and honoring that emotion rather than just brushing it off, and just dismissing it. (Crying)

Although the incident was hurtful, Jennifer chose to put it within the context of all the care she had received:

I look at that interaction with the nurse...not to dismiss what happened but...I am so lucky that's only one person that I've met who's like that. Because ... I had been dealing with health care professionals for a whole

entire month prior to that and they'd been exceptional, exceptional. And so here's this one person that I don't want to dwell on because everybody else has been so exceptional. So, it hasn't changed my view of the health authority or health care professionals at all because I know it's such an isolated event.

### **Choosing to put my needs first.**

Many participants spoke about previous inclinations to put others' needs before their own and said that having advanced cancer had given them "permission" to care for their own needs and to allow others to care for them. Sharon said with her first diagnosis of cancer, she put her energy into being strong for her family and supporting them but when her cancer recurred she made a decision to focus on herself, "I said..."that's it. This is a life or death situation now. I'm doing this my way," and she finally left a job that had been causing her severe stress for years. Similarly, Jennifer said because of cancer, she had given herself permission to state her needs to others. However, she reflected that she would like to give others the same permission regardless of their circumstances:

I was out with people and I said to them "I need to go, I am getting hungry and tired." No one bats an eye. But why do we feel that it's not ok when someone isn't dealing with something serious? Like I've been there before where before cancer diagnosis I've been like really tired, really tired but I would never ever verbalize it and say ok I am done.

Many participants described a newfound freedom to avoid activities that “drained” their energy, things they had felt compelled to do, like working a nine to five job or reading an uninteresting book until the end. Instead, they spent time on activities that “fill [their] cup,” like walking on the beach, eating ice cream or laughing with their grandchildren. Nancy alluded to this sense of release from responsibilities when she joked that her job was to sit down and “keep the couch from blowing away.”

### **Choosing treatments.**

As previously described, many participants’ well-being was enhanced when they were surrounded by social support and health care providers who supported their choices about treatment. Some of their beliefs were contradictory to their health care providers’ view of health and effective treatment. Many participants used what could be termed “alternative’ therapies,” including strict diet regimes, acupuncture, therapeutic touch, “energy blasts,” massage, positive thinking, visualization, and music. Jason acknowledged that the alternative treatments he was using enhanced his well-being even though he was not certain they would be effective to cure his cancer, “I think [using alternative treatments] help[s] me. If nothing else it's giving me more hope.”

Jason and Carol declined to have any medical treatments because they hoped that they could “beat” cancer using alternative methods. Jason described a “spiritual experience” when he felt assured by a “presence” that he did not need to have chemotherapy, whereas Carol simply did not believe it was warranted

and had always been against using medication. In spite of her long-standing use of natural health products, Carol eventually did take prescribed medications when she was disabled by pain. At the time of the interview, she seemed to have resolved her internal conflict around this issue because she was “desperate.” However, she remained committed to alternative approaches to fighting tumor growth. Marissa also described her decision to accept medical treatment as one born from necessity. She had actively protested nuclear weapons in her youth, and found it troubling to accept radiation or chemical therapy for her cancer because of her perception of them as dangerous. She said, “I really don’t believe in this crash and burn as I call it (chuckles) approach to cancer radiation and chemotherapy and yet...I am doing it.” At first, she attributed this decision which seemed in conflict with her values, to her children’s urging her to “try anything,” and her inability to pay for alternative treatments. Yet she later described the ambivalence she was feeling: “I don’t really want to do chemotherapy but I want to live so I’ve got to find some balance between those two.” At the time of the interview, Carol and Marissa seemed reconciled to the decisions they had made because they believed their choices were necessary given the circumstances. They seemed to have found a way to live choosing a treatment that was in conflict with their values or beliefs but in order to survive or to relieve a severe symptom.

Other participants did not seem as conflicted about choosing medical versus alternative therapies. Some used both types and saw them as complementary to each other, like Jennifer, who defined her “chemotherapy” as a

combination of the chemotherapy drugs, therapeutic touch, her positive energy, and the love of her family and friends. Some talked about the need for prayer, laughter, friendship, or “positive” activities but did not directly refer to these activities as “treatment” or “therapy.” Rather, they listed them as activities that enhanced their well-being.

### **Choosing to focus on the positive.**

Many participants described a diminished sense of well-being when they thought about the possibility of dying from their illness or about how challenging their present circumstances were. Several described the work of disciplining their minds to “focus on the positive” to maintain well-being.

For some participants, “focus on the positive” was about living in the moment and enjoying simple pleasures of life without dwelling on the future. They found joy in being outdoors, in humor, seeing beauty in nature, and spending time with loved ones. Many participants made a conscious decision to choose gratitude for the blessings of their life. Some kept a “gratitude journal” and Linda described a “gratitude practice” which she had used in the past and returned to immediately when she got her diagnosis. She countered thoughts about the unfairness or difficulty of her situation with thoughts of what she was grateful for:

I am very blessed. ...I made Sunday an all day retreat day for me ...I made myself do a half hour gratitude practice at least once a day ... [I was] feeling angry...gratitude practice is really hard to do and ... I got to the

point where trying to think of one, (Chuckles) was major....it's actually just simply choosing... gratitude by using your own mind to do that.... [I ask myself] what in my past could I feel grateful for...and then what in my very present today can I feel grateful for. I ask myself the question and then try and answer it. No matter what you're feeling like I could be sitting there thinking, this is all so unfair and I just feel tired of all this...but the idea is that ... if I'm mindful enough...then hopefully something comes. And it does, but it can be a bit of a grind, sometimes. And other times, it's just there for you.

Several other participants also used meditation as a way to focus their mental energy on the positive. The participants as a whole did not directly refer to spirituality as an aspect of their lives that enhanced well-being and none of them talked about spirituality until I asked a direct question about it. However, when discussing how they kept their focus on the positive aspects of their lives, they described practices and beliefs that could be termed “spiritual.” For example, Sharon practiced meditation as well as church participation. Sharon stated that before her cancer recurrence, she felt a “ceiling” of separation between her and God. At the time of the interview, she said that she had a more personal relationship with God and stated she has gone through a spiritual healing even though she has not been physically healed. Although Dave did not consider himself to be a “spiritual person,” he talked about how music engages the “mind, body and spirit.” Nancy thought about her husband looking down on her from heaven but did not refer to spirituality as a source of her well-being.

Marissa's beliefs included a "continuum of life." She has actively supported mothers with newborns as well as dying people in hospice. She was not afraid of dying because she sees it as the "most natural thing in the world."

Jason described an experience he had when first offered chemotherapy, "I was floating and some kind of very, very strong psychological, emotional, spiritual thing happened to me. And I felt I had just grabbed on to the most powerful thing I could ever imagine." Although he had times when he felt discouraged, Jason stated that he never gives up because of this intense experience.

After Jennifer talked about the difficulties due to the unpredictable and ongoing nature of her illness, she quickly spoke about how although she is not able to control her physical symptoms, she can control how she reacts to her circumstances. This life philosophy was a recurring theme throughout her interview. She spoke about choosing to focus on the blessings in her life, some of which she perceived to be a direct result of cancer. These blessings included a newfound acceptance of her body, deepened personal relationships, humility, and empathy towards others. She described her deliberate choice as follows:

I've learned that I have to use my energy some way and I'd rather use it towards the positive than the negative. Also honoring the negative but choosing, it's a choice...When things are really tough it can be easy to spiral down into the negative but I like to choose to try and see it in a different way.

