

**Looking for Understanding:
A Phenomenological Exploration of Artists'
Decisions to Portray Cancer in their Artwork**

Janet L. Gillett

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*Looking for Understanding:
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Abstract

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A diagnosis of cancer brings many changes to individuals' lives, thus becoming part of their identity. Individuals who have cancer typically struggle when adjusting and accepting these changes (Blennerhassett, 2008; Yang, Staps, & Hijmans, 2010; Allen, Savadatti, & Levy, 2009; Lindwall & Bergbom, 2009; Lewis, 2008; Welsh & Guy, 2009; Frith, Harcourt, & Fussell, 2007; Hilton, Hunt, Emslie, Salinas, & Ziebland 2008). Furthermore, medical doctors place more emphasis on the symptoms and side effects individuals undergo rather than the person's experience of the symptoms and side effects (Frank, 1991; Cassell, 1991; Nuland, 2010; Couser, 1997). During this time, some individuals engage in creative tasks, such as painting or writing, as means of coping. This current study will explore why individuals use creativity to cope with cancer. Interviews with seven individuals were interpreted using a phenomenological methodology to highlight the recurrent themes among the participants. Three reasons for creating art reoccurred through many of the seven situated structures: to communicate their experiences, to connect to others, and to face their vulnerabilities. By understanding these themes, interventions and programs can be created to help individuals while they undergo cancer treatment and after the cessation of treatment.

Table of Contents

Acknowledgements.....	iv
Abstract.....	v
Chapter 1: Introduction.....	1
Distinguishing Disease from Illness.....	2
Survivors? Patients? Sufferers?.....	3
Beyond the Disease.....	3
The Power of Creativity.....	5
Using Creativity during Cancer.....	6
Chapter 2: Literature Review.....	7
The Experience of Having Cancer.....	7
Navigating an uncertain world.....	8
When treatment becomes a poison.....	10
Facing death.....	14
The distance between others.....	17
Confronting societal expectations.....	20
Becoming depersonalized.....	22
Illness as Lived Through the Body.....	23
Relearning one's body.....	25
Giving Illness a Voice.....	27

Exploring for meaning.....	29
Unleashing creativity.....	31
Expression of self though face painting.....	33
Telling stories through art.....	35
Chapter 3: Method.....	40
Theoretical Base.....	40
Methods Used.....	43
Participants.....	44
Setting.....	45
Interpretation.....	45
Chapter 4: Results.....	48
Situated Structures.....	49
Mary.....	49
Patricia.....	49
Brian.....	50
Linda.....	51
Jessica.....	52
Melissa.....	52
Charlene.....	53
Meaningful Themes.....	54
Communicating their experiences.....	54
Connecting to others.....	57

Facing their vulnerabilities.....	60
General Structure.....	64
Chapter 5: Discussion.....	66
Implications.....	70
Limitations.....	75
Future Research.....	77
References.....	79
Appendix A: Consent Form.....	94
Appendix B: Semi-Structured Interview.....	96
Appendix C: Analytic Note.....	97

Chapter 1: Introduction

Many individuals will experience cancer. One out of two males and one out of three females will have some type of cancer in their lifetimes (American Cancer Society, 2010). Many times, an individual who has cancer is surprised by the diagnosis and unprepared for the course of the disease. Historically, having cancer was seen immediately as a death sentence (Sikora, 2008). Cancer was not talked about because death was a taboo subject in Western culture. Doctors would treat people for cancer while stating the person had a different diagnosis that was not closely associated with death. Now, medical technology has become more advanced and is better able to treat cancer. However, as cancer becomes a chronic instead of terminal disease, individuals are living with side effects and other distress stemming from having cancer (Sperry, 2008).

Cancer is usually treated by three modalities. Chemotherapy has harsh side effects that can cause more pain and sickness than the cancer itself. For this reason, individuals anticipate the side effects and are anxious about the chemotherapy process (Olver, Taylor, & Whitford, 2005). Most known for its side effect of hair loss, chemotherapy kills fast growing cells, such as cancer cells and hair cells (Batchelor, 2001). Surgery can greatly change the appearance of one's body, especially visible in those who have breast cancer (Lindwall & Bergbom, 2009). Radiotherapy (radiation) concentrates high doses of radiation on the tumor, killing cancer cells. Each treatment is

tailored to the specific type of cancer and has its own unique side effects. Therefore, the treatment, as well as the experience of that treatment, is different for each individual. An individual's experience changes given the course of treatment, type of cancer, and severity of the disease.

