THE REFORMULATION OF IDENTITY IN OLDER WOMEN

WITH ADVANCED CANCER

by

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ABSTRACT

Research on the psychological aspects of the cancer experience rarely takes into account the dramatic physical changes a person is experiencing, while the medical literature tends to ignore identity concerns for those with advanced cancer. When both physical changes and identity are explored, samples typically include women and men who are middle-aged. The current project was aimed at exploring how identity and physical changes were experienced by older women with advanced cancer.

Data were collected from 12 women aged 60 and older from hospices in and around Tuscaloosa, AL and Tampa, FL using a grounded theory approach. Two interviews were conducted with most participants. A model was developed that captured the data. Some of the major findings include: physical changes, interactions with others, and awareness of death impacted the participants’ pre-illness identity; participants engaged in various forms of coping mechanisms and resistance strategies to reformulate their identity or retain important aspects of their pre-illness identity, and this identity reformulation was most often in the service of maintaining an acceptable quality of life.

The data from the study are compared with literature in the areas of social psychology, death and dying, feminist theory, philosophy, nursing and medicine, and developmental psychology. Implications of the model are discussed as well as directions future research in this area may take.
DEDICATION

This dissertation is dedicated to my two grandfathers, Bob Payne and Carl Kuklica, and to Stella Gergotz, a dear family friend. Each of these special people let me participate in their deaths. Thank you for showing me how important communication with the dying individual truly is and how important it is to appreciate life.
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CHAPTER 1
INTRODUCTION

Statement of Problem

Literature in the areas of death and dying and chronic or terminal illness tends to focus on describing one monolithic illness or dying experience rather than discussing nuanced differences based on social constructs that have material implications such as race, ethnicity, age, or gender (Charmaz, 1995; Kübler-Ross, 1969). Moreover, very few studies examine identity reformulation within terminally ill populations, although there are some notable exceptions (e.g., Charmaz, 1995). It is not hard to imagine that identity concerns would be central to the illness experience of the terminally ill individual as physical changes, often drastic in nature, are par for the course (Ma & Alexander, 1998).

The problem with focusing on a standard “one size fits all” model of the dying or illness experience is that it fails to recognize the power of social and environmental influences on the process. If we examine even one demographic variable in more detail we can see the impact that social location has on everyday experience. For example, if we examine gender in detail we find that women have to live with the threat of rape or sexual assault as an everyday possibility (Cahill, 2001). Women also experience very different media messages about their sexuality than men (Kilbourne, 2000), most often make less money than their male counterparts for the same work, and ageist actions and words are often “more derisive” for women because they are portrayed as “thoroughly repugnant and disgusting” (Nuessel, 1982, p. 274). Thus, although men and women appear similar on most psychological assessments of cognitive functioning,
intelligence, personality, and so on, the lived reality for men and women is still markedly different. This difference in everyday lived reality is likely to have an effect on the illness experience. However, most research fails to examine these differences in the illness or dying experience. When research points out differences between men and women’s experience, it is more likely to show greater pathology in women (Hampton & Frombach, 2000; Mystakidou et al., 2005; Thomé, Dykes, & Hallberg, 2004) mimicking other ways in which women are medicalized and pathologized (Morgan, 1998). Thus, research that details the ways in which women experience terminal illness without pathologizing them is sorely needed.

The absence of identity issues in the literature also has significant implications. What information exists in this area (Charmaz, 1993, 1995) suggests that identity issues are a core concern for terminally ill individuals and can explain, or at least contribute, to psychological and/or emotional problems during the illness and dying experience. Further, because we live in a society where the logic of dualism persists, the question remains: How does this mind/body split impact patients’ experiences with bodily changes, identity, and approaching death?

The goal of this dissertation is to begin to fill the gaps mentioned above by examining older women’s experience with terminal cancer with a focus on this relationship between the body and one’s identity without pathologizing their experiences.

**Rationale**

There are specific reasons for focusing on older adult women’s experiences with terminal cancer. Looking at the issue of cancer in this society, the American Cancer Society predicted that in 2005 more than 1,500 people would die of cancer per day (Jemal et al., 2005).
This data also showed that 1 in 4 deaths were attributed to cancer between 1930 and 2002. The number of new cancer cases expected in 2005 was 1.4 million.

While death rates for most cancers have declined, cancer is still a significant health problem in the United States, especially for older adults. Fifty-six percent of diagnoses occur after 65 years of age and 70% of cancer-related deaths occur in this age range as well (Ries et al., 2006). Cancer experiences also appear to be different based on age when older adults are compared to younger adults. Younger adults tend to have concerns about work and sexuality to a far greater degree than older adults while older adults compare the experience of cancer to the process of aging (Foley et al., 2006; Thewes, Butow, Girgis, & Pendlebury, 2004).

Women have cancer experiences that may be different than the experiences of men, thus warranting individual attention. First, women are at higher risk for different types of cancer than men. For women, the most common type of cancer is breast cancer whereas men are most susceptible to prostate cancer (Jemal et al., 2005). Women are susceptible to cancer as a life-threatening illness for a longer period of time than men: cancer is the leading cause of death for women between the ages of 40-79 and for men aged 60-79.

Second, women may have different psychological reactions and issues while dealing with cancer. For instance, in one study of older adults, women who had cancer reported lower quality of life, more general complaints, and lower social functioning than males with cancer and males and females without cancer (Thome’, Dykes, & Hallberg, 2004). In another study of advanced cancer patients, women were shown to report more anxiety and depression than men (Mystakidou, et al., 2005). Posttraumatic stress disorder (PTSD) is also more common among
women dealing with cancer than men (27% vs. 10%; Hampton & Frombach, 2000). It is difficult to know if these findings are reflective of true differences in mental health correlates of cancer or if women’s ways of coping with cancer are more likely to be pathologized than men’s. Regardless, there appears to be a general consensus in the literature that men and women do have different psychological reactions to the disease.

Third, women seem to experience cancer and health-related issues differently than men, contrary to the androcentric bias in the literature (Muecke, 1996). Looking at PTSD symptoms among cancer patients, Hampton and Frombach (2000) found that women’s experiences with cancer were qualitatively different than men’s. Women reported higher intensity of cancer treatment, greater numbers of treatments, and greater problems with health care professionals. Researchers (Hampton and Frombach, 2002; Batt, 1994) suggest the possibility that women may be treated differently in medical settings than men (e.g., receiving more severe or invasive procedures for cancer such as more numerous surgeries).

Fourth, societal and cultural influences may impact the cancer experience differentially for men and women. In a study of on-line support groups, differences in communication, word usage, and focus for men and women were explored (Seale, Ziebald, & Charteris-Black, 2006). According to the findings, men are more likely to seek out information about treatments, diagnostic procedures, and side effects than women, who are more likely to focus on emotion and feelings. Seeking out social support and sharing one’s experiences with cancer were reported as more important for women than men. In addition, women reported a larger social support network than men, whose social support network usually consisted of a single party –
their partner. Finally, women in this study were the only ones to discuss appearance issues such as prostheses and wigs.

In addition to the need for research on older women, there is a dearth of studies that have described self-perception and the relationship with one’s body during the final stages of cancer. The few that have examined this tended to focus on the negative aspects of the restructuring of the self and have neglected potential positive aspects. For example, Waskul and van der Riet (2002) examined patients’ views of their bodies but their analysis was overwhelmingly negative, with the authors using words such as “abject,” “polluted,” “damaged,” and “gruesome” to describe the body in the case of illness. Some patients did mention negative terms to describe their own bodies, but rarely did they use such powerfully negative words as did the authors. In addition, positive aspects of the illness experience have been identified by some researchers. For example, patients have reported stronger interpersonal relationships, positive personality changes, reappraisal of life, and positive spiritual changes as some of the positive consequences of illness (Soderson & Hyland, 2000). Despite these findings, positive themes are not expressed in the few articles on the body-self relationship in dying individuals (Charmaz, 1999; Waskul & van der Riet, 2002). It is possible that positive consequences of illness are not experienced by terminally ill patients but it is also possible that researchers have neglected this area of study.

Research on the distinct social, physical, and psychological experiences of women facing cancer needs more attention, particularly when examining the challenges that life-limiting cancer presents to self-perception and identity. The current project is aimed at providing an
initial glimpse into this area with awareness that there may be positive aspects of this experience.

Research Question

The research question guiding this study is: *What is the nature of self-perception and the relationship with one’s body in terminally ill older women?* In other words, the study is aiming to elucidate the changes women experience in the ‘self’ while dealing with terminal cancer and how or if these changes manifest themselves in their relationship with their bodies.

The main objective of the study was to examine identity during terminal cancer. Specifically, the study aimed to describe:

- How terminally ill women currently feel about and interact with their bodies, as well as how they have felt about and interacted with their bodies throughout their illness;
- How these women’s self-perception has changed and/or remained stable throughout their illness; and
- How these women’s self-perceptions or views of their bodies were influenced by family members, friends, medical staff, and American culture.

The overarching goal is to create a substantive theory that can help laypeople and the medical community better understand the meaning and significance of terminal cancer for older women and how this experience affects construction of ‘the self’ and their relationship with their own bodies. In turn, this could lead to better care in the health care system for these women by highlighting areas of need in their holistic care and provide a springboard for further
examination of gender differences in the research arena. The secondary goal of this study is to identify positive aspects of the cancer experience.

Overview

The purpose of this document is to present the findings of my dissertation project and to contextualize or situate them within the scholarship on death and dying, chronic and terminal illness, feminist theories of the body, and the social psychological theories of the self. First, a review of the literature relevant to this topic will be provided. Next, the politics surrounding death and dying in this country will be discussed in detail. Attention will be given to what is known about how death is viewed, how decisions regarding death are made, and any institutions that impact the dying process. In the last sections of the document, I will review the methodology for my study, discuss the results, and provide a discussion that situates my findings within the extant body of literature applicable to this project.
Defining the “self” has been a difficult task (Baumeister, 1999). Most people claim to understand the concept of the self but have difficulty in communicating their understanding of this concept to others. The complexity of defining the self may be one reason there are so many different related subtopics in this area, including, but not limited to: self-concept, self-esteem, self-actualization, and self-schema. In addition, identity and the self can be defined from different theoretical perspectives (e.g., Erikson, 1956; Hewitt, 1992; Weigert, Teitge, & Teitge, 1986).

Two similar perspectives on the self – symbolic interactionism and social identity theory – detail ways in which social interactions and identifications as well as individual characteristics affect the self. Although there are several other theories of identity and the self, symbolic interactionism and social identity theory have been studied in relation to illness, body image, or the dying process. A description of each theory and research on how it has been applied to the study of illness and/or dying is examined below.

Symbolic Interactionism

According to a symbolic interactionist perspective (common in sociology), the self is situated in the social world and cannot be understood without examining interactions one has with others. Thus, the self is constantly in flux, changing as interactions in the social world take place. According to Mead (1934/1959), the self consists of the subjective I that is “natural” and
not affected by others, the objective me that is a reflection of what others see and “what one sees when looking back at oneself” (Jeon, 2004, p. 251). The I and the me constantly communicate with one another before action takes place.

Another important aspect of symbolic interactionist theory is meaning. Again, according to Mead (1934/1959), humans act based on meanings and these meanings are derived from social interaction. The assumption is that human beings make meaning based on experience (including social experience) and act in a purposeful way while interacting with others and their environment (Charmaz, 1995).

Since the current project is aimed at examining women’s identity and changes to this identity throughout the course of terminal illness, symbolic interactionism is particularly relevant. No illness experience (particularly terminal illness) occurs without social interaction. Oftentimes individuals will have to call on loved ones to care for them throughout the progression of their disease and patients have interactions with healthcare staff. Research has provided evidence that these interactions affect patients’ conceptualizations of their identity (Charmaz, 1983).

In a study on individuals with chronic disease, Charmaz (1995) developed a stage theory of adaptation to limitations. Her goal was to understand identity within a chronically ill population through the lens of symbolic interactionism – focusing on a person’s meaning of the self and body developed from social identifications.