What constituted “positive” varied amongst individuals. For, Carol being positive meant focusing her thoughts on the possibility of cure or long-term survival with cancer. She described it as mental discipline:

Focus on things everyday like there's so many things to be grateful for...all of that stuff helps right? ....It takes a lot of self discipline to keep your thoughts right but...we can control what we think about and it is our choice if we're going to think...about the awful side of it, or ...the potential of what can come of it...I want to focus on that healing is possible and I can, maybe not, I may not ever totally eliminate it, but I can get it to a point where it's under control and that I can live with it and a lot of people do. So ...that's my focus is keeping my thoughts more on the possibility and the potentiality of healing and health.

Some participants found they experienced well-being when they consciously looked for benefits to having cancer. While they could not say they were thankful for their illness, they were thankful for the personal growth they experienced. Nancy described herself as being much less judgmental and easygoing since her cancer taught her that “people are what’s important.” As Linda stated,

OK, so it's not fair [that I have cancer] but the gifts that I have [received as a result of cancer] ...seem to soften the unfairness somehow...personally in my life journey I think is that for the first time in my life I actually feel like I have inner strength and I have a positive attitude and I am coping well, I

actually feel it in a way I have not before in my life... people have said to me all along the way ...”you really have so much strength... you have a wisdom that you have no idea you know you should hold on to that.” I could hear it, I just never felt it. (Crying) ...Whatever has happened along the way...I actually feel it.... you know I really am blessed...and I think if I can leave with that alone that’s a gift that I would not have even anticipated.

Several participants had re-framed their view of cancer from scary, life-threatening, or “aggressive” to words with more positive connotations such as, “an adventure,” a blessing,” or a “growth process.” Jason thought of cancer as an opportunity, which was consistent with his life pattern of re-framing difficulty.

There's always an answer and every time it's a shitty thing [if] you stop and think long enough, there's an opportunity... to learn more about myself, learn new things, figure out how to do things, [have a ] new experience.

Most participants acknowledged the difficulties of their lives but chose not to dwell on them. For some, maintaining well-being involved a very deliberate disciplining of their mind by refusing to “dwell on the negative.” “Negative” had varied meanings for the participants. For some, this was equated with the possibility that they would die from their disease. Although most participants stated that their cancer was serious and expressed knowledge that it threatened their lives, death from cancer was framed as a possibility, not a certainty. They

were quite conscious of their efforts to push away negative thoughts. Jennifer said “I just don’t go there.” She chose not to read books about cancer, hear statistics, or think about the possibility that she “might not make it.” Carol decided to stop attending a relaxation group because several people had died and she didn’t want to think about that possibility for herself:

I stopped going to the relaxation group because everybody I knew there was dying and I really couldn't handle that so, it's just like choices that I have to make to keep myself focusing on what you wanna focus on. Do you wanna focus on health or do you wanna focus on death. So I stopped going cause... you go there, you become friends with people and all of a sudden they're gone. And I just didn't need a constant reminder of ...what this disease does and so I just, I decided to stop going because I didn't want to be around that.

### **Choosing to honor the negative.**

Rather than pushing unpleasant thoughts from their minds, other participants said it actually enhanced well-being to “honor the negative” aspects of their lives because it was more authentic to their entire experience. They talked about giving themselves time to grieve, to be “in the darkness,” but not allowing themselves to stay there. As Jennifer put it, “I just have my time to cry and just sit in that emotion” and Linda spoke about the “bittersweet” nature of her life:

Things are bittersweet. My days are bittersweet days but they are both. And the connection for me has to be that I am open to receiving the sweet. I have to open to it because under the circumstances, it's easy not to want to open to....the bitter part you know although that's useful too.... I don't feel any day at all is a really bad, bad day at all. It seems to be balanced with whatever could be available, certainly on an emotional level, spiritual level and, and physical level you know. ...I have probably have a little bit of a cry everyday at some point along the way and it's just part of what I see as just me being who I am and it's a clearing mechanism that actually really feels...positive to be doing.

The participants all described the maintenance of well-being as work they had to do. They were confident that they could use past strategies or develop new ones which would enable them to experience well-being. They were proactive in their efforts, making deliberate choices about who to spend time with, which health care providers to trust, which treatments to pursue, and where to focus their mental energy.

### **Living in Ambiguity**

Analysis of the interview transcripts has suggested that the participants were not living exclusively in a space where they were fighting against cancer, nor did they seem to be in a space of completely accepting it. They seemed to be experiencing multiple realities, perhaps living in both spaces at once, moving between spaces, or living in a gray area in between. For example, some

participants described themselves as being very healthy while acknowledging that they have an illness which is life-threatening. Other participants were emphatic that they would beat cancer and then minutes later talked about how their families would manage after their death. Their experience of well-being may be due to a willingness to accept this uncertainty and being at peace with living in ambiguity.

Many of the participants seemed to live in simultaneous realities, one of “living in the moment” or “supporting their bodies to heal,” while in the same interview, talking about their anticipated death from their illness. Sharon remembered a member of her support group who was reluctant to plan a year into the future because she did not think she would be alive at that time. Sharon disagreed with this approach, and planned for a future with unknown possibilities, saying, “Cancer may or may not be my demise.” She preferred to “embrace life rather than trying to avoid death” and talked about her vision for the future:

I think about my future in what I would like it to be. I don't think about the future as what if the cancer spreads.... because that instills fear into you. ...I tend to plan ahead... I think of, if the cancer comes back then I will deal with it. Not when the cancer comes back. So, that always opens the door to, it might not come back. ...I do try and do visualization seeing myself in a rocking chair with hundreds of little grandchildren around me and things like that. But, in realistic terms I set goals and I work towards those goals in the future.

Linda described living in simultaneous realities of realizing she is dying while hoping she will live. She had a long-standing practice of meditating on “intentions” for what she wants to happen. Since her diagnosis with cancer she had been practicing an intention of being cured. However, after her “aha” moment, when she realized she would likely die from her illness, she maintained the same intention, while at the same time preparing for her death:

I'm in this dichotomy which my intentions were...my body can and will heal itself. ... being able to go into full remission...I'm also trying to weave in the reality of what I'm looking at which is showing up pretty much as western medicine has said to me would...but keeping the intention that this could at any moment slow down. I could get...more time than I would have ever imagined. It could just happen.... And so [I am] trying to keep that intention going with living the reality of, that doesn't seem to be happening (Chuckles) you know cause...I'm... taking more and more pain meds... some fears have come up more with the changes that have been happening incrementally faster than I expected and so I have been experiencing the fear of this coming around sooner or hearing my own ... intuitive senses about my body. It's losing ground here a little bit. And it's becoming more noticeable to me and that's scary for sure [as the disease] manifests itself physically so.....there's that real big dichotomy there of...balancing my days with knowing what I'm dealing with...my challenge in this is, has been to understand that I get to have both and it's quite all right. I can have the intentions strongly and I can be in the reality of what's

happening and on a journey to passing into some mystery that I, I don't have a fear of actually dying.... think of it as more of a big mystery that nobody knows about except those who have gone you know ...So there's both of them, and you're with both of them all the time. You know, that is your present. That is my present in this right now. I'm just with this at some level all the time.