Distinguishing Disease from Illness

In this study, the constructs of illness and disease will be discerned in order to provide a greater understanding of the cancer experience. Cancer is a disease, a biological happening that sometimes causes symptoms, that also includes many subtypes (named for the site where the growth occurs). A disease is a bodily dysfunction that is primarily caused by a contagion, whether virus, bacteria, or fast-growing abnormal cells (as is the case with cancer) (Sperry, 2006). Illness, on the other hand, is the experience of the disease (Sperry, 2006) or, more generally, the experience of suffering (Cassell, 1991). Although commonly interchangeable, these words mean vastly different things. According to the National Cancer Institute (2010), over 11 million people had received a diagnosis of cancer in the United States in their lifetime as of 2007. Each of those individuals had the same disease (cancer) that occurred in many different sites, that was treated in different ways, and that was experienced differently. Furthermore, each type of cancer has different mortality rates, which are the percentage of individuals who are expected to live at least five years after diagnosis: prostate, 100%; female breast cancer, 89%; lung, 16%; liver, 13% ; and pancreas, 6%, show the vast gap of treatability of cancer types (American Cancer Society, 2010). These mortality rates affect how

individuals understand their disease and experience. Understanding the cancer experience entails looking specifically at the individual's particular illness, given the details of the disease and how one is affected by their symptoms.

Survivors? Patients? Sufferers?

The term "cancer survivors" has been adopted as the term that applies to anyone who has had cancer, starting at the time of receiving a cancer diagnosis (National Coalition for Cancer Survivors, nd). However, "cancer survivors" will not be used in this study because the term imposes the meaning of cancer as a battle (Reisfield & Wilson, 2004). Likewise, the terms "cancer patients" and "cancer sufferers" do not allow for individual differences because they imply that patients should "suffer in silence" and have treatment done to them. Many individuals who had breast cancer refused these common labels because, although they believed they had changed, they were still the same people as before the diagnosis (Bitsika, Sharpley, & Christie, 2010; Lewis, 2008). Using the term "individuals who have cancer" in this study will allow leeway for individuals to create their own meaning out of their cancer experience.

Beyond the Disease

Many times, becoming sick means losing much of what a person used to be. Disease may cause the loss of body parts or independence (Stein, 2007). Individuals experience their body as more than just an "object" (Leder, 1991). People communicate and build their identity through their body, which is known as bodyhood. Due to changes

in how they experience their body, individuals may not feel “at home” in their body anymore (Lindwall & Bergbom, 2009), which can be distressing. Cancer is associated with many stressors and experiences of distress beyond the disease. However, the non-physical side of cancer is rarely discussed in the medical setting. Diseases may be cured by relieving physical symptoms, but people cannot.

Emotional distress caused by illness is largely ignored because people and doctors focus on the facts of the disease: the stage, the treatment, and other factors. By not looking at the experience of the individual, medical doctors essentially regard the individual as an object (that is, a disease carrier) instead of as a person. During the 19th century, the physician was no longer considering the sick person’s lifestyle or story (Cassell, 1991). Healthcare began to rely on medical technology to understand the disease (Nuland, 2010). Medical doctors then began to focus on symptoms instead of individuals who have the symptoms or the experience of the symptoms (Wilberg, 2003). By listening to the symptoms instead of individual’s stories, physicians have become medical scientists instead of medical clinicians (Cassell, 1991). Yet, with the advent of the biopsychosocial theory in the 1990s, psychologists began to look at the numerous factors affecting an individual (Sperry, 2006). Physical, psychosocial, and sociological dimensions are interwoven, meaning that if one is affected, the others are as well. Disease may reside in the physical dimension, but other aspects of one’s life are affected (Frank, 1991; Stein, 2007). Merging psychological and medical care, if integrated, could treat the illness, not just the disease.