From her study of 55 adults with varying diagnoses she developed her stage theory which includes: experiencing an altered body, coping with changes in bodily appearance,
changing identity goals, and surrendering to the sick body. The first stage involves noticing physical changes that occur with illness and acknowledging that they are “real.” During this stage, the previously experienced unity between the self and the body is disturbed and individuals often compare their current physical state to their past. According to Charmaz, it is in this stage that individuals experience a loss of self and a loss of control over their bodies. Individuals engage in a variety of reactions to this loss. Sometimes individuals will attempt to separate the body and self in an effort to keep illness out of their lives. Others struggle against their illness, engaging in a continuous battle over control of their bodies and their future. Still others struggle “with illness” (p. 663) by attempting to keep their body functioning as normally as possible within the given circumstances.

The second stage, coping with changes in bodily appearance, involves living with the possibility that the ill individual will be identified by others as disabled or ill and this may undermine her own sense of self. To cope with the outwardly altered body individuals may engage in hiding appearance changes through “camouflage” such as prostheses, wigs, or clothing that covers shunts, ports, or other medical devices. Charmaz notes that women under fifty were particularly concerned about the effects illness had on their appearance.

The third stage of Charmaz’s theory involves changing identity goals. Identity goals are defined as “preferred identities that people assume, desire, hope or plan for” (p. 659). In her study, shifts in identity goals were based on physical changes in the body, emotions, and social interactions. Upward changes occur when treatment or rehabilitation helps the individual become more able. Downward changes occur when physical limitations force an individual to
function differently than they had previously. Charmaz discusses these changes in identity goals almost as if they are shifts in roles. For instance, one of the participants in Charmaz’s study was working full time with a chronic illness and would come home exhausted, unable to cook for her husband or to do much of anything but rest. She eventually decided that she should quit her job, thereby losing that identity goal but was able to maintain her image as a wife. Ill individuals do not always make downward shifts in identity goals, even if their physical condition is deteriorating. If ill individuals perceive that others need them to function as they did previously they will resist lowering their identity goals in an effort to maintain that previous identity. In some cases the loss of identity is too great and ill individuals will attempt to function normally while putting their bodies at risk for harm.

Finally, the fourth stage of adapting to limitations with chronic illness is surrendering to the sick body. According to Charmaz, there are three conditions that must be met for surrender to occur. First, the individual must relinquish control over their body. Second, they should stop fighting their illness and give up fantasies of overcoming the illness. Third, individuals must acknowledge that the ill body and the self are inseparable. Once an individual surrenders, illness “becomes subjectivity” (p. 673). The individual can now experience a new view of the self.

This theory of adaptation to chronic illness is applicable to the current study because of the focus on the body-self relationship. Although Charmaz’s theory is focused only on adaptation to physical limitations and therefore communicates a preferred or positive way of coping with an illness while pathologizing other options, it is still useful to examine the
experiences in the body-self relationship with chronically ill adults and how this relationship is affected by social interactions.

There are important limitations to stage theories that should be noted. First, the principle assertion of stage theories is of sequential and directional progression of the individual. This does not leave room for individuals to experience multiple stages at once or to move backwards through them. Second, some individuals view stage theories as a threat to the unique coping or development of individuals (see Corr, Doka, & Kastenbaum, 1999 for a discussion of this topic as it applies to death and dying).

While Charmaz’s study shares similarities with the current project (focus on the body-self relationship, focus on the ways in which social interactions impact the illness experience), her study focused on adults she described as middle-aged (aged 40-60) with chronic illness. Younger and middle-aged adults with chronic illness often have different concerns than older adults. For instance, her younger participants had more difficulty in their intimate relationships than did the few older adults she had in the study. Additionally, her participants often had hopes of regaining some functioning or possibly achieving a cure for their illness, whereas those who are diagnosed with terminal illness have no hope for recovery and are preparing for the ultimate threat to self unity – death.

**Social Identity Theory**

According to social identity theory, identity is partly derived from group memberships (Tajfel & Turner, 1979). This theory posits that individuals evaluate themselves based on group memberships through interpersonal comparisons as well as intergroup comparisons. In
intergroup comparisons, individuals evaluate their group (the *ingroup*) to other groups (*outgroups*) through a process of social categorizations. These social categorizations create one’s social identity.

The motivation behind social categorization is based on the drive for positive distinctiveness (Tajfel & Turner, 1979). This means that group identity is more likely to form among individuals with high status attributes because group membership distinguishes this group from others in a positive manner. Low status groups, on the other hand, may or may not form group membership because they are looking for other, positively valued attributes on which to form group identities or fighting to change their group’s negative image. According to Tajfel and Turner (1979), one option for members of low-status groups is to deny membership.

Social identity theory relates to the current project in a couple of ways. First, membership in the group *older adults* (whether by choice or others’ categorization) can impact one’s risk of developing cancer, getting adequate treatment, and others’ reactions to a cancer diagnosis (Harwood & Sparks, 2003). For instance, older adults are at risk for ageist discrimination and research has shown that perceived discrimination may cause stress (Williams & House, 1991). Stress has been shown to influence the course of cancer via immune system functioning (Eysenck, 1994; 1995). Thus, the stress caused from discrimination may have an impact on the development of cancer. In addition, stereotyped groups such as older adults may not receive an adequate or timely diagnosis because illness is often seen as a “normal” part of aging (Hamel et al., 2000).
Second, *cancer patient* group membership may have either negative or positive consequences (Harwood & Sparks, 2003). Receiving social support from others with cancer or information seeking are possible positive consequences of identifying oneself as a cancer patient. However, negative consequences may ensue if an individual sees cancer as an integral part of the self. For example, individuals who see cancer as a central aspect of the self may identify with the sick role which can lead to reduced feelings of control (Charmaz, 1999).

Additionally, patients may experience discrimination based on cancer patient group membership (Harwood & Sparks, 2003). For example, the diagnosis of cancer is oftentimes seen as a death sentence (Chapple, Ziebald, & McPherson, 2004) and others may treat the patient as if she is already expired. For some individuals who receive differential treatment based on their status as a terminal patient it may be their first encounter with receiving discriminatory treatment (Harwood & Sparks, 2003).

Social identity theory is applicable to the current study in that it sheds light on motivations to either accept or deny cancer patient group membership and provides a theoretical framework for analyzing how discrimination based on cancer status might impact individual’s coping and cancer trajectory.

The symbolic interactionist and social identity theory perspectives on the self acknowledge the importance of individual characteristics as well as social interactions and group memberships. The research in the area of illness has indicated that people suffering from cancer talk about the changes in the self both from a personal and social perspective (e.g., Charmaz, 1995, 1999; Mathieson, & Stram, 1995; Waskul & van der Riet, 2002).
The Self, Illness, and the Body

From the perspective of many philosophers and researchers the body is seen as a necessary requirement for the self to exist (e.g., Baumesiter, 1999; Charmaz, 1995; Gadow, 1982). According to this view, cognition and consciousness are dependent upon a physical body and physical feelings in turn can affect the mind. In some researchers’ views (Gadow, 1982) even though the body and the self are inseparable, they are not the same. Prior to illness the body and self are often experienced in unity but an illness can disrupt this sense of integration (Kestenbaum, 1982). Chronic illnesses, like cancer, often lead to progressive declines in bodily functions which can then lead to progressive loss of identity (Charmaz, 1999). Losses in identity can occur because a person is no longer in control of their body, but instead is at the mercy of the body. Gadow (1982) describes this as a shift from “the lived body,” or the experience of unity between the body and self to “the object body,” which distinguishes the body as something outside of the self that is hindering our movement through the world. Consistent with this view, patients who are ill will sometimes describe their bodies as an other or it– something apart from the self (Waskul & van der Riet, 2002).

Waskul and van der Riet (2002) conducted a qualitative study examining cancer patients’ views of their bodies. They interviewed patients in either a palliative care unit or in their homes while administering massage therapy. The themes they discovered included powerlessness and alienation due to medical treatment or interaction with the medical staff as well as a strong drive to manage a dignified selfhood while experiencing an out of control body.
Patients often felt that they were being treated as an object while being treated in medical institutions (Waskul & van der Riet, 2002). They discussed feeling left out of decisions regarding their own treatment which contributed to the sense that their body was an “other.” Sometimes personal boundaries were violated, especially during examinations or medical procedures. Violations of personal boundaries can be interpreted as a threat to the self (Goffman, 1971), which is what these patients described.

In addition to the powerlessness experienced while being cared for in a medical institution, patients also expressed a sense of helplessness because of the loss of bodily control (Waskul & van der Riet, 2002). They mentioned a myriad of unpleasant physical symptoms that were embarrassing and affected their sense of dignity. The self was unable to control the body and its functions, an experience that some likened to being a baby or young child (Waskul & van der Riet, 2002). The authors discuss how the out-of-control body becomes a source of shame because it is hard to conceal it from others.

Physical Changes in Advanced Cancer

Specific bodily changes that occur in advanced cancer or because of prolonged cancer treatment can have affects on a person’s sense of self and the way they relate with the world. In particular, there is evidence that cancer-related weight loss (cachexia), pain, fatigue, treatment side effects, and loss of hair (alopecia) may impact self-perception.

Advanced cancer is oftentimes associated with deterioration of the body. In approximately 80% of advanced cancer patients, cachexia is present (Ma & Alexander, 1998). Cachexia is defined as weight loss consisting of 10% of a patient’s premorbid weight (Del
Fabbro, Dalal, & Bruera, 2006). It is associated with decreased appetite and changes in body image. Cachexia due to cancer is oftentimes present in older adults (Del Fabbro, Dalal, & Bruera, 2006) and this weight loss can have profound negative effects on quality of life (Hopkinson, Wright, & Corner, 2006). Changes in body image also affect emotional, spiritual, and social aspects of the self (Hinsley & Hughes, 2007). Patients often try to readjust to their new body image and the consequences of the altered body, but the emotional withdrawal of friends and family due to severe bodily changes is often difficult to overcome.

Pain may also be a problematic symptom for those with advanced cancer (Portenoy et al., 1994). Pain may not be completely controlled by medication in some cases, which can have significant effects on psychological distress (Portenoy et al., 1992). In addition, pain can affect physical activity and general functioning, mood, ability and desire to work, as well as the ability to enjoy life (Portenoy et al., 1994). Thus, pain can affect the ability of a patient to interact with others and engage in pleasant activities. These limitations can have serious effects on self-perception, sometimes resulting in self-blame (Fobair et al., 2006).

Alopecia (loss of hair) is oftentimes reported in patients undergoing chemotherapy treatment (Munstedt, Manthey, Sachsse, & Vahrson, 1997). Loss of hair can affect body image because hair is a symbol that communicates with others about many different factors including one’s class, gender, religious affiliation, etc. The presence and absence of hair has been especially important for women because it is often an indicator of beauty, femininity, and personality (Wolf, 1991). Hair loss is a visible cue that the individual is dealing with cancer. Although participants in the current study were not receiving chemotherapy treatment at the time
of the interview, many had experience with chemotherapy and alopecia. Experiencing alopecia can often have substantial and lasting affects on a person’s self-concept (Nerenz, Love, Leventhal, & Easterling, 1986).

Body image concerns and changes in self-concept are quite common (Charmaz, 1995), especially for patients who have had mastectomies or chemotherapy treatment (Nerenz, Love, Leventhal, & Easterling, 1986; Yurek, Farrar, & Anderson, 2000). Body image changes may occur because of bodily changes from the cancer or treatment (Nerenz, Love, Leventhal, & Easterling, 1986; Yurek, Farrar, & Anderson, 2000) or stigmatization (Chapple, Ziebland, & McPherson, 2004). Body image concerns can further affect relationships with friends and relatives and cause sexual problems with intimate partners (Fobair et al., 2006).

In addition to the specific physical effects of cancer, general feelings of fatigue are commonly reported among patients (Portenoy, 2000). Fatigue is one of the most long-term, troublesome symptoms for cancer patients (Curt et al., 2000) and has a significant impact on their quality of life (Asbury, Findaly, Reynolds, & McKerracher, 1998). It often contains physical, psychological, cognitive, and affective components (Curt et al., 2000; Del Fabbro, Dalal, & Bruera, 2006). The experience of fatigue is highly subjective and has been shown to be associated with patient characteristics (Stone, Richards, & Hardy, 1998), type of cancer, and treatment (Portenoy & Itri, 1999). Despite these individual differences, studies have reported that cancer-related fatigue is extremely common, with over 75% of metastatic cancer patients reporting this symptom (Portenoy et al., 1994). Because fatigue has such an impact on quality of life, it is reasonable to believe that this will affect one’s self perception and relationship with
one’s body. Indeed, patients with a diagnosis of chronic fatigue syndrome report a loss in self-esteem and in identity (Clarke & James, 2003).