When feeling physically well, other participants also did not readily associate themselves with having a diagnosis of advanced cancer. Dave said having advanced cancer had not really affected him very much because of his lack of symptoms. Sharon described a previous mental image she had of her cancer as being very aggressive and powerful. At the time of the interview, she was not experiencing any troubling symptoms and had used many strategies including “energy blasts” and imagery in an attempt to decrease her tumor size. When asked how she visualized cancer in her mind presently, she replied, “not at all.” As already noted, for some participants, an increase in symptom severity, decrease in physical functioning, or a disappointing test result seemed to contribute to a gradual perception of their cancer as life-threatening. Nancy said that her recent increased shortness of breath made it impossible to forget she had cancer, it was “in [her] face all the time.” Nancy remembered the first time a health care provider used the word “palliative:” “Palliative, I think that was the one that really brought it home to me, oh my goodness.”

Other participants also talked about times when words or actions of the health care provider challenged them to transition from ambiguity into acceptance of the life threatening nature of their illness. Linda remembered her first visit with the pain and symptom management team,

When I saw them the first time they registered me full blown in the palliative care program and you know so the reality hits you know... I wasn't not unprepared in some ways but it felt very emotional for me to cross to officially being in that category... it was like whoa, okay, so this is happening

Similarly, Jennifer remembered an interaction with a physician who was blunt about her prognosis:

We met with a doctor at the cancer agency and I was asking questions and they were harder questions, it was just a lot of reality in my face about my situation. And I'd heard it all before, I mean the reality of advanced cancer and what chemo might look like and what the future might look like. And so the information he gave wasn't anything new but like I said it was all at once that I was re-hearing all this information it was just really overwhelming ...[he said] [the cancer] will come back.

Some participants did not acknowledge living in ambiguity in a conscious way, although analysis of their interview transcripts suggested they vacillated between the belief they would survive and the belief that they would die. For example, as previously presented, Jennifer avoided hearing or reading any

information about her prognosis because, as she stated, “I just don’t go there.” When confronted with the physician’s prediction that her cancer would not be cured, she said, “how does the doctor know that will be my path?” She was focusing her energy on “complete eradication of the tumor,” yet a few minutes later she tearfully remembered a recent incident when she was not sure if she should spend money on new rubber boots because she “might not make it.” Other participants spoke openly about their anticipated death from their cancer. Nancy discussed with her four -year old grandson how she wanted to be remembered and Marissa had a strong desire to prepare her family members for her death, saying, “I have a strong will to live but I’m not afraid to die.”

Some participants seemed to experience well-being because they believed they could have well-being whether or not they survived their cancer. As Sharon said, “I can be healed without being cured” and stated her goal was to improve her quality of life. Similarly, Linda said, “you have pain [and illness] but you don’t have to suffer.” Linda’s goal was to live “with integrity...completely believing that [she] is a worthwhile person...living and feeling at a deep level...a sense of kindness and compassion.”

## **Conclusion**

The participants in this study have described well-being as a complex, dynamic process. It is reminiscent of a leaf floating down a stream, changing directions when a rock or twig blocks its path. However, unlike the leaf, they were not passive but were allowing the process; choosing to let the river take them.

They were open to change, willing to embark on an adventure, curiously watching the riverbank as they meandered by. They made daily choices, often with great effort, about how they would respond to their circumstances. The journey of well-being as understood by the participants is one that they had some control over, due to a firm belief that they have sovereignty over how they chose to respond to the difficulties of advanced cancer. They choose which relationships to invest in, how to care for themselves, which treatments to have, and where to focus their mental energy. They acknowledged difficulties while focusing on the blessings of their lives and seemed to accept living in ambiguity.

## **Chapter 5 – Discussion**

The purpose of this study was to gain a better understanding of the experience of well-being of people with advanced cancer. Well-being was described by the participants as something that “goes up and down” and takes hard work to maintain. They all had a strong belief in their ability to affect their own response to advanced cancer. They took a pro-active approach to sustain well-being which included choosing supportive relationships, choosing to put their own needs first, choosing treatments, and focusing on the positive while honoring the negative. For some, spiritual practices and beliefs enhanced their well-being. The participants’ descriptions of living with advanced cancer suggested that they were in an in-between reality. They seemed to be simultaneously living in the moment, fighting for survival, hoping for a cure, and anticipating their death.

In this chapter, I discuss the findings in relation to what has been reported in relevant literature. Then, I explore implications for research, nursing practice, education, and health care programs and organizations.

### **Findings in Relation to the Literature**

Many of the findings of this study are congruent with what is found in the literature, including “choosing to focus on the positive,” “choosing supportive relationships,” and “choosing to put my needs first.” However, the following findings have not been reported or have been reported in a limited way: “the fluctuating nature of well-being,” “honoring the negative,” “living in ambiguity,” and the aspect of conflicting values within the theme of “choosing treatments.”

### **Findings supported by existing knowledge.**

There have been many studies and discourse in social media about the effect of having a “positive attitude” on advanced cancer (McGrath, 2004; O’Baugh, Wilkes, Luke, & George, 2008), which may be part of the reason why “focus on the positive” was such a dominant theme in my study. As mentioned in Chapter 4 the meaning of the word “positive” had varied meanings for the participants. Differing meanings of being positive have been reported in the literature as well. McGrath (2004) describes “being positive” as “a way of talking and acting that reflects an optimistic or positive attitude or feeling state” (p. 26). As discussed in Chapter Two, other studies have also associated being positive with optimism (Cohen, de Moor, & Amato, 2001; Petersen, Clark, Novotny, Kung, Sloan, Patten, et al, 2008; Winterling, Wasteson, Sidenvall, Sidenvall, Glimelius, Sjoden, et al, 2006). Some of the participants in my study equated thinking positive with only allowing oneself to imagine oneself as cured, while for others, it meant being thankful and reframing negative thoughts and experiences into positive.

For all of the participants, “focusing on the positive” was an important element of their well-being experience. They were grateful for the blessings in everyday life and chose to think about those rather than the difficulties of their circumstances. Many talked about choosing gratitude, which was reported by all of Hutchings’ (2007) participants as a strategy they used to “struggle in change” at the “end-of-life” (p. 31). Most of the participants in my study said their well-

being was enhanced by thinking about the secondary benefits of having cancer such as personal growth, which is similar to findings in a study by Lethborg, Aranda, Bloch, and Kissane (2006) who found that people with advanced cancer do not always think of it as a “lose, lose situation” (p. 37). In their efforts to “focus on the positive,” many of the participants in my study talked about consciously re-framing their illness experience as something that had enhanced their personal growth. Re-framing to see benefits of life-threatening illness is a strategy for enhancing well-being which is supported by other studies (Lethborg, Aranda, Bloch, & Kissane, 2006; Lipsman, Skanda, Kimmelman, & Bernstein, 2007; McGrath, 2004; Mount, Boston & Cohen, 2007). Many of the participants in my study made deliberate choices about which social and professional relationships to invest in. They recognized that spending time with some people improved their sense of well-being while time spent with others diminished it. Some felt that having cancer had given them “permission” to be released from problematic relationships. Similarly, Reb (2007) noted that some participants she interviewed actively avoided people who were “negative” or “unsupportive” (p. E74) as a way to maintain hope in advanced cancer.

The participants in my study sought out social relationships with people that were “supportive.” The choosing of supportive relationships by people facing advanced cancer has been reported in other studies (Lethborg, Aranda, Bloch, & Kissane, 2006; Reb, 2007). Reb (2007) noted that women with advanced ovarian cancer went through a process of appraisal of their social networks to

determine who would be most helpful, and chose to spend time with people who were “optimistic” and “encouraging” (p. E74).