The Power of Creativity

Emotions are frequently a precipitating factor of artists' creativity and their act of creating. In fact, artists reported dysphoria prior to enhanced creativity, suggesting that individuals may use their sadness in order to create (Jamison, 1989). Many artists draw from their experience when writing or painting (Csikszentmihalyi, 1996). By using art to examine individuals' self, situation, emotions, and values, individuals open themselves up to transform and grow (Rhodes, 1990; Cameron, 1992; Gedo, 1996; Piirto, 2004). The act of creating becomes a self-introspection, and can in turn, help lead to healing.

Creativity also stems from becoming intimate with one's own emotions: fear, excitement, and joy (Cameron, 1992). As individuals face a diagnosis of cancer, they begin to experience many different emotions. Art therapy in its various forms (for example, music, art, and opera) has been used with individuals who have cancer to allow them a way to express their emotions (Visser & Hoog, 2008; O'Brien, 2006; Steffens, 2004). Art, then, is a process that allows individuals time to experience their feelings and a way to convey their emotions to others.

In fact, many creative projects are undertaken in relation to cancer. Fundraising for cancer involves a multitude of artistic projects, including painting bricks (Breast Cancer Bricks, 2011), decorating bras in remembrance or honor of someone who had cancer (Bra Art, 2009), and body painting (The Living Breast Project, 2009; Body Art by Keegan, 2011). By understanding the connection between cancer and creativity, more interventions can be created to best serve individuals who have cancer.

Using Creativity During Cancer

This study is designed to look at the experience of individuals who have engaged in a creative pursuit during, after, or while awaiting a possible cancer diagnosis. These individuals used their artistic talents to showcase their experiences through various media, such as writing, photography, and painting. A qualitative/phenomenological design will be utilized in order to address the entirety of each individual's experience.

The results section will outline how individuals make meaning out of their experience of creating in order to inform the nature of cancer care. Health care professionals will learn what individuals who have cancer go through and what treatment was like for them. In the discussion section, the implications of these findings will be described. By exploring the stories of individuals who have cancer, professionals can create and implement interventions related to what concerns people experience during their cancer care.

Chapter 2: Literature Review

The Experience of Having Cancer

No one experiences cancer in the same way. Early detection campaigns, such as mammograms and prostate checks, can be utilized to find Stage I cancer, in which no discernible symptoms are exhibited. Yet, other cancers are harder to detect until they have metastasized (grown to other parts of the body). Tumor locations and stage of advancement determine what type of treatment will be used. Symptoms range from pain to fatigue, and vary widely. No two people who have cancer have the same disease because of the variation of symptoms and how the person experiences each symptom.

Even if people have the same disease, they have different illnesses and experiences. As Cassell stated: “Same disease, different patient—different illness, pain, and suffering” (1991, p. 48). Many individuals have breast cancer, yet their illness is a personal experience. Each person who has breast cancer has a unique story of how cancer has played a role in their life. Suffering stems from the individual difficulties arising from the symptoms and the meaning assigned to the disease by that individual. Physicians and psychologists need to know individuals and their particular illness in order to be able to accordingly treat each individual and their unique needs separately (Cassell, 1991). Many cancer memoirs or quotes from individuals who have had cancer called for an understanding of who they are as a person instead of just a patient

(Blennerhassett, 2008; Frank, 1991; Silver, 2009; DasGupta, 2001). Nuland (1997) is one of a few doctors who call for being attuned to individuals' needs, and the ramification of treatment on the entirety of the person. These memoirs, and many more not mentioned in this review, strongly suggest that people who have cancer require that health professionals be aware of individual knowledge specific to a person's body, mind, experience, and needs.

Navigating an uncertain world. A diagnosis and treatment plan for cancer carries a lot of weight, since most people have some understanding about the seriousness and course of the disease. However, cancer treatment is unpredictable and is not always explained adequately, which begins the experience of being objectified (Blennerhassett, 2008). Individuals experience terror because of inadequate explanations, which exacerbates the uncertainty of the future or the projection of the illness (Stein, 2007). Having cancer may mean individuals have to face unpredictable challenges daily (Rom, Miller, & Peluso, 2009). To counteract this uncertainty, individuals make predictions about what will happen and what chemotherapy will mean: hair loss, sickness, the inability to do certain things, etc. (Cassell, 1991). Also, cancer challenges and changes one's identity. Individuals tend to use markers, such as hobbies, careers, and other describers of self, to depict their identity (Charmaz, 2006). When an individual is diagnosed with a chronic illness, such as cancer, the marker of illness has to be integrated to one's self. Thus, the identities of diagnosed individuals are not the same as before the diagnosis. Their worlds have changed and most things are more precarious than before.