Illness and Social Experience

How do relationships between the individual with cancer and loved ones change during a serious illness experience? When dealing with cancer, patients’ bodies show outward signs of physical change that represent loss of functioning. One study found that some women see changes in appearance as a test of close relationships (Charmaz, 1995). During such a vulnerable time individuals may hope and expect that their loved ones will be able to accept or look beyond the physical changes of an advanced illness.

Changes in functioning brought on from an advanced illness also make it harder for individuals to participate in social functions (Charmaz, 1983). The inability to engage in social activities can lead to social withdrawal, which has negative effects on a person’s sense of self.

The social activities that do take place are also different than before the onset of the illness. Typically, the sick individual is receiving company and the company must interact with the patient differently. For example, the visitors may be required to help transport the dying individual to a new location for their visit. Reciprocity is no longer the norm for these social interactions. For the ill individual, this may lead to the sense that she is a burden on those around her (McPherson, Wilson, & Murray, 2007).

Approximately 39% of patients with advanced cancer report mild distress from self-perceived burden to others while an additional 38% report moderate to extreme distress (Wilson, Curran, & McPherson, 2005). The worry about being a stressor for others is reported as the
number one social concern for those patients with cancer receiving palliative care (de Faye, Wilson, Chater, Viola, & Hall, as cited in McPherson, Wilson, & Murray, 2007). Individuals who are ill often worry that their illness is interfering with the other responsibilities of their caretakers or family members (McPherson, Wilson, & Murray, 2007).

In addition to the effects that cancer has on intimate relationships between the patient and loved ones, effects are also seen with the interaction between medical staff and the patient. Patients who are dealing with advanced cancer are immersed in a system where their body has become an object to be studied and treated and may experience disconnection from their body as a result (Waskul & van der Riet, 2002). Patients complain that the medical staff may not communicate in a desired way with the patient, making them feel that they have little or no choice in their treatment or have little worth as a person. The social interactions that take place within the medical system can have a direct impact on the patient’s sense of self by reinforcing the idea that their bodies are objects and out of control (Waskul & van der Riet, 2002).

Stigma Theory

Stigma theory, developed from Goffman’s work (1963), asserts that individuals displaying physical signs of a disorder are marked as “tainted.” Those who do not share this particular stigma are seen as “normal”. This stigma can be felt by the recipient of the stigma, resulting in shame or fear of being discriminated against on the basis of this mark (Chapple, Ziebold, & McPherson, 2004). Stigma can cause stress and may threaten an individual’s sense of identity.
Stigma is dependent on others’ perceptions of the person’s responsibility in acquiring the mark (Chapple, Ziebald, & McPherson, 2004) and the degree to which this mark interferes with social interactions (Rosman, 2004). The cancer diagnosis itself may be associated with stigma, possibly because the causes may be unknown and because cancer is often seen as resulting in death (Chapple, Ziebald, & McPherson, 2004). Treatments may also add to the stigma the patient feels by contributing to the outward display of illness (Rosman, 2004).

Several studies have examined the role that stigma plays in the lives of those with cancer. Chapple, Ziebald, and McPherson (2004) interviewed 45 individuals with lung cancer (in various stages) in the U.K. Lung cancer was the focus of the study because it is often associated with a particularly gruesome death (e.g., gasping for breath). Patients in the study reported experience with stigma that ranged from having others avoid physical contact to complete isolation by family and friends. Patients were often aware that others viewed them as dirty or responsible for their illness (e.g., because of smoking), although older adults received less blame for their cancer.

Some of the participants in the study became angry and resisted blame. They often talked back to individuals who assumed they had smoked or explained how the attitudes and knowledge about smoking had changed over time. Sometimes they blamed other entities for their condition or the blame they experienced, including the tobacco industry and advertisers.

In a similar study, Wilson and Luker (2006) interviewed 26 adults with various cancer diagnoses. Their original study was meant to examine discharge planning at a local cancer center but they became sensitive to themes of stigma that were expressed by the patients and
included questions about it in their interviews. The participants in the study felt like they had been marked by their disease. As a consequence, individuals often avoided contact, particularly when the participants talked about their experiences with cancer or treatment. However, when they were admitted to a cancer center they were surrounded by other members who belonged to the group “cancer patient.” Most of the participants felt that they were at much more liberty to discuss their illness and were treated in more of a positive way than outside the hospital.

Interactions with “normals” outside of a hospital or cancer center can be particularly difficult for individuals who have significant alterations in appearance, which serve as visible reminders of disease. In one study, a researcher interviewed 35 individuals with chemotherapy-induced alopecia (Rosman, 2004). Participants discussed attempts to camouflage themselves by wearing wigs. This attempt to blend in was usually an exercise in the protection of others. One participant stated, “I only did it to protect my children from other people’s remarks” (p. 337). Interestingly, it was only the women in the study who hid their hair loss, assumedly because of the lack of social stigma attached to men without hair. Some women resisted complying with unspoken rules about appearance and refused to wear a wig, instead wanting to make sure others knew they had cancer.

In summary, stigma theory as it applies to cancer shows how changes in the body due to cancer or cancer treatment effectively mark the cancer patient as “tainted.” “Normals” often discriminate against the cancer patient through verbal or nonverbal communication, including avoidance. As the above studies show, the patient is often aware of differential treatment and
chooses either to hide the disease from others or to openly display physical signs of cancer in an act of defiance.

Cancer and Mental Health

Cancer is also associated with decreased well-being, anxiety and depression. For example, as many as 5-10% of patients diagnosed with breast cancer met the criteria for PTSD and these symptoms have been associated with lower quality of life (Cordova et al., 1995). Estimates of depressive symptomology in late-stage cancer patients range from 23-35% (Breitbart et al., 1995; Chochinov et al., 1994) and anxiety symptoms occur in about 25% of patients as well (Brandenberg et al., 1992; Derogatis et al., 1983).

The term suffering is an ambiguous concept, but nonetheless is prevalent in discussions of people with terminal cancer (Rydahl-Hansen, 2005). Rydahl-Hansen (2005) conducted a qualitative study to determine the nature of suffering for patients with incurable cancer. She discovered that suffering for most participants consisted of three major components: existing in a persistent struggle to maintain and regain control; increases in the sense of powerlessness; and increasing loneliness and isolation. These three major categories were related to the following characteristics: being at the mercy of the body, illness, death, and treatment; being at the mercy of professionals; and being at the mercy of the past, present, and future. Being at the mercy of the past, present, and future may require a little explanation.

Rydahl-Hansen (2005) explains that most of the patients in his study tended to place emphasis on holding on to the present because the future was sure to bring more physical decline. However, because of their failing health, most patients were unable to live life in the
present moment as they wanted. Instead they were at the mercy of professionals who defined
the present time in terms of symptomology and treatment of the patient’s body. The patients
reported not having a good sense of what expected physical changes would mean for their future
existence. They rarely discussed their concerns about the future with their families and doctors
and became increasingly fearful of the future and what it might bring.

The sense of suffering for these patients was rarely communicated with professionals and
yet was expressed during the research interviews. This suffering deeply affected the emotional
well-being and quality of life of individuals with terminal cancer.

Rydahl-Hansen’s (2005) findings on individuals with cancer focusing on the present fits
the lifespan developmental socioemotional selectivity theory (Carstensen, Isaacowitz, &
Charles, 1999), in which an individual’s perception of time left to live affects motivation and
behavior. Motivation drives behavior and is aimed either at the acquisition of knowledge (e.g.,
seeking out knowledge of the social or physical world) or emotion regulation (e.g., finding
meaning in life, increasing social intimacy in close relationships). When an individual perceives
no time limit in life, the individual will be more likely to engage in knowledge-related goals,
whereas when time is viewed as limited emotion regulation and the pursuit of meaning will be
prioritized. Although socioemotional selectivity has not been applied to illness, it has been
applied to lifespan development with findings supporting the basic tenet that, as one ages and
time grows short, emotion-related goals are prioritized.
Death and Dying

The literature on death and dying is quite large and involves many different topic areas from coping styles to end-of-life decision making. Some of the relevant work in this area will be discussed, including the stage theory of dying (Kübler-Ross, 1969) and Dorbratz’s (2002a, 2002b, 2006) work on self-transacting dying.

*Kübler-Ross’ Stage Theory of Death and Dying*

Kübler-Ross’ generative work on death and dying (1969) was based on interviews she and a group of professionals (physicians, chaplains, psychiatrists) and students conducted with terminally ill individuals in a hospital setting. These interviews were focused on the topic of dying and the intent was to learn about the dying process from the patients’ perspectives.

Based on these interviews, Kübler-Ross developed a 5-stage theory on the process of dying. In the first stage, the dying individual is said to deny the fact that she has a terminal diagnosis and may even isolate herself from others. According to Kübler-Ross, this defense mechanism is often short-lived and deals with the initial shock of the diagnosis. After recovering from this initial shock patients may selectively chose with whom they discuss their illness. Kübler-Ross reported that several of the patients she interviewed were aware that loved ones could not handle the thought of the patient’s death and so the patient refrained from acknowledging their illness in the presence of these loved ones.

The second stage of the dying process is anger. During this stage, many dying individuals ask the question, “Why me?” Anger and rage are expressed over the interruption of life’s activities and patients may become hostile towards others that they see as better off or
Kübler-Ross reported that it is during this stage that family, friends, and hospital staff have the most difficulty working with the patient because often that anger could be directed towards them.

The third stage of the dying process involves bargaining. It is during this stage that individuals who are dying try to make an agreement with a higher power to extend life. The patient may offer good deeds or a life devoted to religion or spirituality in exchange for more time. Kübler-Ross reported that patients often keep their bargaining a secret and use this technique in an attempt to postpone death.

In the fourth stage of dying, individuals may exhibit signs of depression. Kübler-Ross explained that this is due to the fact that the patient is no longer able to deny her illness and begins to experience a great sense of loss. According to the theory, the patient at this stage is experiencing preparatory grief and may feel guilty about leaving loved ones behind. Kübler-Ross explained that if the patient is allowed to express these sorrows she will be more likely to enter into a state of acceptance, the final stage in the dying process.

The fifth stage – acceptance – may be reached if the dying individual has had enough time to process her impending death and if she has been given the resources and help she needs throughout the process. Kübler-Ross described this stage as “almost void of feelings” (p. 100). It is a time of quiet and rest before the actual death takes place. Patients in this stage often request fewer visits from loved ones and engage in more nonverbal and less verbal communication with others.
In addition to the five stages of dying, Kübler-Ross also pointed out the importance of hope for the dying process. Based on the interviews, she concluded that almost all patients who are dying retain hope whether it be for a cure or that the whole experience is just a nightmare. She describes hope as a nourishing idea that can aid the dying individual through difficult times.

Kübler-Ross’ work (1969) was important to the medical community because it legitimized research in the area on death and dying. In addition, it encouraged society to examine death, regardless of the fear it invokes, in an effort to improve the dying process for all. Her work sparked an entire area of research that continues to develop today.

**Criticisms of Kübler-Ross’ Stage Theory**

Serious criticism has been leveled against Kübler-Ross’ stage theory on dying. Kastenbaum (1998) and Corr (1993) have provided particularly useful critiques of her work which will be summarized by themes below.

The existence of these stages as such has not been demonstrated.

Kastenbaum (1998) states that there is no evidence to suggest that individuals actually move through a set of stages during the dying process. Additional coping strategies and reactions to a terminal diagnosis have been found in other studies (Buchman, 1993).

No evidence has been presented that people actually do move from stage one through stage five.

Additionally, the theory lacks evidence on the movement of patients from stage one all the way through stage five. In fact, Kübler-Ross’s own data do not match well with her theory. Kastenbaum (1998) has purported that none of the patients she interviewed went through all five
stages in order. Instead, patients exhibited qualities of some of the stages at various points throughout their illness.

The limitations of the method have not been acknowledged.

Kübler-Ross does not provide a description of her sample or her method of analysis of the data she has collected from patients. It is unclear how she defines certain concepts and terms and if the theory is based on more than just her clinical impressions of the interviewees. It is difficult to know without this information how valid and reliable her theory is, particularly because she did not provide additional support for the theory in her later work. Interestingly, Kübler-Ross admits that some of her relationships with her patients were non-traditional in that she sometimes brought them gifts or established close relationships with them. It is unclear how such a relationship might have impacted the data collection.