Several participants in my study persistently sought out health care providers that encouraged them in their efforts to maintain well-being, or at least did not discourage them. Other studies have also found that well-being is supported by health care providers who take a personal interest in their patients (Richardson, 2002; Wilkes, O’Baugh, Luke, & George, 2003). A few of the participants felt that health care providers were not supportive when they talked about statistics and prognosis before the participant was ready to hear the information, which was noted as detrimental by Wilkes, O’Baugh, Luke, and George, (2003). Their study used semi-structured interviews to understand the meaning of “positive attitude” (p. 412) for cancer patients. Many of their participants said they needed the health care providers themselves to have a positive attitude, which for the participants, meant avoidance of morbidity or mortality statistics.

Participants in my study also said they realized what was important to them and wanted to care for themselves by spending time on activities that enhanced their well-being. They had a newfound freedom to say no to activities that diminished well-being or did not add to it. Similarly, the participants in Lethborg, Aranda, Bloch, and Kissane (2006) described the “permission to say no” as the “biggest gift” cancer had given them (p. 37). The participants as well as those in other studies cared for themselves by choosing activities that brought

them joy (Volker, Kahn, & Penticuff, 2004) such as time with loved ones, time in nature (Mount, Boston, & Cohen, 2007), enjoying every moment, and simple pleasures (Lethborg, Aranda, Bloch, & Kissane, 2006; Lipsman, Skanda, Kimmelman, & Bernstein, 2007).

### **Findings adding to existing knowledge.**

Well-being was experienced by the participants as something that fluctuates rather than a static state. They described times when they felt “down” and had to make choices to work at rising again to a place of well-being. This finding is supported in other studies (McGrath, 2004; Wilkes, O’Baugh, Luke & George, 2003). McGrath (2004) describes overall well-being as cycles of despair / negativity, readjustment and returning to positivity. Through interviews with cancer survivors and hospice patients, McGrath found that a “positive outlook” (p 25) had to be continuously re-negotiated as part of an ongoing process. However, much of the literature describes well-being as a finished product; referring to people with well-being as those who *have* a “positive attitude” (O’Baugh, Wilkes, Luke, & George, 2008, p.109) or *are* “acceptors” (Thompson, Chochinov, Wilson, Chary, O’Shea, Kuhl, Fainsinger, et al., 2009, p. 5757). In contrast, most of the participants in my study did not see themselves as people who are always “up.” They needed to work to maintain well-being by making deliberate choices. Some participants stated that they needed to experience the negative as well as the positive in order to have authentic well-being. A few described their experience of well-being as a journey that is not finished.

Some participants in my study deliberately forced out negative thoughts, which is congruent with Wilkes, O’Baugh, Luke, and George (2003), who found that participants “dare[d] not be negative for any length of time” (p. 415). While the participants in my study sometimes needed to exclude “negative” thoughts from their mind, it was also important for them to “honor the negative”. Linda characterized her experience of well-being as “bittersweet.” She used an example of special times with her loved ones as “sweet”, yet “bitter” because she knew she may never see those people again. She needed to find a way to accept both parts of the bittersweet. This is congruent with Hutchings (2007), who found that many participants had a “co-existence of sorrow and gratitude” (p. 35).

Although there are a few studies that refer to co-existence of negative and positive outlooks, most refer to people as either being “positive” or “negative.” Lethborg, Aranda, Bloch, and Kissane (2006) write about people’s efforts to maintain equilibrium between negative and positive experiences, suggesting they are two opposite ends of a pendulum. Many of the participants in my study stated that they needed to allow themselves to grieve losses and “honoring the negative” was essential to their experience of authentic well-being.

Kearney (1996) states that everyone who is dying has a turning point when they realize that continuing to fight against death will only add to pain and suffering. He observed that a sense of peace is apparent once people have made a noticeable shift from struggle to acceptance. Kearney says that many

people who have been validated by previous successful overcoming of life crises take on a “heroic stance” (p. 49) and “relentlessly” (p. 48) seek a cure for life-threatening illness. He writes that eventually these people will realize that a cure cannot be found and will experience “hurt pride and an indignant sense of disbelief that ...a cure cannot be found despite all one’s courage, ingenuity and best efforts” (p. 48). This description is similar to Jason and Carol’s experiences when they received test results indicating their tumor markers were continuing to rise in spite of all they were doing to lower them.

Although I had not read Kearney before beginning data collection, his ideas about the dying process were congruent with my own beliefs. I too believed that people needed to accept the life-threatening nature of their illness in order to have well-being. I imagined a “pivotal moment” when they realized they were dying (Reb, 2007, p.E74). I thought that by limiting participants to those who were aware of their advanced cancer diagnosis, I would only be interviewing people who were in a phase of preparing to die. However, the participants in my study did not describe a distinct shift or transition from living to dying. This is congruent with Thompson, Chochinov, Wilson, Chary, O’Shea, Kuhl, Fainsinger, et al. (2009), who stated, “being aware of one’s terminal illness and accepting impending death are two different phenomena yet are often conflated with the other” (p. 5761). The authors conducted a national survey of 381 people with advanced cancer to identify the impact of prognostic acceptance on well-being. They categorized their participants as either “acceptors” or “non-acceptors” of the life-threatening nature of their illness (p. 5757). They found that

acceptance of illness was correlated with well-being and non-acceptance with emotional distress.

As mentioned in the presentation of findings, the participants in this study did not seem to have an “either-or” experience of either accepting death or fighting cancer. Many of them described living in both realities, either simultaneously or back and forth over time. A few studies report similar findings. Sand, Olsson, and Strang (2008) conducted interviews with 20 participants with advanced cancer. They described participants as being accepting of death, while still “clutching at straws to keep hope that death would not occur” (p. 6). The authors wrote that the stories were about a process of swinging on a pendulum between death and life, rather than a linear progression from living to dying. They theorized that there may be a difference between coping with a life-threatening illness while focusing on living as long as possible and coping with one’s impending death when realize that life will soon come to an end, which is congruent with Hutchings (2007) who said that acknowledging that death is near is not necessarily the same as ceasing to fight death. Benzein, Norberg, and Saveman (2001) found that people with life threatening illness experienced “belonging both to life and death” (p.120), meaning that they were aware that their death was likely imminent, but stated they had to keep on living during the time they had left. Write and Flemons (2002), when reflecting on research they had conducted with terminally ill people, observed the “doubleness of dying” (p. 266) , which they described as simultaneously “hanging onto life and reaching out to death” (p. 266). McGrath (2004) found that hospice patients described

“beating disease juxtaposed with acceptance of death” (p. 30) and Reb (2007) said “women [with ovarian cancer] struggled to hold onto the belief that they would be okay while not being certain” (p. 74), which is congruent with the participants in my study, who mostly talked about death from their illness as a possibility rather than a certainty. Barnard, Towers, Boston, Lambrinidou, & Towers (2000), in their collection of narratives of people facing terminal illness described this ambiguity:

The norm [of death awareness] is a frequent oscillation between hope for cure and acceptance of decline and death. A transition from active treatment to palliative treatment may happen smoothly and unidirectionally, but more often is a gradual, confusing, ambivalent process for all concerned (p. 10).

The participants in my study seemed to be living in ambiguity to varying degrees. Several of them spoke about only thinking about the possibility of cure, yet would contemplate their death later in the same interview.