Individuals who have cancer usually experience shock, anxiety, denial, depression, anger and hostility, and adjustment difficulties when confronted with a cancer diagnosis. Struggles faced by a sample of individuals who were diagnosed with cancer involved body image, loss and grief, self-concept, stigma, and changes in quality of life (Livneh & Antonak, 2005). In a study of 67 females who had been diagnosed with cancer, feelings of hopelessness predicted depressive symptoms when the participants were retested four months later (Brothers & Andersen, 2009). Hopelessness was more likely to predict depression in women who did not currently have a partner at the time of diagnosis than in those who had a partner. These intra and interpersonal impacts in turn cause losses in interpersonal, financial, and work resources (Banou, Hobfoll, & Trochelman, 2009). Individuals with fewer resources are more likely to experience psychological distress and deny problems. The loss of a support system or interpersonal resources predicted posttraumatic stress disorder (PTSD) symptoms and depressive moods in individuals who had cancer, whereas financial problems and work loss did not.

As individuals come face-to-face with new limitations, their existence as they have come to understand it has been irrevocably altered. Henoeh and Danielson (2009) conducted a meta-analysis of studies to determine what interventions are being offered to individuals, as well as what concerns individuals may have. In the list they compiled, individuals who had cancer reported facing struggles with maintaining self-identity, such as values and relationships, and threats to identity, such as suffering, loss of life values, loss of relationships, and bodily expressions. Since these areas pertain to one's own sense of existence, they are called existential concerns. As they went through treatment,

individuals struggled to integrate having cancer into their identities.

Understanding individuals' reactions at time of diagnosis may indicate their distress later in treatment. In a cancer memoir, Blennerhassett (2008) described the lack of support that she received throughout her cancer experience. Doctors and nurses were less than forthcoming with information and did not attend to her fears. In fact, the doctors escalated her distress by withholding information. Being attuned to a patient's experience of distress is important, as individuals with cancer who are distressed can become noncompliant with chemotherapy (Thomas, Thomas, Nandamohan, Nair, & Pandey, 2009). Implementing earlier interventions and exploring fears and anxieties with individuals throughout the process may prevent feelings of hopelessness from escalating into depressive symptoms later in the treatment while increasing compliance. Meraner et al. (2009) developed a short screening tool for a physician to implement in a regular check-up appointment in order to identify distress early. This assessment effectively delineated individuals who would benefit from psycho-oncological treatment based on endorsing a higher number of anxiety and depression symptoms (that is, more likely to meet the criteria of a depression or anxiety disorder). Once these individuals were identified, they could be referred to therapy. Having support in place for individuals who have cancer, starting at diagnosis, would give individuals the opportunity to express their fears and distress.

When treatment becomes a poison. Chemotherapy induces many of the physical symptoms typically associated with cancer and is, in fact, highly toxic.

Subjective side-effects, such as nausea, were highly affected by individual expectations of having certain symptoms (Olver et al., 2005). Individuals were already anticipating how they would be affected by chemotherapy before beginning their treatment. In fact, women's narratives showcase a fear of losing a breast or hair instead of the actual illness or dying from the disease (Garrison, 2007). Many individuals found themselves anticipating hair loss and wondering how they would handle the loss. Most women, although informed beforehand, were shocked when it happened to them, expecting that they would be one of the few that were able to escape the side effect (Rosman, 2004).

Indeed, one of the most distressing side effects of chemotherapy is hair loss. Most research focuses on hair loss in females because it is thought to be more devastating (Frith et al., 2007). Hilton et al. (2008) show in their results that males are just as distressed by hair loss. However, the area of distressing hair loss differed by gender. Males were more concerned with losing body hair (arm, leg, abdomen, and pubic), while females were more concerned with above the eye hair loss (eyebrows, eyelashes, and head hair). This difference reflects cultural standards of women having luscious, long hair on their heads and men having hair on their bodies (Welsh & Guy, 2009). Little thought is given to hair loss that is not immediately visible, even in professional research. The differences in how medical personnel approach the gender differences may need to be reevaluated, since men were as distressed and devastated by hair loss as females were.