The line is blurred between description and prescription.

Kübler-Ross’s theory on death and dying has become very well-known. Medical professionals who are familiar with the theory have reportedly engaged in efforts to try to move patients through these stages to reach the last stage of acceptance (Rainey, 1988). Although not explicitly stated, there is some implicit assumption within the theory that the stage of acceptance is a goal for which to strive.

The totality of the person's life is neglected in favor of the supposed stages of dying.

The stages in this theory do not take into account the uniqueness of each individual and neglects a holistic view of an individual’s life. The theory itself is an insufficient framework to account for such a view and proposes a mechanistic approach to dying. It does not include, for
example, spiritual or physical dynamics involved in the dying process (Corr, 1993) and is therefore limited.

The resources, pressures, and characteristics of the immediate environment, which can make a tremendous difference, are not taken into account.

There is a suggestion that those who are dying in a positive, supportive environment may exhibit very different patterns of dying than those who are in a non-supportive environment (Kastenbaum, 1998). Kübler-Ross’ theory does not take into account these types of variables and therefore is limited in what it can describe.

Kübler-Ross’ theory on death and dying has been a powerful and generative theory. It is well-known throughout the medical community and is still cited in end-of-life work today. However, there has been serious criticism of the theory because of the proposed universality of the dying stages and the lack of information about the study’s sample and methods. Despite these criticisms, there are three lessons that can be learned from the stage theory on dying (Corr, 1993). First, those who are coping with dying are living human beings who are unique and will act in their own individual ways to the dying process. Second, in order to become an effective care provider for the dying patient, the care provider must actively listen to the person’s psychological needs. Third, individuals should learn from those who are dying that they themselves are also limited, vulnerable, and mortal but are also resilient and adaptable.
Dorbratz and Self-Transacting Dying

Self-transactions refer to a hierarchy of responses (social, psychological, emotional) that compose a dying person’s experiences (Dorbratz, 2002a). These self-transactions include both environmental and personal influences.

Dorbratz (2002a) found that hospice patients’ experiences tended to fit into seven patterns of self-transacting dying: transcending, becoming, reconciling,anguishing, avoiding, relinquishing, and repressing (see Table 1 for a description of each of the patterns). She also identified integrating forces (social-psychological and physical factors) that affected dying. These include: interpreting meaning, bodily feelings, connecting others, weighing expectations, adjusting expectations, and sustaining tasks. These forces shift between positive and negative dimensions. For instance, within the interpreting meaning category, one can interpret the inability to dress oneself as either a loss of autonomy (negative dimension) or satisfaction with a higher frequency of receiving positive human touch (positive dimension; see Figure 1).

Dobratz’ work is important for the current study for several reasons. First, it gives importance to the physical as well as psychological and social aspects of a person’s experience in relation to the self. Second, the work was done with home hospice patients and thus is particularly applicable to the current study. Third, she focuses on the negative and positive meanings derived within the context of dying.

The current study differs from this work in focus. The current study, while focused on the self is also focused on the self in relation to the body and the social factors that influence this relationship. In addition, Dobratz’ (2002a) sample was very different than the proposed sample
for this study. Her sample was mostly male and included participants aged 30-89 with variable diagnoses.

Western Views of Dying

Western views on death are dying have important implications for those who are dying, are sick, or are old. The processes of terminal illness and aging are viewed as directional, ending in death (Tomer, 2000). Therefore, illness and aging can invoke thoughts about death and dying.

Attitudes towards death and dying can be categorized in the following way: resignation to death, acceptance of one’s own death, fear and fascination with death, and viewing death as shameful or prohibited (Aries, as cited in Backer, Hannon, & Russell, 1982). The view most relevant to the current time period is the view of death as forbidden. The factors that contribute to this view
of death include: changing mortality patterns, an increase in the number of individuals dying in institutions instead of the home, American values, and family structures.

Mortality rates continue to decline and have remained relatively stable over the past 30 years (Backer, Hannon, & Russell, 1982). Because mortality rates are so well controlled it is usually older adults who die and often individuals do not think about or confront death until they reach old age. This control over mortality rates allows individuals to have longer relationships, perform important life tasks at later ages (e.g., going to school, having children), and develop treatments that may help to prolong life or eradicate disease.

Because Western ideals aim at controlling death, hospitals have become the site for most deaths. The rate of deaths in institutions has steadily increased over the years and very few deaths occur in homes, effectively reducing the role of the family in death and dying. Because death occurs in institutions, individuals are less likely to have personal experience with the process and death becomes invisible. Unfortunately, institutions are usually not equipped to handle dying but instead are there to “cure” the patient. One notable exception to this rule is hospice, which often restricts the use of curative care with a focus on comfort care measures during the dying process.

American values include: innovation, progress, efficiency and mastery and the general sentiment is that humans should be able to solve all natural problems. Death is approached in much the same manner. There is often focus on causes of death and attempts to develop solutions. For example, data are available to calculate how much life expectancy would increase if we were able to cure certain health problems, such as heart disease. Essentially, Americans
focus on the controllable aspects of death and try to “conquer” death itself. Americans also
value happiness and youth. Many of the advertisements in the media show young individuals
and there is a plethora of anti-aging advertisements. Death, dying, illness, and aging interfere
with our notions of happiness and therefore death is avoided at all costs.

The nuclear family’s function has changed throughout history. Initially, families stayed
together for economic and survival reasons. Now the nuclear family is held together for
purposes of emotional gratification. Individuals are often emotionally dependent on their
families and the thought of losing a member is particularly threatening.

The mentality of “forbidden death” can be seen in many facets of our culture. We use
terms like “passing on” or “rest in peace” instead of using the word “death.” Corpses are
doctored to look as alive as possible and discussions of death are often described in terms of
“casualties” in the case of war.

This concept of forbidden death has implications for those who are dying. If our culture
promotes a sort of denial of death until one reaches old age then those who are not ready or old
enough to confront death will likely try to avoid situations in which they would have to
acknowledge their mortality. Avoidance of the dying individual (or ill or aging individual) can
have negative consequences for them, particularly if they are seeking love and support from the
very people who are avoiding contact. Such avoidance also can have negative consequences for
those surrounding the dying individual, as opportunities for forgiveness, resolution, and learning
may be missed.
CHAPTER 3

METHODOLOGY

Study Design

The research question for this study lends itself well to qualitative inquiry because the focus is on the discovery of the meaning of cancer for older adult women as it relates to ‘the self’ and the body. The focus is on the participant’s experiences, instead of preexisting theory, with the overall goal of creating a theory grounded in these experiences. Thus, for the current study a qualitative research approach is desirable.

Qualitative inquiry usually takes place in a natural setting, uses the researcher as an instrument of data collection, uses inductive analysis of data collected from participants, and focuses on the meaning of what the participants say (Creswell, 1998). This means that data is collected from participants without a priori hypotheses. In addition, the process of conducting qualitative work is iterative – the processes of analysis and data collection each inform the other.

Qualitative studies vary based on the tradition of inquiry used. Grounded theory was chosen over other qualitative methods based on the research question for the current project and the goal of developing a theory about changes in self-perception and women’s relationship with their bodies. Other methodologies, especially phenomenology, overlap with grounded theory in some ways and a discussion of the differences and similarities between them is warranted.

In an article about the similarities and differences between grounded theory and phenomenology Baker, Wuest, and Stern (1992) discuss the foundations of each of the traditions. They describe phenomenology as having roots in philosophy and define it as the
study of a phenomenon. The goal is to discover the essence of a phenomenon and this essence is
discovered by talking with participants who are living the phenomenon under study. The
researcher then participates in an intensive reflective experience in which they ‘bracket off’ their
preconceptions about the phenomenon. The result is a description of the participant’s world as
she experiences it.

Baker, Wuest, and Stern (1992) explain that grounded theory, on the other hand, was
developed from the symbolic interactionist perspective in sociology and focuses on the
meanings people make. According to this perspective, the self-concept and the ability to
communicate with oneself is fundamental to the process of meaning making (Blumer, 1969).
Thus, ‘the self’ is an important area of study. Meaning is also seen as dependent on social
interactions.

These researchers also elucidate the differences in methodology between
phenomenology and grounded theory, including: the researcher’s preconceptions about the
phenomenon under study, the unit of analysis and data source, sampling procedures, data
collection and analysis, and validity (Baker, Wuest, & Stern, 1992). First, phenomenology treats
the researcher’s preconceived notions of the research topic as potentially detrimental to the
discovery of the essence of the phenomenon. Grounded theory, on the other hand, treats the
researcher’s experience with the subject of study as an asset to theory development and allows
these previous experiences to be used as data.

Second, the unit of analysis for phenomenology is the individual’s experience and thus
the only source of data appropriate for this type of inquiry is the participant herself. In this case,
verbal or written descriptions from the participant are sought. In grounded theory, the unit of analysis is the social and psychosocial processes of meaning making. Commonly used forms of data include: discussions with participants and non-participants about their experiences with the phenomenon and other people, other researchers’ writings on the matter, and personal experience. This data can be collected in interviews, readings, participant observation, and self-reflections of the researcher.

Third, phenomenology uses purposive sampling of participants who have lived through the experience being studied. The sample size is kept small purposefully because the aim is to describe the participant’s experience in rich detail. In contrast, grounded theory begins with purposive sampling but shifts to theoretical sampling because the development of a theory is dependent on the participants selected for the study. Specific participants are selected to help elucidate the variations in situation or experience and this selection is based on emerging theoretical concepts that arise from the interviews. Saturation, which can be defined as “the point in…which no new properties, dimensions, or relationships emerge during analysis” (Strauss & Corbin, 1998, p.143), is used as a tool to ensure that theoretical categories are fully explored and detailed.

Fourth, data analysis in phenomenological studies involves intense reflection to avoid contaminating the analysis with the researcher’s preconceived notions. Thus, data collection involves open-ended questions in an effort to decrease the likelihood of contamination. In grounded theory, data collection and analysis co-occur using the constant comparative method, which is defined as making constant comparisons and contrasts between the data throughout the
process of data collection and analysis. The constant comparative method includes comparisons within a single interview and comparisons between interviews. Data is coded in a theoretical way rather than a descriptive way, which is used in phenomenology.

Fifth, validity in phenomenology is determined by taking the researcher’s description back to the participants to determine if the researcher’s findings are an accurate description of the participant’s experience. In contrast, the validity of a grounded theory study is dependent on how useful the theory is itself. The theory must meet the criteria of fit, grab, and work (Glaser & Strauss, 1967). Fit means that the theory matches with the data and that the generated categories are present in the data. For a theory to have grab it must be relevant to practitioners and the participants themselves. Finally, for the theory to work it must be explanatory and have the ability to predict and interpret.

Despite these differences, some researchers use a combination of phenomenology and grounded theory in their studies. However, according to Baker, Wuest, and Stern (1992) the combining of qualitative research approaches, which they term “method slurring”, is a growing concern. In the interest of research rigor they see a clear need to explicitly state data collection procedures and to ensure that these procedures are consistent with the assumptions of the selected research approach. Baker and colleagues (1992) focus on the fusing of grounded theory and phenomenology in their analysis of this issue, as they seem to share a couple of commonalities. First, both focus on the personal experience of the participants in an effort to gain rich descriptions of a phenomenon. Second, both methods involve flexible procedures for data collection. However, the authors argue that both approaches are based on different
assumptions, as described above, and thus have different methodological approaches. They conclude that combining these approaches is detrimental to the credibility of qualitative research.

For the current study a grounded theory approach was used. Grounded theory involves the process of discovering a theory related to a particular situation or condition (Creswell, 1998). Because the purpose of conducting a grounded theory study is to develop a theory, no specific theory should initially guide a researcher (Strauss & Corbin, 1998). Instead the theory should emerge from the data. However, this is not to say that a researcher is lacking a theoretical lens. For example, many of the studies cited in the literature review used grounded theory but interpreted the results from a symbolic interactionist or social identity theory point of view, depending on the researcher’s interpretations and the data (e.g., Charmaz, 1995).

Grounded theory is used to describe social or psychosocial situations and to describe the core and peripheral processes involved in the situation (Baker, Wuest, & Stern, 1992). The core process or factor in the theory is the principle that is linked to most of the other processes involved in the situation being studied. To accomplish the role of theory development, this method uses inductive analysis of social or psychosocial processes.