The people I interviewed described a need to be active participants in treatment decisions, which is supported in the literature (Henselmans, Sanderman, Helgeson, de Vries, Smink, & Ranchor, 2010; Ramfelt, Severinsson, & Lutzen, 2002; Volker, Kahn, & Penticuff, 2004). Many of the participants felt they could regain control of their illness experience by choosing complementary or alternative therapies (CAM). This finding is also supported by literature, which states that CAM may decrease emotional distress and enhance well-being due to

providing people with therapies they can seek out and manage themselves (Lengacher, Bennett, Kip, Gonzalez, Jacobsen, & Cox, 2006). Participants in Truant and Bottorff's (1999) qualitative study of how people make decisions about complementary therapies stated that they used CAM in order to feel they had some control and "could influence what was happening to [them]" (p. 138). This is similar to Jason's statement, that using alternative treatments enhanced his well-being even though he was not certain they would cure his cancer. Truant and Bottorff's participants stated that the "illusion of control" (p. 134) gave them hope and decreased their anxiety whether or not they believed CAM would increase their survival time.

Some of the participants described inner conflict as they made decisions about treatment that were in conflict with their values. Radley and Payne (2009) reflected on published case studies about why some people with cancer refuse medical treatment. The authors suggest that people decide whether or not to have conventional cancer treatment within the context of their values and previous ways of coping with illness. Furthermore, their beliefs about health and illness may be different from the medical ethos of their health care providers. Some of the participants viewed chemotherapy, radiation and pain medication as drastic measures, yet accepted these treatments, seemingly out of desperation. I could not find studies that explored this inner conflict around cancer treatments. However, Pound, Britten, Morgan, Yardley, Pope, Daker-White, et al. (2005) in their discussion of published studies about why people refuse to take medications, state that there is a growing trend of disconnect between the view

of medicine by patients and by health care providers, and Radley and Payne state that the medical system has decreasing authority in the eyes of the public.

In summary, this study confirms the current state of knowledge about the experience of well being in advanced cancer in regards to the choices people make about where to focus their mental energy, how to care for themselves, and which relationships to invest in. This study adds to existing knowledge in that people with advanced cancer may not experience a distinct transition from living with their illness to preparing to die. Similarly, people do not have to be always optimistic or upbeat to maintain well-being. In fact, some people may need to spend time grieving and feeling sad in order to feel true to themselves. As well, there may be a discrepancy between the values of health care providers and patients, especially about alternative therapies, and this discrepancy can lead to inner conflict for the patient. The limitations and potential implications of this study will now be discussed.

### **Limitations and Areas for Further Research**

As previously mentioned, the people in this study were only willing to participate when they were experiencing a time of well-being, so their report of being generally “upbeat” may have differed if they were interviewed during a “down” time. Yet, they were affirmed by health care providers and loved ones as people who experience well-being most of the time. It is unclear whether their internal experience differed from how others perceive them, or if they are experiencing well-being the majority of the time. The existing state of knowledge

would benefit from longitudinal studies of people facing advanced cancer. Questions about the nature of well-being over the disease trajectory could be explored. In addition, a comparison could be done between the perceptions of well being by people with advanced cancer, their health care providers, and their family members.

Some participants described a conflict between their values around health and the treatment offered by the cancer agency. This area is beginning to be reported in research into the reasons people choose alternative and complementary treatments. However, there is room for further exploration into how people feel when their values and beliefs are in conflict with those of their health care providers and the impact this conflict has on decision making.

Living in ambiguity has been reported in a few studies. However, most literature refers to the transition people make in their minds from curative to palliative care. The experience of living in the in-between, and how people can have well-being in a place of ambiguity needs to be more fully explored. Future research could use single interviews, focus groups or journal writing to understand the experience of living with a life-threatening illness in more depth.

Most of the findings of my study are supported by literature and the observations of clinicians. Therefore, they may be considered trustworthy even though the sample size was small. However, insights about the nature of well-being over time, inner conflict between patients' and health care providers' values, and living in ambiguity would benefit from further study.

### **Implications for Nursing Practice**

The findings of this study have potential to impact current nursing practice by affirming the value of the relationship nurses form with patients, encouraging clinicians to focus care on the goals of their patients, and to be self-reflective of how their values and language use may affect the well-being of those they care for.

Nurses need to be self-reflective about the relationships they form with patients. Many participants related incidents when they felt unsupported or devalued by their health care providers, which diminished their sense of well-being. Therefore, it is critical that nurses understand how they are perceived by patients and strive to engage in supportive relationships with them.

As can be understood from my study, people with advanced cancer work hard at well-being and health care providers have the power to diminish well-being if they are not sensitive to their patients' efforts. The health care providers described by the participants seemed to disagree with alternative or complementary (CAM) methods of maintaining well-being, and this translated into their relationship with their patients. Regardless of personal values and beliefs, it is critical that nurses, as care providers, see the motivation behind our patients' efforts, rather than the specific methods they are using. They may be using CAM to regain control over their illness, to find a way of coping that is congruent with their view of illness and healing, or to honor their whole personhood (Ramfelt, Severinsson, & Lutzen, 2002).

To enhance a sense of personal control, nurses can ask patients about their goals and develop a plan together to meet those goals. When nurses perceive the patient's goals as unattainable, it is important to take cues from the patient and give them time to mourn the loss of goals when *they* realize they are unattainable. As Gum and Snyder (2002) state, "goals chosen by the person ...are more positively associated with well-being than goals determined by other people" (p. 886).

Both patients and oncologists have been known to pursue aggressive treatment so they can "do something" (de Haes & Koedoot, 2003, p.43). This may be seen as a way to exert control over the illness; however, it may also decrease the quality of supportive care when patients with little chance of cure are labeled as curative (de Haes & Koedoot, 2003). Nurses and other health care providers need to explore the reason for patients' treatment decisions, as it may have more to do with values and feelings rather than weighing the pros and cons, which is often how it is presented by oncologists (Huijjer & van Leeuwen, 2000). Huijjer & van Leeuwen (2000) interviewed oncologists and their cancer patients who had refused treatment. Using grounded theory, they examined the decision-making process of the patients as well as the way the decisions were presented by the physician. They found that none of the oncologists talked about the context or values of the patients. Patients made decisions based on personal circumstances, attitudes about death, and opinions of family and friends (Huijjer & van Leeuwen). We should strive for person-centered care by working closely

with patients to understand their perspective and context, as flexibly as possible, to enhance health in a way that is meaningful to them (Price, 2006).

Nurses and other health care providers must approach their patients with an attitude of curiosity rather than judgment, and seek to know them as people. Medicalized ideas about effective coping may not resonate with patients' personal contexts, and pressuring them to conform to a particular way of enhancing well-being could be more damaging than helpful (McGrath, 2004). Richardson's qualitative study examining the perception of palliative nurses by their patients revealed that professional skill and knowledge is not enough; the 12 participants experienced interactions with nurses as therapeutic only when the nurse was both competent and caring (Richardson, 2002). Care was perceived as most supportive when provided in the context of a relationship where the patient felt warmly regarded as a person (Richardson, 2002).

Nurses, as care providers to family as well as patients, can also provide family members insights into patients' decisions. They may not be perceived by the patient as supportive, and nurses could encourage them to have open, non-judgmental discussions with their loved ones about how they can support them to avoid severance of the relationship. As well, nurses can encourage patients if they have made a decision to choose to meet their own needs first. This may be difficult for family members if they are used to their loved one putting *them* first. There could be family meetings with a counselor to facilitate open discussion about how best to meet the needs of the person with advanced cancer.