One of the most common side effects of cancer treatment is pain. Pain, although elusive and invisible, greatly affects the person who experiences it. For many, pain is inexpressible using words. To express pain, people use cries and grunts (Scarry, 1985).

In a literature review, nine studies showed a statistically significant correlation between pain and depression (Laird, Boyd, Colvin, & Fallon, 2009). Overall results indicated that individuals who were depressed used more affective labels of pain, like “punishment,” and described the pain as having a higher level of intensity. Being in pain sets individuals who have cancer apart from their family and friends because they live in the world of pain alone. Even if they were able to describe the pain, others cannot feel their pain as they do. Furthermore, individuals who were still in pain were more likely to worry about their future health (van den Beuken-van Everdingen, 2008). Although pain is a part of cancer treatment, individuals encounter severe difficulties when dealing with pain.

Many of the side effects of chemotherapy and radiotherapy change how individuals interact on a day-to-day basis. Individuals who had cancer described having many severe physical symptoms, such as lack of energy, loss of hair, and lack of appetite (Yeşilbalkan & Okgün, 2010). Individuals who underwent chemotherapy or hormonal therapy for breast cancer experienced a decrease in sexual activity, quality of relationships, desire, and anxiety (Biglla et al., 2010). These physical symptoms also affect the psychological well-being of the individual.

“Well-being” and “quality of health” (QoL) have become key terms when looking at how one experiences life during and after cancer treatment. QoL is measured by looking at individuals’ physical, mental, social, and spiritual well-being (Sarvimäki, 2006). Individuals who have cancer usually score lower on QoL at diagnosis than six months after their diagnosis (Härtl et al., 2010). However, one study found that socially

and cognitively, QoL for individuals who have breast cancer was lower one year post treatment than individuals who did not have cancer (Schou, Ekeberg, Sandvik, Hjerstad, & Ruland, 2005). Although QoL typically increases in the months following treatment, individuals who have cancer still have residual effects from the cancer experience.

Even after treatment is finished, individuals are not free from the suffering of cancer. People still have the memories of sickness and tend to experience a loss of trust in their bodies. The illness experience goes beyond bodies and disease, and encompasses the entirety of one's life (DasGupta, 2007). Blennerhassett (2008) stated that "...the cancer experience does not end with treatment. Everything has altered. My perspectives. My values. Me. It is difficult to describe adequately my sense of feeling 'different'" (p. 124). Individuals know their bodies can betray them again, and although the disease and symptoms no longer exist, they can still experience suffering and illness (Cassell, 1991; Frank, 1991). In these instances, illness lingers after the disease because of the fear that the body will once again lose control. Although individuals may have been declared recovered by medical doctors, they may not be feeling well (Rasmussen, Hansen, & Elverdam, 2010). Furthermore, lasting fatigue and other symptoms do not allow individuals to return to prior functioning (Blennerhassett, 2008; Rasmussen & Elverdom, 2008). Frank (1995) coined the term "Remission Society" to describe individuals who are likely to get sick again and those who have not quite returned to their prior functioning levels. Having cancer is not just the period between diagnosis and end of treatment. Cancer becomes a part of one's life experience and becomes integrated into

who the person is.

Fear of Reoccurrence (FoR) is the phenomenon of individuals who have cancer worrying that their type of cancer, or another type of cancer, will grow back. In a study of 1336 individuals who had testicular cancer, the individuals who had a high level of FoR also tended to face more mental distress, fatigue, and neuroticism (Skaali et al., 2009). They also tended to have less self-esteem, fewer coping skills, and a lower quality of life. In a study of 136 breast cancer patients, 56% of the participants reported a moderate to high level of fear that cancer would reoccur (van den Beuken-van Everdingen, 2008). FoR does not occur just in cancer patients. In a study of 101 individuals who had neck cancer, along with their caregivers, the caregivers scored higher on FoR questions than the individuals who had cancer (Hodges & Humphris, 2009). Managing mental and physical symptoms may reduce FoR in people who had cancer, which suggests psychologists and physicians should be attuned to individuals' fears, needs, and distress during the cancer treatment (Skaali et al., 2009). Addressing these uncertainties before the end of treatment may help curb unnecessary distress afterward.