In grounded theory, data is collected from participants in a natural setting. The data is then interpreted by the researcher, hypotheses are generated, and a theory is developed. However, data collection and theory development coincide so that data collection is informing theory and theory is informing further data collection (Creswell, 1998; see Figure 2 for a visual depiction of this process).
Grounded theory was chosen for the present topic for a couple of reasons. First, it is based on a symbolic interactionist perspective, which includes social interaction in its analysis – an important component of this study. Second, the purpose of the study is to generate a theory based on participants’ descriptions. Grounded theory allows for theory to emerge from the commonalities in participants’ experiences. Theory is also a helpful vehicle to advocate for policy change and to inform current practice as well as to establish a program of research.

Recruitment and Procedures

Originally, participants were only to be recruited from Hospice of West Alabama in Tuscaloosa, AL for this study. However, recruitment proved to be more difficult and took longer than expected with one data site and thus other hospices in Birmingham, AL (Comfort Care Hospice, Holistic Health Care, and New Beacon Hospice) and Tampa, FL (Life Path Hospice) were added. Letters of support were gathered from all participating recruitment sites and forwarded to The University of Alabama Institutional Review Board. Participants were interviewed only if their life expectancy was at least two months in the opinion of hospice staff.
to ensure that the participant was lucid and not acutely dying. Additional eligibility criteria for the study included: being female, being 60 years or older, having a diagnosis of cancer, and being cognitively intact.

Theoretical sampling was used when possible. Because data collection in Alabama proved to be more difficult than anticipated, there was little control over what types of participants were available for the project, thus resulting in a convenience sample. The census at Life Path Hospice in Tampa, FL was larger than the hospices in Alabama, which made data collection from the Tampa site easier. The census range for Alabama hospices was from 20-100 individuals whereas the Life Path Hospice census was 2,000 per day. Overall, it was difficult to recruit African American participants into the study because there were fewer African Americans on each of the hospices’ census, a fact consistent with national characteristics of hospice enrollment and use. For instance, in 2002 only 9.2% of hospice patients were African-American and 16% were non-African American minorities (Radulovic & Person, 2004). Hospice patients also tend to be from the middle class (Kinsella, n.d.), as were almost all of the participants in this study.

Two semi-structured interviews were conducted with each participant. The focus of the first interview was to establish rapport with the participant and gather information on diagnosis and treatments for her cancer. The second interview focused on the woman’s current relationship with her body and self-perception as well as her reflection on how these things were affected throughout the course of the disease and treatment. All interviews were tape recorded and later transcribed.
Appendix A lists the guiding questions used at different points in the study. The questions shifted in focus as data were collected, consistent with grounded theory methodology (Creswell, 1998; Strauss & Corbin, 1998). Initially, a large portion of the first interview included questions aimed at getting a detailed history of the patient’s past. As time passed it was clear that very little useful information was being collected during this interview. The information collected on their past did not provide any insight into how their identity had changed or remained stable throughout their illness. In fact, oftentimes participants spoke about their identity at the time of the interview and much simpler questions, such as “Have you always been this way?” provided enough contextualization and information on changes that were specific to dealing with advanced cancer. Thus, several questions pertaining to the patient’s life history were dropped and fewer questions pertaining to life history were asked. Additionally, participants had difficulty answering abstract questions about self-perception including, “How did you perceive yourself during adolescence? Adulthood?” and “How do you think of yourself now?” Oftentimes, participants freely provided information on how their self-perception had changed throughout the course of the illness without direct prompting. To simplify the interview these questions were dropped as well.

Two additional questions were added to the interview protocol. First, several participants had mentioned previous experiences with cancer in their family of origin, which often had implications for how they reacted to their illness or made decisions on treatment. A question was added to deal directly with this phenomenon. Second, the theme of loss kept
presenting itself during interviews. An explicit question about loss was added to further develop the theme.

The second round of changes to the guiding questions provided further adjustments to the amount of questioning related to the patient’s past. There was still a significant amount of time being allocated to the details of a life history that were not providing relevant data for the project. Thus, further cuts were made, leaving two rapport building and life history questions: “Where did you grow up?” and “What was it like growing up in your family?” These short questions provided enough time to establish a relationship for further questioning and provided more time to devote to questions more relevant for the task at hand.

Several questions were added during the second round of changes to the questions because of new material being presented in interviews. Several new themes emerged including: spirituality or spiritual coping, the impact of other health problems on the cancer experience, quality of life, dignity, burden, and appearance changes. A question for each of these themes was included for all subsequent interviews.

In addition to the participant interviews, the researcher kept a set of field notes throughout the experience to detail anything noteworthy about interactions with participants, emerging ideas about the project, etc. These field notes were later used in the analysis and write-up of the project.

General Description of the Data

A total of 12 hospice patients were interviewed for the study. Five participants were recruited from the hospice in Tampa, FL and the rest were recruited from hospices in and around
Tuscaloosa, AL. A convenience sample was used in this study due to the specificity of the population and the difficulty in recruitment encountered during the project. All participants were selected by hospice staff. The staff members explained the purpose of the study and asked the potential participant if they were interested in being contacted. Very few potential participants (N=2) declined to participate in the study when they were contacted by hospice staff. Reasons given for not participating included the lack of knowledge of the diagnosis on the part of the patient (N=1) and lack of energy (N=1). If the participant agreed to be contacted (N=13) the primary researcher contacted the participant, explained the study, and set up a time for the interview. One participant who agreed to participate was not included in the study because of her cognitive difficulties and the level of pain she was experiencing. Although the researcher met with the participant, once it was determined she would not be eligible, the interview stopped and the researcher informed the participant that she did not qualify. A follow-up phone call was made to the hospice center to alert them to the level of pain the patient was experiencing during the visit.

Data Analysis

A coding team was assembled early in the data collection phase. This team consisted of the primary investigator (Kristen Payne), the dissertation chair (Dr. Allen), and an expert in qualitative analysis (Dr. Hamner). The group met approximately every month to discuss interview technique, the validity of the questions being asked, and coding, including the types of coding discussed below.
Microanalysis, a line-by-line analysis of the data, was conducted throughout the process of data collection. This process aided in development of initial categories, helped to show the relationship between categories, and helped to define the categories themselves. This process involved careful interpretation of single words and phrases in an effort to challenge the researcher’s first impressions of participants’ language (Strauss & Corbin, 1998). This process also helped to structure the set of questions used for subsequent interviews. Throughout the coding process comparative methods (Glasser & Strauss, 1967) were used to illuminate similarities and differences between data. Comparative methods were used to evaluate statements and incidents within one participant’s data and to compare the experiences among participants.

Open coding is usually the first phase of coding and involves the initial formalization of categories (Creswell, 1998). Open coding involves intensive examination of the transcribed interviews and use of word processing software to label and describe segments (words, lines, paragraphs) of the data. Large numbers of codes were developed during this phase (both conceptual and descriptive). This process fragmented the data, allowing the researcher to examine the coding fragments in many ways. In addition, subcategories were identified which helped to clarify higher ordered categories. For example, coping mechanisms was a higher-ordered category that had various subcategory codes including avoidance and acceptance.

Axial coding is a more abstract process and was used to link categories together by similarities and differences (Strauss & Corbin, 1998). The purpose of axial coding is to reconsider codes that were developed during open coding and to piece back together data that
were fragmented during this initial coding. This was done through several tasks, including: defining the dimensions and properties (which began during open coding); identifying consequences, conditions, and interactions surrounding a category; and detailing the relationship between categories and subcategories with information about how the categories are related (Strauss, 1987). Codes are often dependent on conditions, which help to explain why, where, how, and when a specific phenomenon occurs (Charmaz, 2006). Identifying these conditions helps to provide further comparisons between the data. Interactions or actions explain who is involved in the phenomenon or how the phenomenon takes place. Consequences describe what happens because of the actions or interactions.

Development of a theory was pursued during selective coding in which the researcher revisits the data and the codes (Strauss & Corbin, 1998). During this process, examples were identified within the data which illustrated the themes developed previously. Conclusions were confirmed by providing instances of support which were grounded in the data. Patterns were tested by referring back to the data and identifying instances in which the proposed patterns did not fit. It was within this phase that core categories in the developing theory were tested and several modifications were made to the theory based on data in the interviews, field notes, and memos. Data analysis within grounded theory follows a standard format (Creswell, 1998; Strauss & Corbin, 1998). Each of the analytical tools discussed here were used throughout the analysis and data collection procedures. Thus, the tools were not discrete steps in the analytic process.
Memos refer to written records “that contain the products of analysis or directions for the analyst” (Strauss & Corbin, 1998, p. 217). Unlike field-notes, which are mainly descriptive, memos are analytical. Memos vary in form and can include diagrams, coding notes, theoretical notes, etc. For the current project, memos were handwritten immediately after the interviews and throughout the analysis process.

Sorting is the process of taking all of the notes and memos collected from the project and thoroughly examining them. Reading and re-reading the memos and notes helped the researcher and coding team to put an order to the story being told and to examine the relationships of the categories to a core category.

After the initial theory was developed, the coding team refined the theory several times. This process involved re-examining the data to see if it was consistent with the overarching theory, eliminating unnecessary categories, expanding on categories that were insufficient, and identifying gaps in the theory that needed to be addressed (Strauss & Corbin, 1998).

Protecting Confidentiality

The Institutional Review Board at The University of Alabama and the review boards at Hospice of West Alabama, Comfort Care Hospice, Holistic Health Care, New Beacon Hospice, and Life Path hospice approved this study. Each participant was given a code name to protect their identity and fake names are used throughout this document. Electronic information and the audio recordings of the interviews were password protected. Audio files will be permanently deleted at the close of this project.
CHAPTER 4
RESULTS

Demographic Data

Demographic characteristics for the sample are provided in Table 2. There are a couple of interesting and unique characteristics of this sample. First, this sample is heterogeneous in terms of education and income status. The range of education was from a 9th-grade education to a graduate education. Although no participant reported having a “very difficult” time paying for basics, they were about evenly split between “somewhat difficult,” “not very difficult,” and “not difficult at all.” Second, differences in demographic variables were present between the Tampa and Alabama sites (see Table 3). For instance, one participant at the Tampa site was born in Trinidad but mostly raised in the U.S. At least one other participant at the Tampa site was born and raised in another state (e.g., New Jersey) and had come to Tampa to stay with family while no one from the Alabama sites reported being born in a place other than Alabama. The participants from the Tampa site were also younger and reported a higher level of education than the participants from the Alabama sites. Although these were substantive differences, the coding team did not notice any differences in the themes expressed by site.

Model of Post-Diagnosis Identity Development

Data analysis of the interviews uncovered several constructs related to the development of a post-diagnosis identity, which seemed to be a major theme across interviews. Further analysis provided a framework for the model of post-illness identity development (See Figure 3). All participants appeared to be actively engaged in constructing a new identity after their
diagnosis, usually in an effort to increase their sense of quality of life. For example, some participants began to take pride in their identity as a cancer patient. Although participants used different strategies and mechanisms to achieve this reformulated identity, the goal was the same – to produce a sense of identity stability that was congruent with the physical, emotional, psychological, and social changes that they were experiencing as a result of cancer and treatment.

![Image of Model of Post-Diagnosis Identity Development]

**Figure 3. Model of Post-Diagnosis Identity Development**

Essentially, what this model describes are the pathways from changes that occurred as a result of the cancer diagnosis and illness experience to maintenance of or an increase in quality of life, which is mediated by identity reformulation post-diagnosis. Patients experience changes in their physical abilities, appearance, interactions with others, and awareness of death because of their diagnosis and illness experience. The patient’s sense of dignity, their previous quality of
life, and their pre-illness identity were all areas that are threatened or challenged by the new physical changes and limitations, the different kinds of interpersonal interactions they encountered, and the changing awareness of death that they experienced. Based on this threat, participants engaged in coping mechanisms and resistance strategies in an effort to create some stability out of a situation constantly in flux. Many of the coping strategies they engaged in were aimed at the reformulation of a new post-diagnosis identity. However, it is important to note that this is not a formulation that occurs at one point in time. Instead, these women described going through day-to-day changes in their self-perception as their physical symptoms, limitations, and quality of life change, which is why there is a feedback loop from quality of life back to bodily changes, interactions with others, and awareness of death.