Working with patients who are not black and white about their prognosis can be difficult for nurses, who may want to categorize patients as “curative” or “palliative,” or even “living” or “dying.” It can be confusing when a patient states they are fighting to beat their cancer and in the next breath talks about their funeral arrangements. How should nurses approach these conversations? I think the key is to take cues from the patient and start from where they are rather than bringing them to a place that is more comfortable. Nurses must find a way to accept ambiguity themselves, and provide a safe place for patients to share their experience. Patients offer nurses the honor of walking with them throughout their journey, through the gray times as well as the black and white, and nurses are in a position to provide them with a trust relationship that allows for the expression of their true experience.

Encounters with people who experience well-being while having advanced cancer can be inspiring to nurses and other health care providers (Block, 2001; Kendall, 2006). Block (2001) explored the nature of personal growth at the end of life using a case study exemplar. The physician in Block’s account states, “I feel so much better after each visit with him. It’s almost like he’s a doctor to me” (p. 2903). Kendall asked oncology nurses which patients they admired and they described those who were cheerful, and one nurse referred fondly to a patient who “was always smiling regardless of her situation” (Kendall, p. 328).

Health care providers learn from their interactions with people with life-threatening illness about how there may be opportunities for growth in the dying

process, how to be strong in times of hardship, and how to maintain a positive attitude towards difficulties (Block 2001; Kendall, 2006). As Block (2001) states,

Seeing life from the perspective of someone who has limited time enhances clarity about personal priorities. The intimacy of the experience offers deeper understanding about the nature of life, an appreciation of the gifts of being alive, and constantly renewed inspiration and hopefulness about human resilience (p. 2904).

The health care providers I talked to echoed the above reflections. They seemed to enjoy spending time with their patients who were experiencing well-being. Their countenance brightened and their speech was enthusiastic when they referred to these people. Some health care providers have said to me that interactions with people experiencing well-being are the reason they continue to work in palliative and cancer treatment settings. I have felt that way too. One of my initial reasons for conducting this study was because I looked forward to being inspired by my study participants. In fact, following one of my participant interviews, I wanted to return to direct patient care because I missed the personal interactions. After the interview, I reflected, "He's exactly the kind of person I wanted to talk to because it's so inspiring... it's such an honor and such a privilege to talk to him today. You know I just feel so, so blessed and so enriched by talking to him. .. it really, really makes me miss doing palliative home care."

Being inspired by patients certainly promotes job satisfaction. However, I wonder how patients may be affected if they perceive that their health care

providers want to learn from them or be inspired by spending time with them. Would patients feel pressured to be “always smiling?” Byrne, Ellershaw, Holcombe, and Salmon (2002) interviewed 30 people with advanced cancer and the participants said they felt pressure from family, friends and their health care providers to stay positive and continue “fighting” (p. 15). This pressure was perceived as a burden and sometimes caused them to repress or hide their emotional responses (Byrne, Ellershaw, Holcombe, & Salmon, 2002). We must be careful in the language we use and provide a safe place for the patient to express a full range of emotions (Clayton, Butow, Arnold, & Tattersall, 2004; McGrath, 2004). “Clinicians should be aware that their use of language of effort and fighting, while appearing to empower patients, can in reality serve clinicians’ emotional needs at the cost of burdening patients” (Byrne, Ellershaw, Holcombe, & Salmon, 2002 p. 21).

We as nurses should also be careful about how they interpret the meaning of the word “positive” when used by patients. With patients who have advanced disease, we may think they are saying they are only anticipating a cure, which can cause us discomfort if the medical evidence shows this is unlikely. However, in this study, some participants meant that they chose to think about the blessings of their life, or to only do activities that brought them joy. We can promote positive thinking of this nature regardless of the likeliness of survival.

## **Implications for Education**

Nursing education and education for health care professionals could be informed by the findings of this study and others focused on how people with life-threatening illness experience well-being. As will be discussed in the following sections, the presentation of a Do Not Resuscitate Order, referral to a palliative care specialty, or registration with a palliative benefits program can trigger a transition into non-curative care that the patient may not be ready for. Since nurses are often the ones who present these triggers, they should be taught and mentored how to present them in a way that allows for ambiguity. Such as; referring to palliative care as complex symptom management that is focused on the individual's goals and priorities, within a philosophy of holistic care, towards a goal of quality of life, rather than as a label that indicates health care providers think they will die from their illness. These conversations require sensitivity and careful timing.

Often, nurses feel at a loss because they perceive they have little to offer patients when their illness has no cure. However, management of physical symptoms can improve overall well-being, as was shown in the participants' accounts and in the literature review. Therefore, nursing education should include an extensive symptom management component, for patients with all illnesses, and not just cancer or those deemed as "palliative." Nurses sometimes perceive that only physicians, who can prescribe medications, have a role in symptom management. However, there are a plethora of supportive and non-

pharmacologic measures that are helpful for managing symptoms and fall within the nursing scope of practice. As well, nursing education should include the notion of the therapeutic nature of walking alongside a person on their journey. The participants said they wanted health care providers who would support them as people and accept them wherever they were at in the moment. Just being present with them and providing a safe place to express their full range of emotion *is* an intervention.

### **Implications for Health Care Programs and Organizations**

Health care programs and organizations can be affected by understanding the themes that enhance well-being in a larger scale and a programmatic level. Organizations should facilitate the building of supportive relationships between patients and health care providers, allow for ambiguity rather than strict “curative” or “palliative” program designation, careful use of language, and reflection about potential conflict between our values and the values of those we care for.

It is challenging to provide equitable, individualized, person-centered care with limited human resources. Price (2006), in his discussion on person-centered care, notes that nurses and other health care providers may be frustrated trying to provide person-centered care when it differs from standard pathways or protocols. When a health care provider spends time trying to understand one person’s unique context, it may take time away from other patients (Price, 2006). However, as the results of my study show, and as confirmed by the literature, the relationship between health care providers and patients is an important element

that enhanced well-being. Health care organizations may need to reorganize existing human resources more creatively to meet the need for relationships that will be perceived as supportive and place value on relationship-building efforts between providers and patients.

There is a definite shift in care when a person is designated as palliative in British Columbia. Specific benefits and home care services are only available if a person has less than a six month prognosis. The participants referred to words or actions of the health care provider that indicated that their disease was life-threatening. Examples were using the word “palliative”, registering for palliative benefits and being referred to the pain and symptom management team. These were perceived by the participants as a signal that they were dying, forcing an abrupt transition many were not ready for. Several of the participants in my study as well as other studies said that health care providers diminished their well-being when they focused on statistics and prognosis before they were ready to hear it. Much of literature instructs clinicians to gently nudge people into accepting their illness so they can make the necessary transition from curative to palliative (Schofield, Carey, Love, Nehill, & Wein, 2006). However, our health care system is divided into categories of curative and palliative. We need to find ways to allow patients to be in ambiguity, and not force them to make a premature transition because it meets the needs of the system rather than the individual. Some people may not receive the supportive care they need because they do not want to be labeled as “palliative” and are not yet ready to transition into a dying phase. A palliative approach, which includes symptom

management, person-focused, and holistic care is appropriate and aligned with nursing philosophy regardless of the illness or prognosis. This approach could be integrated into all of health care, perhaps without using the term “palliative.”

### **Conflicting values.**

Research is shown to be a priority in cancer centers by the physical space allotment, disbursement of donated funds, and media coverage. As well, academic and medical knowledge is valued as demonstrated by the proportion of conference presentations and in-services the agency. Certainly research and knowledge are critical in order to develop more effective treatments to cure advanced cancer and to provide safe, competent care. However, none of the participants in my study said their well-being was enhanced because of curative treatment. None of them said they appreciated that their health care providers seemed to be knowledgeable. Rather, they felt supported by professionals who supported *their* values, and tailored care to meet their goals. If we want to promote well-being of our patients, we should consider carefully what we value and how those values may be perceived by those we care for.