Facing death. Having cancer is a vulnerable experience because cancer is commonly believed to be fatal. Death is a primal human fear that becomes undeniable in times of crisis, such as a cancer diagnosis (Kissane et al., 2004). Ernest Becker (1973) argues that terror of death is present at birth in order to keep the organism alive. However, this fear is not always conscious because individuals would be unable to

continue functioning if constantly facing death. Cancer makes individuals face the prospect of their own death, quite possibly for the first time (Yang et al., 2010).

Individuals who lived in denial (as many do) are suddenly in the position where they face their fallibility.

Lichtenthal (2009) showed that individuals with advanced cancer experienced higher levels of existential distress as death approached, but did not exhibit symptoms of anxiety and depressive disorders. The increased existential distress could be caused by the acceptance of being terminally ill and facing the possibility of death. In addition, caregivers also showed increased levels of anxiety and depression in the year prior to the death of the person in their care (Burrige, Barnett, & Clavarino, 2009). Both caregivers and the person with cancer became more aware of the advanced stage of cancer as the year went on. Younger individuals are more likely to exhibit anxiety or depressive symptoms and not acknowledge the status of their illness as terminal (Lichtenthal, 2009). By not accepting their illness, individuals and caregivers are more likely to become distressed during the course of illness and may not be able to accept their impending death.

Yang, Staps, and Hijmans (2010) found that individuals who confront and accept the inevitable end of their life as a result of cancer became more connected to the “here and now.” They are able to experience their life and situation more deeply, and experience a feeling of being more “themselves” than before. Supportive-expressive group therapy (SEGT) is used with individuals who have advanced cancer in order to address their fear of death (Kissane et al., 2004). In SEGT, therapists aim to be with

individuals who have advanced cancer as they face their death. One study showed that women who were in group for over a year were able to express their negative affect, such as sadness and anger, while increasing their ability to restrain from impulsive, aggressive, and irresponsible behavior (Giese-Davis et al., 2002). Although this group is believed to help individuals have a higher quality of life as they come to terms with their death, other studies show that it may not be an effective way of addressing these issues. Another study showed that women who had breast cancer did not have a reduction in emotional distress based on a twelve-week structured group (Classen et al., 2008). Death is an imminent, recurring theme in cancer care because individuals are facing and acknowledging their limitations.

Some interventions have been created to address the existential concerns of people who have cancer. By looking at their life, an individual is able to assign meaning to their life and have part of them continue existing past their death. Creating a legacy (a physical remnant of one's life) helped individuals who were approaching the end of life, as well as gave their families something to remember them by (Allen, 2009). Children who were in the hospital were able to make autobiographical scrapbooks to describe their experiences and the fears they had during that time period (Romero, 1986). As individuals faced the anticipatory grief of loss of their lives, they began to think of what they would leave behind for their families (Cheng, Lo, Chan, Kwan, & Woo, 2010). Creating a Legacy Project, such as a scrapbook or tape-recorded stories, helped relieve caregivers' stress as their loved one became sicker (Allen, 2009). The terminally-ill individuals who became active in this project reported experiencing more talkativeness

and religious meaning, while the control group showed a decrease in these areas. By overcoming a fear of death, individuals were free to engage in the present.

The distance between others. Loneliness is an inherent part of illness because patients are often de-individualized in the medical system (Stein, 2007). Because of the sense of isolation, interpersonal contact outside group therapy is encouraged for individuals who have cancer (Kissane et al., 2004). People surrounding an individual with a chronic illness may not understand their experiences with illness, leading those who have the chronic illness to feel they are different from others. Their sense of transformation might have made them feel distanced from those they were once close to. Individuals may have thought friends and family avoided them or stared at them (Rasmussen et al., 2010). In an interview, individuals who had oral cancer expressed themes of being transformed by their experience, pitied by others, and wanting to be normal again (Röing, Hirsch, Homstrom, & Schuster, 2009).

Interpersonal relationships usually change between individuals diagnosed with cancer and their family members. Usually someone in the family becomes the primary caregiver for the individual who has cancer. The primary support giver often feels a huge sense of burden in this role (Silva-Smith, Theune, & Spaid, 2007). This burden may induce a strain on the relationship. Individuals with a chronic illness reported feeling detached from their spouse (Eriksson & Svedlund, 2005). The change in roles (from spouse to caregiver) partially caused this feeling of detachment. The spouse with the chronic illness reported striving for normalization and feelings of limitations that also fed