An important point about the data should be noted. Interviews were collected at one point in time during the participants’ illness experience. In spite of this, participants’ experiences with illness and identity issues were longitudinal, sometimes spanning as long as fifteen years. Thus, the interviews are their retrospective accounts of how they changes and remained stable over time as well as their current feelings and experiences while dealing with cancer.

Support for Model

A discussion of each of the model constructs will follow with supporting quotations and information from the interviews with participants and a literature review.
Changes in the Body

All participants reported some changes in their physical appearance or abilities as a result of the cancer or the treatments for cancer. Some of the most commonly reported changes included nausea, weight loss, limitations in mobility and activities of daily living, and appearance changes.

Many times patients described giving up driving because of the changes they experienced. Some participants either abstained from or limited their driving because they were concerned about their abilities to safely drive by themselves.

*I haven’t been driving myself. He drives my car and takes me where I need to go. I, um, the reason why because I was afraid of driving because of no feelings here (shows hands) and in my feet* (Yvonne, 60, breast cancer).

Yvonne experienced neuropathy, likely due to the chemo and radiation treatments she received for cancer. Because of the neuropathy she was afraid she would not be able to grip the steering wheel appropriately or feel the gas and brake pedals. She elected to have her son drive when she needed to go out.

Other participants, who did not have severe symptoms often elected to keep driving with some limitations.

*I, don’t-Well, in the last few months now I have stopped driving – well, I say stop driving-I have not stopped completely. I limit myself from 5 miles from home (laughs). And I can get practically everything I need within 5 miles of where I live so I don’t have to depend on them, you know, for a lot of things* (Helen, 78, colon cancer).

Maintaining as much independence as possible helped participants retain a sense of independence and avoid feeling like a burden on others. However, giving up this mobility and
sense of independence was not easy for every participant. Geri (60, lung cancer) eventually accepted the fact that she could not drive, but not without a stern warning from her brother.

  K: Yeah. How did you accept that?
  G: Not very well at first. And I cheated but then when [her brother] said, ‘You know, if you get into a wreck whether it’s your fault or theirs your insurance doesn’t have to cover you and they would take everything we own’ and I know they would.

Geri had a difficult time accepting the loss of driving privileges, particularly when they were initially taken away. Even though she had not been driving for about six months at the time of the interview, during visits to the doctor she continually asked him to give her permission to drive.

Physical mobility was often threatened, particularly when participants were receiving cancer treatments. Sometimes participants were bedbound or chairbound, but most often participants in this study were able to get up and move around some with assistance from others or mobility devices such as wheelchairs or walkers. The use of mobility aids increased with the length of time that a participant was up and about.

  But, he still does all the grocery buying. He has to go, if I want like this yarn here, he goes and buys it for me. And I have to write down what I want and all this. Every once in a while, if I feel up to it we go out, he takes me. But I have to go in a wheelchair, even though I use a walker, I don’t trust myself enough to use a walker for any length of time shopping. So, I use a wheelchair (Gloria, 67, breast cancer).

This change in mobility was difficult for some participants to accept. Yvonne (60, breast cancer) had purchased a walker for when she needed it but often chose to use the wall instead, stating, “I started – I use the walker. I would basically walk close to the wall and hold on to the wall because I’m a proud old 60-year-old.”
Impairments in activities of daily living were expressed by all participants. Eight of the twelve participants stated that they were unable to cook. Betty (62, lung cancer) explained, “I used to cook every day for my husband, and I don’t do that anymore. We eat out most of the time, which gets very expensive.”

Sometimes impairment was so great that the patient needed help with using the bathroom or bathing. This was a particularly distressing event for these patients.

A: I’m used to doing everything myself and then you got to call somebody to do this for you. Do that for you. And sometimes you want to do something and you get ashamed to ask them. I still got pride.
K: Okay. Why do you think you’re ashamed to ask for...
A: I don’t know. Maybe they’ll get tired of me, I guess.
K: Okay. You’re afraid they’ll get tired of you. You said you still have your pride, too. Can you explain that to me a little bit more.
A: (A little choked up). Oh just like they come to bathe me but I always have to do those down there for myself (pointing to pelvic area). And other things.
K: So in a way then since this has happened, you’ve lost some of your privacy too.
A: Mmmhmmm. I really have. You really give up everything (Alice, 75, breast cancer).

Needing help in self-care was upsetting to participants because it threatened their sense of dignity and selfhood, a concept discussed later in this chapter.

All but two participants described being fatigued either from their illness or the treatments they had been getting.

K: Ok. That’s great. What about your friends?
H: I have to tell them not to come.
K: You have to tell them not to come?
H: Because I don’t have energy, to even talk to someone. (Hazel, 76, uterine cancer)
As Hazel explained, fatigue often limits the amount of time one can spend interacting with others. Sometimes the patient had to excuse herself from social get-togethers. “Even now, I have to stop and think when I have company, ‘Hey, I’m tired, I gotta go lay down’. Just get up and leave” (Gloria, 67, breast cancer). Participants reported finding this hard to do because it was a change in how they usually interacted with others.

Participants often compared their current state of functioning to a previous state. Wendy, who was not very mobile at the time of the interview because of pain and fatigue stated,

I’ve always, ah, been used to doing for everybody else, looking after them and taking care of them and this is new, you know, for somebody to have to look after me, you know the other way around, so it’s made a difference (Wendy, 60, ovarian cancer).

She experienced a challenge to her previous identity based on physical changes in her body.

Some researchers call this a shift from “the lived body” or the experience of unity between the body and self to “the object body,” which distinguishes the body as something outside of the self that is hindering our movement through the world. Similarly, Mary (60, breast cancer) commented on how her physical limitations had impacted her sense of independence. She explained, “I’ve always been an active, independent person and at first I feel shackled to my husband...I couldn’t drive, I fell often, and I needed him badly.” Being unable to do the tasks one is used to doing can lead to a drastic sense of loss.

H: Sometimes I can’t do everything I used to do. When you’re sick you can’t do things that you want to do. Sickness changes....
K: OK. What do you think it changes?
H: Sickness almost changes everything (Hazel, 76, uterine cancer).
Some of the participants in the study had health problems before they were diagnosed with cancer. Most of the comorbid health issues did not seem to pose any significant restrictions on the participants’ functioning.

> And uh but other than that I’m fine, like I said, I have diabetes and I have liver problems and I just take them too one day ata time. I take my medication and I go for my checkups and I take my uh treatments for iron because I was anemic, very anemic. And so I get these iron shots every two weeks and I go and take them and I’m doing just fine (Rachel, 73, lymphoma).

Only one participant had experienced severely limiting health problems in addition to cancer. Teresa (66, breast cancer) had been diagnosed with several debilitating disorders. She described her experience with them in a similar way to how she described the cancer – affecting her mobility and thus her identity as an independent woman.

> [I have] Lyme disease, CF – chronic fatigue syndrome, fibromyalgia, hyperthyroidism came from that…um, it’s a whole long list. For two years I couldn’t walk. I was crawling to the bathroom, but I was unable to walk. My muscles or nothing would work so it took me a whole to get through that. And when it was happening to me, well the Lyme disease was undiagnosed right away…and as it was going along, you know, you’re kind of like in a spiral, wandering in a blur. You’re wondering what the heck is going on? You know- am I a hypochondriac? You know, what’s happening? ‘Cause that’s not me, you know. I was active, I did everything, workaholic.

Changes in appearance often had a significant impact on an individual’s sense of loss. Weight loss affected many of the participants in the study but to different degrees. Some like Betty (62, lung cancer) experienced substantial weight loss.

> K: When you lost the weight, how did your appearance change?
B: Well I didn’t notice any, but my family said that I looked like a skeleton. I don’t know. I didn’t…pay that much attention. I was just too sick to care.
Betty, like many of the participants, recounted her experiences during her active treatment, which occurred prior to the interview.

Helen reported the most dramatic weight loss in the sample. She looked so physically different that others did not recognize her.

K: When you say you looked really bad, did you think you looked really bad? Did other people tell you?
H: Nobody ever told me but the way that I knew that other people knew it, they didn’t recognize me. My looks have changed that much. Well, now some recognized me, you know, but a lot of people, especially at church they didn’t know who I was and, and I was not offended at all, because I knew that I had lost a lot of weight and I knew I didn’t look like I did before (Helen, 78, colon cancer).

Several of the participants in this study lost enough weight that, coupled with others’ reactions to the weight loss, the patients did experience a renegotiation of their previous identity. This topic will be examined further in the next section.

Like weight loss, other appearance changes had a profound effect on interactions with others and paired together these two factors challenged an individual’s previously held view of themselves. Wendy (60, ovarian cancer) explained one appearance change that was particularly problematic for her, “Well, ah, I not only lost my hair, I lost my eyebrows, my eye lashes. Which is a big change, a big, big difference, you know?” The hair loss was an especially traumatic experience for Wendy because “I guess the cancer and all it just hit me at one time… it just uh made it more real I guess.” And Mary stated, “That second loss of hair like I think it was, by that time it was, I must be dying and everything’s gonna have to go before I’m finished.” They literally saw themselves differently in the mirror and were confronted with the seriousness of their condition and the reality of death. Now that they could actually see the physical effects of
the treatment (and so could others), this physical “proof” provided further confirmation of their identity as a cancer patient. It should be noted that at the time of the interviews, each of these women had regrown their hair and were discussing their past experiences with treatment.

For women, attractiveness is often an important element of self-esteem (Kilbourne, 2000). A woman’s sense of attractiveness is often dependent on her hair (Rosman, 2004). Not only is the loss of hair problematic because it is an outward sign of the illness, it is an undesirable sign. Mary (60, breast cancer) was particularly upset by the alopecia. “That was harder than the treatment almost. Talk about ugly – you’re real ugly when you don’t have hair.”

We can understand bodily changes as particularly difficult events, especially if we examine the theorization of the body as “neither – while also being both – the private or the public, self or other, natural or cultural, psychical or social” (Grosz, 1994, p. 23). Essentially, if we conceptualize embodiment as a person’s holistic experience we cannot separate out the body from cultural, social, or psychical factors. Western thought, which divides subjectivity into its physical components (i.e., the body) and mental components (i.e., the mind), is challenged by lived experience, which includes mental and physical dimensions that can never be separated from others. Evidence for this conceptualization comes from the participants’ experience that changes in the body or one’s physical appearance are on display for others to view – making the body both social and physical. Many participants reported being looked at differently, particularly when they experienced changes in their appearance.
It should be noted that not every participant experienced dramatic changes in their physical abilities or their appearance. One participant, (Rachel, 73, lymphoma), who opted not to receive any cancer treatments, did not experience any appearance changes although she did have limited mobility that was partially related to cancer. For this participant, physical and appearance change themes were less present in the interview.

*Changes in Interactions with Others*

Social exchanges can take place with a whole range of individuals from doctors and hospital staff to family and friends to strangers on the street. Interactions with healthcare staff are interesting because relationships with doctors and nurses are often brief. Patients often see many staff members from radiologists to oncologists, ophthalmologists to nurses or technicians. The brevity of interactions and the specialization of medical professionals can lead patients to feel poorly understood. Mary (60, breast cancer) described her experience with medical staff this way:

*M: No, I was angry a lot of the time that I went through the chemotherapy part which was run by three doc, three male doctors. Um, when I would drag in there sick as a dog from...the chemotherapy there wasn’t any um compassion. There wasn’t any, ‘You’re gonna be all right, you just hold on to my hand and you’re gonna be alright’. Um, it-it was, ‘You have a very aggressive kind of cancer and it tends to come back’.*

*K: So, more like matter of fact?*

*M: Yes. And um [the] surgeon was the most uplifting of all of them. Um, the cancer center was just um business as usual. Um, the nurse practitioner, said um, ‘I’m a nurse practitioner and I’m here to help you but don’t call me at home’. Uh ‘I wasn’t planning on calling you at home, I don’t even like you’. Hah, so um it was rough...The head of the radiation was a female and I said I have been put with the male um radiation, whatever you call the radiologist um and I said no I want somebody with breasts...um because the men don’t have any empathy.*
Here Mary described a negative interaction with medical staff in which she felt reduced to her illness (“business as usual”) while she desired more holistic care, including empathic understanding and emotional support. In cases like these, the patient may be impacted by others’ reactions or behaviors but does not necessarily share the point of view that these individuals express.