The use of complementary and alternative therapies was identified as a way that participants maintained a sense of control in keeping with their values which was important to their well-being. These therapies may be in conflict with the medical and empirical research ideologies, yet they are clearly of value to many of our patients. While a program does exist within the British Columbia Cancer Agency called Complementary Medicine Education and Outcomes

(CAMEO) to provide decision support for patients exploring these options, the dismissive attitude of many health care providers about CAM has been shown in my study to be damaging to the supportive relationship and may be enough for the patient to disengage and look for other health care providers. We as an organization need to be sensitive to the possible dissonance between the predominant medical paradigm and the paradigm of patients.

### **Conclusion**

The experience of well-being in advanced cancer is a complex and varied one. The participants in my study have provided insights into that experience. Well-being is not a passive process; rather, it is an active one that takes hard work to maintain. People with advanced cancer encounter challenges which have the potential to overwhelm them. However, they have developed strategies that enable them to describe themselves as “healed without being cured” and “happy.”

Nurses need to approach their patients with an open attitude, seeking to understand them as people with a unique history and context. The relationship formed is as important if not more important to their well-being than the treatments we provide. We need to be sensitive to where they are in the moment, and anticipate that they may not have a clear-cut reality. We need to focus on their priorities and their needs. People who experience well-being often do so using resources they have developed themselves, so we need to be humble enough to support their own efforts instead of pushing our agenda.

The participants in my study have inspired me to be more person-focused in the care I provide. They have challenged me to be self-reflective, questioning my long-standing values and beliefs. As they have experienced personal growth as a result of their illness, I too have grown as a result of knowing them. I hope by sharing their experience with others, I can inspire health care providers to question themselves as well, and to learn from people who are on this journey. I have been honored to walk alongside them even for a brief moment and will be forever changed.

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## **Appendix A – Instructions for Participant Invitation:**

### **Pain and Symptom team**

Dear Pain and Symptom Management Team Members;

I am a Master's of nursing student conducting my thesis research study entitled, "*The experience of well-being in the midst of advanced cancer*". The purpose of this research is to understand the experience of well being from the perspective of people with advanced cancer. I would be very grateful for your help in identifying potential participants and introducing the study to them.

Potential participants will identify themselves in one of two ways: by rating their well-being from 0-3/10 on the Edmonton Symptom Assessment System (ESAS), or by responding affirmatively to the question in the invitation letter.

#### **Self Identification Using ESAS**

1. The patient will complete either the electronic or paper version of ESAS in the waiting room before meeting with the Pain and Symptom team.
2. The team will use ESAS symptom ratings as a starting point for consultation and discuss interventions to help manage those symptoms, as per their usual practice.
3. If the patient has scored between 0 and 3 /10 for well-being on the ESAS, the team member will:

3.1 Confirm that the patient understood the counter-intuitive rating (i.e.: a low rating for well-being actually indicates they are experiencing well-being).

3.2 Consider the following inclusion criteria:

3.2.1 Participants for this study will be those who have been diagnosed with advanced cancer, defined as: “a disease in which there is little chance of cure and in which the aim of treatment is usually to achieve palliation” (Redmond, 1998, p. 31). This diagnosis and intent of treatment will be documented in the oncologist notes and known to the Team before they see the patient.

3.2.2 The patient must make reference to the advanced nature of their disease during this or previous visits to the Pain and Symptom Clinic. The patient will have referred to their death as an expected outcome or have stated that he/she sees his/her illness as being very serious.

3.3.3 Due to the nature of the interview questions, which require the participant to describe subjective experience using introspection, participants must be able to communicate verbally in English.

### **Self-identification via the Invitation Letter**

If the patient has either misunderstood the ESAS “well-being “question (i.e.: they have given themselves a rating from 4-10/10, when they meant to rate themselves as having well-being), or has not completed the ESAS, continue with “recruitment procedure”.

### **Recruitment Procedure**

1. If the patient satisfies the criteria, the Pain and Symptom team member will give them the information brochure, introduce the study using the following script,

“There is a study being conducted by a Master’s nursing student. She is interested in the experience of people with advanced cancer who experience well – being. If you would like to ask questions or hear more about the research, you can either give me permission to share your phone number with her, or you may contact her directly. Your participation is completely voluntary and will not affect your care in any way. No one in your health care team will be aware of whether or not you are participating, unless you inform them yourself“

This study has received ethical approval by the University of Victoria and the BCCA Ethics review board. Please contact me if you would like more information or to view the proposal.

Thank you and warm regards,

Kathleen Yue, MN candidate.

[kyue2@bccancer.bc.ca](mailto:kyue2@bccancer.bc.ca)

250-686-8822

**Appendix B -Instructions for Participant Invitation:  
Patient and Family Counselors**

Dear Patient and Family Counselors;

I am a Master of Nursing student conducting my thesis research study entitled, "*The experience of well-being in the midst of advanced cancer*". The purpose of this research is to understand the experience of well being from the perspective of people with advanced cancer. I would be very grateful for your help in identifying and inviting potential participants. You would be inviting participants you interact with either in a one-on-one therapeutic interaction, or when facilitating a support group for people with advanced cancer.

Following your therapeutic interaction with a potential participant, consider the following inclusion criteria:

1. Participants for this study will be those who have been diagnosed with advanced cancer, defined as: "a disease in which there is little chance of cure and in which the aim of treatment is usually to achieve palliation" (Redmond, 1998, p. 31). This diagnosis and intent of treatment will be documented in the oncologist notes and known to you before you see the patient.

2. The potential participant must make reference to the advanced nature of his/her disease during this or a previous therapeutic interaction. The patient may have referred to their death as an expected outcome or have stated that they see his/her illness as being very serious.

3. Due to the nature of the interview questions, which require the participant to describe subjective experience using introspection, participants must be able to communicate verbally in English.

4. During your therapeutic interaction with a patient, he/she has described his/her self using phrases similar to “coping well”, having “inner strength” or a “positive outlook”.

If the above criteria have been met, please give the potential participant an invitation brochure using the following script:

“There is a study being conducted by a Master’s nursing student. She is interested in the experience of people with advanced cancer who experience well – being. Here is some written information about the study. If you would like to ask questions or hear more about the research, you can either give me permission to share your phone number with her, or you may contact her directly. Your participation is completely voluntary and will not affect your care in any way. No one in your health care team will be aware of whether or not you are participating, unless you inform them yourself“

For potential participants you interact with when facilitating support groups for people with advanced cancer, they will consider the inclusion criteria themselves, as described in the invitation brochure. In this case, please introduce the study with the above script and have the brochures and set out on a table where they may choose to take one or not.

This study has received ethical approval by the University of Victoria and the BCCA Ethics review board. Please contact me if you would like more information or to view the proposal.

Thank you and warm regards,

Kathleen Yue, MN candidate.

## **Appendix C – Participant Invitation Pamphlet**

***“Coping well”***

***“Inner strength”***

***“Positive outlook”***

### **Do these phrases describe you?**

A study entitled, *“The experience of well-being in the midst of advanced cancer”* is being conducted by a Master’s of Nursing student from the University of Victoria.

The study’s purpose is to understand the experience of well being from the perspective of people with advanced cancer and factors that contribute to that experience.

This study has been approved by the ethics boards of the University of Victoria and the BC Cancer Agency.

### **What would be involved?**

If you choose to participate, you would be interviewed by the Master’s student for about 1 hour.