Not all patients’ interactions with medical staff were negative. In fact, some participants had a very different experience than Mary.

K: And you said that Dr. C has a lot of compassion?
Y: Oh! She is wonderful! That’s the surgeon. She does, I mean, when I when I had to go back to her and get the port in, she looked at me and she said, ‘I don’t know what I want to do with you, but you’re strong.’ She hugged me, she cried, I cried. And she was always there for me. I worked at [Name of Hospital], when I worked she would come up visiting other patients, she would look for me. So much compassion. I’ve never seen a doctor like her, with so much compassion. I mean, she runs every year for breast cancer and that says a lot. They care about their patients (Yvonne, 60, breast cancer).

It is clear from Yvonne’s description that these interactions actually helped her to feel like she was more than just her disease (see section on Dignity).

Sometimes participants described being reminded of their appearance and physical changes by others. Alice (75, breast cancer) was reminded of the loss of her hair by others who were uncomfortable with it.

K: Did you feel like people treated you differently when you were walking around with your bald head?
A: No. They’s remind me for it. They thought I was embarrassing them. I said, ‘Okays, okays, I’m happy with it.’ [Laughs]. And see the wigs and hat and things give me a headache. So I figured the Lord would bring it back. And if they couldn’t accept that then that’s their business.
K: Okay. So it really didn’t bother you but it might have bothered other people.
A: Unnnhuh. It didn’t bother me at all. I’d rather not have a headache [laughs].
Although Alice disregarded what others said about her appearance, focusing on her own comfort, the attention they paid to her appearance at this point in her illness made her aware that she had changed physically, again pointing to the social nature of the physical body. Betty (62, lung cancer) spoke about a similar situation for her.

K: OK. Have other people noticed that you look different?
B: They comment on me being tired. I have lost so much weight. At one point I got down to 113. And they commented on the weight loss – that was most of it.
K: What did they say?
B: That I didn’t look as good, that I needed to eat and put on the weight.
K: Mmhmm. And how did that affect...
B: That would aggravate me, especially my sister, because I was the one sick – not them. And they didn’t know how nasty everything tasted but then I realized they didn’t know so I stopped being angry with them. And I’d just tell them, ‘You know, I’m doing the best I can do.’

Here Betty expressed her frustration that her sister was judging the situation without insider knowledge of the experience of cancer. This situation was not limited to loved ones. Some participants mentioned that children in the community often commented on their appearance – particularly their loss of hair. Geri (60, lung cancer) mentioned an instance where her friend’s children were taken aback by her appearance. “They um, they would look at me and they would go (in a whisper) ‘Mom, what happened?’ And she’d say, ‘Well, she’s been sick,’ you know.”

On the extreme end of the spectrum, appearance changes could be so drastic that others may not have even recognized the individual. Helen (78, colon cancer) had this experience. She stated,

Well, actually it was after I finished the chemo that I noticed people didn’t recognize me. And it was mainly people that I went to church with, you know that I was
accustomed to seeing every week. And uh, if they had not seen me in a few weeks and then saw me they didn’t recognize me.

Although Helen was not angry or disturbed by the lack of recognition, she did state that it led her to believe that she had significantly changed in her appearance.

Sometimes interactions with others were a positive influence on the patient’s illness experience. Gloria (67, breast cancer) experienced self-consciousness because of her appearance after she had a mastectomy but found her husband’s reaction to her physical appearance a buffer.

*I don’t think I could have made it without it, and I guess that’s why I never really considered the change in my body, because he never made me think about it. We thought about other things more, more important things.*

What these experiences illustrate is that an individual’s body is not simply out there in space but is continuously interpreted and read by others. While individuals in the terminally ill person’s life may not have firsthand experience with cancer, they do have experience with that person’s physical appearance and are able to notice substantive differences. Simply, others comment on what they can know of the individual’s cancer experience – the outside display of illness. Sometimes individuals in the patient’s life can help to reduce the patient’s concern over their appearance or the internalized stigma they experience by focusing less attention on their body.

*Changes in Awareness of Death*

According to the Merriam-Webster dictionary the word “terminal” is defined as “approaching or close to death; being in the final stages of a fatal disease” (http://www.merriam-
Those patients who are diagnosed with a terminal illness and who are aware of their diagnosis inevitably become conscious of their impending death.

Betty (62, lung cancer) explained how the diagnosis of terminal cancer affected her more than watching her brother die.

*I think we all try to ignore the thought of death, especially people your age, my kids’ age, my grandkids’ age – even me. I don’t feel 62. So I never really thought about it, until I became ill. Of course, when my brother was sick and dying, I thought about it some, but I was still young. I was in my 40s.*

She attributed some of this awareness of death to her advancing age but acknowledged that the diagnosis of a serious illness prompted her to begin thinking about death seriously. Thus, the diagnosis itself is often the event that causes awareness of one’s mortality.

Some patients live with cancer a long time and others have remissions and reoccurrences, allowing them a longer period of time to adjust to or cope with the inevitability of their death. This was the case with Rachel, a 73-year-old woman with lymphoma, who had outlived her life expectancy.

*Uh, I was diagnosed on two this is going on three years, so I’ve lived that long. So if death came tomorrow or the next day or today then it wouldn’t be no shock to me. I’d be expecting it.*

Thoughts about death can impact patients’ behaviors and emotions. As Dorbratz (2002) notes, individuals who engaged in the pattern of the becoming-self, a pattern characterized by conscious awareness of approaching death with attention being paid to living in the current situation (with disease),

replaced physical movement with cognitive motion and focused on inner, self-directed activities. Having reached a stage where their physical illness could not
be contained, they directed cognition toward that which could be attained—their inner self (p. 138).

In fact, Betty (62, lung cancer) discussed a shift in some of her behaviors because of the proximity of her death.

*K:* Mmhmm. Has it—has the disease changed you at all? Do you think?
*B:* Yes, it’s made me more aware that we are mortal. Um, it’s made me think of death more and leaving my family which saddens me and I’m in the process of trying to write letters to my family to tell them how much I loved them and how I’m going to miss them. You know, and I will tell them to just, remember me with fun and laughter. That’s how I’m going to remember you, with love, and fun, and laughter. And if you can only think of me with sadness and unhappiness, don’t think of me at all. Think of me the way I was not with sadness. Think of me with love and happiness.

Death was a threat that she was trying to cope with by ensuring that her loved ones remembered her in the way that she saw herself— as happy. She was aware that she would not have control over how people remembered her but she was trying to preserve her ideal identity by encouraging others to remember her in that way.

The shift in focus and behavior that occurs because of awareness of death has direct implications for the reformulation of identity into a cohesive yet flexible post-diagnosis identity. Awareness of death along with changes in the body and interactions with others often challenge previously held views of dignity, quality of life, and the patient’s pre-illness identity, as depicted in Figure 3.

**Challenges to Dignity**

The topic of dignity was spontaneously brought up during some of the early interviews and questions related to dignity were then added to the following interviews. The literature on dignity in terminally ill populations (Chochinov et al., 2002; Chochinov et al., 2006) has
identified several threats to dignity, including: not being treated with respect, feeling like a burden on others, feeling a lack of control over one’s life, not being able to carry out tasks of daily living, not being able to carry out important roles, not feeling like who you were (before illness), and changes in physical appearance. Participants in the current study were asked to identify in their own words what dignity meant to them. Several themes emerged that were consistent with the literature described above.

Many participants believed that being treated with dignity involved compassion, which was often expressed through verbal and non-verbal behavior.

K: My question to you about Dr. C and the compassion was basically, what about her actions communicate compassion to you?
Y: The way she speaks. The way, the eye contact. Hands on. That tells me a lot.
K: What do you mean by hands on?
Y: Touching.
K: Oh, like physical touch.
Y: Physical touch.
K: OK. And, um, you said her tone of voice. What...
Y: Very soft. Caring. You can...in her voice, you can hear the hurt. She’s feeling for her patient. I wouldn’t say, cracking, but when she speaks sometimes the voice goes lower. She’s very soft spoken, but it even goes lower. To me that tells me, she’s hurting for her patient. Speak for myself. I know if she’s this way with me she’s that way with all of her patients (Yvonne, 60, breast cancer).

Patients appreciated being spoken to as an adult who was active in their own care and who was a human being – more than their illness.

And I’ve seen with other people they care for your own personal cleanliness and that’s dignity. Being treated with dignity is not having somebody talk down to you. To me that’s very important. And to make eye contact. Let me know that you’re not just sugarcoating this. I want, to me dignity is having a lot of different things, they may be small things, but they all kind of group up, to me at least, as far as like being able, if somebody asks you, doesn’t say, ‘Oh honey you want something to drink (says this in a sing-song voice)’? No. ‘Would you care for something to drink (even tone)?’ (Joann, 62, breast cancer)
Many participants were sensitive to the way in which they were spoken to, often feeling that they were being treated in a negative fashion. Rachel described a past experience during which she felt she was being talked to in an inappropriate way.

*I didn’t want to uh be talked down to, I, I, understand things. If you got time to explain it, I, I’m very apt about you know understanding* (Rachel, 73, lymphoma).

Participants were careful to make a distinction between pitying someone and treating that person with dignity. They described pity as “feeling sorry” for someone and this pity was oftentimes expressed in verbal interactions with loved ones.

*Well, I just don’t want the pity party, because I don’t want people to feel they have to call me and say, ‘oh, you poor thing’. No! no, no. I know they care, caring doesn’t mean you have to say, ‘oh, I feel I could cry, I feel so bad for you’. ‘Cause I told my one sister-in-law, she calls me and ‘Ah, you must feel so sick, you must…’ I said ‘No, I’m not that sick. I’m just nauseous; I get sick and tired of people feeling sorry for me’* (Joann, 62, breast cancer).

For some patients dignity was directly related to being able to maintain some semblance of their previous life. Teresa (66, breast cancer) had difficulty maintaining a sense of dignity because her husband began packing her belongings away or giving them away to others.

*You don’t have to know them to treat them well, you know. And if you treat them well they are going to respond well. So, it’s not just boil down to having to know a person, just having to have human compassion and putting yourself in their place. If you were there in that bed, how would you like to be treated? If you were there in that bed, would you want somebody out there selling your life? Getting rid of your life, the only life you know? You know, what happens if you make a come back, you know? Wait until I’m dead to take all that stuff away.*

For Teresa, ridding the house of her belongings was the equivalent of getting rid of her in the present and giving up hope that there would be better days ahead. Although she knew she was
going to die she wanted to be a part of the decisions that concerned her, even if they were about
her possessions. She defined dignity as,

\[\text{Being able to be self-sufficient, and die the way you want to die or live the way you want to live. You know, um, being able to take care of the personal matters you’ve always took care of before, um, being able to be consulted when decisions are being made about you.}\]

Control was a key component to dignity. Patients wanted control over their death, healthcare,
self-care, possessions, and their bodies. Betty (62, lung cancer) defined dignity in the following
way:

\[\text{To allow me to die the way I want to die. Uh, and I’m with my family, uh...to be in control of what happens to me at the end. Not have someone else make all my decisions for me.}\]

Teresa (66, breast cancer) explained the almost absolute loss of control she was
experiencing as a result of her cancer and treatments. “Here again, your control is totally taken
away, as far as any of your own personal decisions and mobility.” This quote shows how
changes in the body result in challenges to a patient’s dignity by stripping them of control over
their day to day functioning and activities.

In many ways a threat to a terminally ill individual’s sense of dignity is also a threat to
their pre-illness identity. Previous aspects of their identity or everyday behaviors were under
their control pre-illness but they are now experiencing those aspects of the self as challenged.
Threats to both dignity and the pre-illness identity were dealt with by patients in a variety of
ways, which are discussed in the sections on coping mechanisms and resistance strategies.
Challenges to Quality of Life

The World Health Organization (1958) defines health as “not only the absence of infirmity and disease but also a state of physical, mental and social well-being” and most quality of life measures aim to assess these three factors – the physical, mental, and social (Moipour, et al., 1989). Participants in this study were asked how they would define quality of life. Some of the components they discussed were broad or vague constructs. Hazel, a 76-year-old woman with uterine cancer who was bedbound explained, “What’s a good quality of life? Being comfortable, happy, having beautiful and close family members. That’s it.” More often, participants had specific ideas about what a good quality of life would look like. Often a good quality of life included mobility. Yvonne (60, breast cancer) explained, “Getting around, doing, and not always being in my bed, which I was.” The activities that participants wanted to engage in, which would aid them in achieving a good quality of life, were often dependent on that mobility. Gloria (67, breast cancer) stated, “A good quality of life to me would be, able to do anything I wanted to do, travel...uh...mostly just travel, going to see friends like I used to do.” Thus, quality of life for the participants in the study included mobility and independence, having good relationships, and general feelings of comfort and happiness.