The interview will take place in your home or at the Vancouver Island

Centre of BCCA, in a private location where you feel comfortable. The interview will be audio recorded.

You will be asked to describe your experience of well-being and the factors contributing to that experience.

### **What are the benefits of this study?**

The understanding gained through this study has the potential to improve the support provided to people with advanced cancer

During the interview, you will be given the opportunity to reflect on your experience, which you may find beneficial.

### **Who may volunteer for this study?**

You may volunteer if you:

- Would describe yourself as someone who is experiencing well-being
- Have advanced cancer
- Speak English fluently

If you would like to hear more about this study and/or would like to volunteer to participate, please either give your permission to your health care team for your contact information to be shared with the nursing researcher, or contact her directly:

**Kathleen Yue, RN, MN (in progress)**

[kyue2@bccancer.bc.ca](mailto:kyue2@bccancer.bc.ca) 250-686-8822

### **Appendix D – Sample Interview Questions**

1. You have a serious illness, and you have identified yourself as someone who is experiencing well-being. Can you tell me more about that?
2. Please tell me about your experience of well-being at this time in your life.
3. What challenges your well-being?
4. What has contributed to your well-being?
5. How does your present well-being compare to your well-being in the past?

## Appendix E – Participant Consent Form

### Consent Form

#### *The Experience of Well-being in the Midst of Advanced Cancer*

**Principal Investigator:**

Kathleen Yue, graduate student in the School of Nursing at the University of Victoria (UVIC).

Email: [kyue2@bccancer.bc.ca](mailto:kyue2@bccancer.bc.ca) or phone 250-686-8822.

**Co-Investigator and British Columbia Cancer Agency (BCCA) supervisor:**

Dr. Maxine Alford, Professional Practice Leader –Nursing

Email: [malford@bccancer.bc.ca](mailto:malford@bccancer.bc.ca) or phone 250-519-5607

**UVIC Faculty thesis supervisor:** Dr. Kelli Stajduhar

Email: [kis@uvic.ca](mailto:kis@uvic.ca) or phone 250-721-7487

**Purpose:**

The purpose of this research project is to understand the experience of well-being for people living with advanced cancer. Research of this type is important because it has the potential to impact health care practices, such as how health care providers can support the well-being of people who have advanced cancer. You are being asked to participate in this study because you have identified yourself as someone with advanced cancer who is experiencing

well-being. Participation is voluntary, and if you decide not to participate, or to withdraw at any time, you will continue to receive the best available care.

**Study procedure:**

If you choose to participate in this research, your participation will include a single interview of approximately 1 hour duration. During the interview you will be asked questions about your experience of well being and the factors that contribute to it. The interview will take place either in your home or at the Vancouver Island Center of BCCA, whichever you prefer, in a location where you feel comfortable and privacy can be assured. The interview will be audio-recorded.

**Potential Risks:**

Participation in this study may cause some inconvenience to you, including the time taken for the interview. There is a possible risk of emotional distress caused by the personal nature of the interview questions. These questions will be designed to understand your experience of well-being at this point in your life. If at any time you feel overwhelmed, emotionally distraught or fatigued, you may ask for the interview to be stopped and you will be provided with contact information for counseling services if you wish.

At that time, we may agree to re-schedule the interview or you may choose to withdraw from the study. If you do withdraw, data collected up to that

point will only be used with your permission. If you prefer, it will be removed from the data base and destroyed.

**Potential Benefits:**

There may be no benefit to you for participating in this research. If there are any benefits, they could include the opportunity for you to reflect on and explore your experience of well-being and to contribute to the understanding of that experience by others. If health care providers can more fully understand this experience, they will be better able to support other people with advanced cancer.

**Confidentiality:**

The main researcher is employed by the BC Cancer Agency as a nurse educator, and it is possible you may encounter the researcher during your care at the center, either as a presence in the public areas of the center, when introducing nursing students to the Pain and Symptom Management Clinic or when observing the use of the electronic ESAS tool (ISAAC). Encounters that are not directly related to this research project will be conducted so as to conceal the fact that you are known to the researcher as a research participant.

Your confidentiality will be respected. No information that discloses your identity will be released or published. Your identity will not be used in any reports about the study. No records will leave BCCA. All information associated with this study will be kept in a locked file cabinet or in secure computer files. The

audio recording will be labeled with a pseudonym before given to the transcriptionist. This recording will be transcribed verbatim by a transcriber who has signed a confidentiality agreement. All potential identifiers, including specific disease and demographic information (gender, age, and ethnicity) will be removed, and a pseudonym will be used in the final reports. The typed transcripts will be kept in a locked file cabinet at the Vancouver Island BCCA, and any data stored electronically will be on a password protected computer account on a BCCA computer. Data from this study will be kept for 5 years and then disposed of by erasing electronic data, shredding paper transcripts and erasing audio-recordings.

It is anticipated that the results of this study will be shared with others in the following ways: the thesis manuscript at the University of Victoria Library, journal articles, conference presentations and presentations at BC Cancer Agency. You or your family may request a summary of the research findings from the researcher. At the end of the study, audio recordings will be deleted. Typed transcripts obtained in this study will be retained by the researcher for 5 years to be used for educational purposes, to publish scientific papers, and develop conference presentations. Any additional research projects that use the anonymized data will be approved by the appropriate university research ethics committees.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you

the right of access to the information about you and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to the researcher whose contact information is provided below, or the UBC BCCA Research Ethics Board.

**Remuneration:**

You will not be paid for participating in this study. If the interview takes place at the Vancouver Island Center of the BC Cancer Agency, you will be reimbursed for parking fees.

**Contact for information about the study:**

Any questions about this study may be directed to any of the following:

Principal Investigator:

Kathleen Yue, graduate student in the School of Nursing at the University of Victoria (UVIC).

Email: [kyue2@bccancer.bc.ca](mailto:kyue2@bccancer.bc.ca) or phone 250-686-8822.

Co-Investigator and British Columbia Cancer Agency (BCCA) supervisor:

Dr. Maxine Alford, Professional Practice Leader –Nursing

Email: [malford@bccancer.bc.ca](mailto:malford@bccancer.bc.ca) or phone 250-519-5607

UVIC Faculty thesis supervisor:

Dr. Kelli Stajduhar

Email: [kis@uvic.ca](mailto:kis@uvic.ca) or phone 250-721-7487

Ethical approval has been granted both by the University of Victoria and by the BC Cancer Agency. You may verify the ethical approval of this study, or raise any concerns you might have, by contacting:

UVIC Human Research Ethics Board at (250) 472-4545 or email [ethics@uvic.ca](mailto:ethics@uvic.ca)

UBC/BC Cancer Agency Research Ethics Board at (604) 877-6284 or email: [reb@bccancer.bc.ca](mailto:reb@bccancer.bc.ca)

**Contact for concerns about the rights of research participants:**

If you have any concerns about your rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or email to [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

**Consent:**

I understand that participation in this study is entirely voluntary. I may choose not to participate or I may withdraw from the study at any time and I will continue to be offered the best available care. I understand that I may ask questions about this study in the future.

I will receive a signed copy of this consent form including all attachments, for my own records.

I consent to participate in this study.

\_\_\_\_\_  
*Name of Participant*                      \_\_\_\_\_  
*Signature*    \_\_\_\_\_  
*Date*

\_\_\_\_\_

Signature of                      Printed name                      Study Role                      Date  
Person Obtaining Consent

***A copy of this consent will be left with you, and a copy will be taken by the researcher***