Participants were also quick to verbalize what threatened a good quality of life or what a bad quality of life would look like for them.

J: You know, quality of life to me is when, you know, you can get up everyday, take care of your personal needs, ‘cause I’ve always taken care of my personal needs on my own and the thought of having where you have that time where it comes that you can’t feed yourself or you have all these things going on. People coming and going, giving you shots or oxygen or whatever, that to me is not quality of life.
K: And you said good quality of life to you means you can do personal things. What are those personal things?
J: You know, your personal care, feeding yourself, grooming, you know. Being able to get up if you want a cup of tea that you don’t have to depend on your family or someone else to make sure you can get that (Joann, 62, breast cancer).

Sometimes patients had already experienced a period either in the past or in the present where they had negative quality of life and they needed help with personal care.

H: I have took a bath, [unintelligible] and I just have to have somebody else give me a bath, it’s just...just think about it. Somebody has to give you a bath every day. If you’ve been taking baths as long as you can remember, then it’s a change.
K: Big change. So that sounds like it’s pretty difficult for you.
H: Yes. I don’t let them know. It’s my secret (Helen, 78, colon cancer).

Having control of personal care was mentioned most often when describing threats to a good quality of life. This highlights how changes in interactions with others (i.e., having to be intimately cared for by others) can challenge or threaten an individual’s quality of life, producing a negative experience.

Other threats to quality of life included side effects that the women had experienced during their treatments.

K: Okay, so what does a bad quality of life mean to you?
G: Being sick. I was taking this [name of chemo] I was sick all the time. I lost, um, I weighed 248 when I started, which was fat, and now I weigh 173 (Geri, 60, lung cancer).

Sometimes patients focused on the sickness they experienced from their treatments, like Geri. Other times patients discussed the negative impacts the treatments had on their mobility.

So I spoke to my kids and I decided that whatever time I have left I want to have it with a little quality and being, taking the chemo wasn’t giving me any quality – I was in bed most of the time (Yvonne, 60, breast cancer).
Both the illness and restrictions in mobility that participants experienced were negative because of the activities this prevented them from engaging in as well as the physical feelings they produced.

When defining what quality of life meant to them, participants often referenced previous experiences they had with disruptions to their quality of life because of treatments or cancer. Participants’ ideas of what a good quality of life was sometimes changed based on these experiences.

Well, I have to give it to you in uh the state I’m in now and the things they want me to do. If I have chemotherapy, I would be vomiting, I would be more helpless, I would be, um, oh several things. I’ll be a bigger burden on my daughter, for one. I won’t be able to be who I am around anyone who comes to visit because, you know, the immune problem. Not having one and uh or because I’m not feeling up to dealing with anyone. So, to me that’s a poor quality of life. Since basically I’m riddled with cancer, um, so I think instead of going for a few weeks quantity or a month’s quantity, I’d rather have the quality with, with them and uh being able to have some of my faculties about me to – to work on my computer, to play my keyboards, or whatever it takes, you know, to maintain some kind of normalcy from who I was ‘cause chemo would put me to who I am not and to me, just being able to enjoy the people around me is a big factor in my life. Basing it on how sick they say I am, I would say, you know, if I get up and have a good day and I’m able to walk there, uh to say hello or whatever, or just be up in here reading, working on the computer, whatever, to me that’s quality for me now. But that does not compare to what my standards of quality were (Teresa, 66, breast cancer).

Participants continually assessed their functional abilities and determined what would make a good day or a good life in spite of the limitations they experienced. Their sense of what a good quality of life was, therefore, was dependent on the changes they experienced in their bodies as a result of cancer or treatments, providing support for the feedback loop in the model.
Like reactions to the challenges to dignity that the patients’ experienced, reactions to the threats to quality of life were varied. Coping mechanisms and resistance strategies that patients engaged in as a result of this threat to quality of life are described in later sections.

*Challenges to Pre-Illness Identity*

How exactly do interactions with others, physical changes, and awareness of death impact a patient’s pre-illness identity? Often they cause an incongruity between the pre-illness identity and their current state.

Looking at physical changes we can see how changes in functioning impact one’s previously held view of the self. Alice (75, breast cancer) made this clear when she said,

\[ A: \] Can’t do no cooking, can’t do no washing, can’t do nothing but sit down and lay down.
\[ K: \] Okay. So it sounds like its getting in the way of some of the things you want to do.
\[ A: \] Unnhuh. I’m used to doing things.

These women described a shift in their identity based on their physical limitations. Alice is simply pointing out the incongruence between her pre-illness identity and her current state.

Participants in the study often discussed changes in their roles as their illness progressed. Oftentimes they spoke about their role as a caregiver. Wendy (60, uterine cancer) for instance, talked about not being able to care for her husband and her house the way she used to before she was diagnosed.

\[ K: \] And that sounds like a big difference from what you’re used to.
\[ W: \] Yea, I’m used to doing everything, and stuff and he’s doing most of it so. He’s been folding up clothes while we’ve been in here talking and doing some laundry and already did one load this morning and got um put up and folding up some more then, so primarily he does most of the stuff like that and uh and things and I said I’m us-usually the one that does ever-use to do everything for every else and uh it’s hard to be on the receiving end of it people doing for me and stuff. A lot of
people would enjoy it, but I’m just used to doing for everybody else and enjoy doing for oth-you know other people.

Wendy took pride in her identity as a caregiver but was finding it hard to adjust to being the one cared for. Most participants discussed this during their interview. Sometimes the difficulty stemmed from losing one’s independence and the effect this had on the self but others were concerned about their loved ones and the strain that being dependent placed on the relationship.

Some of those who were married discussed particular difficulties with this relationship.

W: My the marital relationship part of being married, the sexual part of that, there’s not anything of that a long, long time ‘cause I haven’t been able to do, do that with all this other and stuff and that’s been a long time, that’s been a big change, uh I know and uh but that uh had already changed some from the back and uh neck and uh the other stuff too but that has you know changed and, and stuff, but...

K: Does that bother you?

W: I can’t help it. It does ‘cause I don’t feel like I’m being the wife that I should be, yet I know I’m not able to do it and he said it doesn’t bother him.

Her ideas of what it means to be a “good wife” included a healthy, fully functioning body.

Without this type of body, she could not function in this role. Thus, social relationships and changes in the body together can produce a challenge to one’s pre-illness identity.

A few participants had to retire or quit jobs as a result of their cancer.

But round two the radiology, I said can I go back to work and he said I think this cancers going to keep you too busy to do that, so I closed up my office and that was the end of the counseling (Mary, 60, breast cancer).

It was difficult for Mary to leave a job that she enjoyed, but it was harder for her to give up her position as a deacon. She had been ordained just before she had been diagnosed with cancer.

Another thing that I gave up was I was an ordained deacon in the Episcopal Church. And, was loving it, um but you know so unsteady that I, I couldn’t pour
the wine at the altar without...I didn’t even want to try ‘cause I knew I couldn’t get it in the right place. So I...became a, what I call a deacon in the pew.

These women were experiencing a dramatic change in their previously held self-concepts. The identity that they had spent decades formulating was now in flux and seemingly more and more out of their control. In reaction to these changes, some of the women identified the cancer as “other.” Joann (62, breast cancer) expressed her desire for distance from cancer in a colorful way. “It’s one thing if you’ve got a splinter but you know you have breast cancer and it’s like you’re carrying this alien that you want no part of.” For Mary (60, breast cancer) this resistance to identifying as sick influenced her behaviors. “Uh, I just didn’t wanna be a patient, I’m not a sickly person and so I just kept going.” The literature on identity in cancer patients is consistent with the notion that patients do not want to identify as or with their illness. For instance, a patient in a study (Mathieson & Stam, 1995) similar to the current project stated:

I've never lost my hair but there was a time I thought, 'Forget it, . . .I'd rather die than just kind of go out with such a visible thing.' . . .The hair thing . . . would have marked me as a cancer patient, and there would have been pity, sympathy, and all those emotions that are hard to deal with in people (p. 195).

A similar comment was made by a participant in this study.

In my situation if I didn’t have faith I wouldn’t be who I am – cancer is happening to me but it’s not going to define who I am or who I was. So, I’m going to be me whether, you know (Teresa, 66, breast cancer).

It is clear from these statements that women’s previous sense of self is threatened by both changes in the physical self and others’ reading of the altered body, again providing evidence that the physical self always exists within a social context.
Although many of the challenges the women talked about surrounded the theme of loss some women described more stability in their identity.

*K:* Um, let’s see. *When you think of the person that you are right now – what qualities stand out to you?*

*H:* Well, like I said, I can’t tell there’s a lot of change in myself. There’s a lot of change in my body but, uh, I still think the way I always have, you know. And um, I’m pretty independent (Helen, 78, colon cancer).

Helen’s quote is a good example of how some women came to retain their pre-illness identity, at least to a certain extent. Helen divided her body from her self and assessed them separately. Her body had changed but the self had not. This may have been easier for Helen than some of the other participants because she had very few physical limitations. She was living alone, was fairly mobile, and only needed assistance with driving. Participants who reported the most changes in their pre-illness identity were those who had more physical limitations, including those who were bedbound and had mobility issues.

Approaching death is the ultimate threat to identity – the complete loss of self as has been previously experienced. Participants did not spend a lot of time in the interviews discussing death but some participants made it clear that death was the ultimate loss. Mary (60, breast cancer) was a previous hospice volunteer. A saying that she learned during one of her trainings stuck with her and had particular meaning for her during her cancer experience.

*And, in the training, it said someone who’s dying gives up everything... and I don’t know why that stuck with me, but it did and it’s true. I mean to die everything goes...*

This knowledge of death disrupts the feelings of stability, particularly in identity. Patients dealt with these disruptions in identity, dignity, and quality of life in a variety of ways (see Figure 3
for a pictorial representation of these pathways) in an effort to provide more stability and control in their lives, a topic to which we now turn.

Coping Mechanisms

The literature on coping describes and defines coping in a variety of different ways. Sometimes coping is classified as “emotion-focused” versus “problem-focused” (Folkman & Lazarus, 1980), “monitoring” versus “blunting” (Miller, 1995), or in a more complicated fashion such as “confrontive,” “distancing,” “self-controlling,” “seeking social support,” “accepting responsibility,” “escape-avoidance,” “planful problem-solving,” or “positive appraisal” (Folkman & Lazarus, 1988). The coping literature suffers from a proliferation of types of coping and instruments to assess these constructs which often are psychometrically unsound (Parker & Endler, 1992). Because there is no clear consensus on the types of coping, in this study general questions regarding coping style were asked to participants during follow-up questioning (e.g., How did you cope when you received your diagnosis?) and a general definition of coping was used. Coping was defined as “efforts, both action-oriented and intrapsychic, to manage (that is, master, tolerate, reduce, minimize) environmental and internal demands” (Cohen & Lazarus, 1979, p. 219).

Participants in this study used a variety of coping mechanisms in response to the changes they were experiencing in their lives. Some strategies shared similar themes and are therefore organized in such a fashion below. Coping styles reported by participants did not always neatly fit into only one category and all participants used multiple types of coping. While there is not
enough space to discuss every type of coping response, the most common strategies are listed below.

Avoidance and Acceptance

Avoidance and acceptance were reported by all of the participants in the study. Avoidance was sometimes reported as a reaction and other times as a coping strategy. Reactions appeared to be relatively automatic and occurred typically immediately after a stressful event, such as receipt of cancer diagnosis or receipt of bad testing results.

And so they referred me to a pulmonary specialist and I was still really hurting then and then they said, well, I went back to the regular, you know, chemo doctor at University and they said, “It would appear that you have lung cancer.” Well, (laughs), you know how when you go to a play they have those big velvet curtains. Well, this is what, I sat there and I listened to him and everything, you know, fine. I wasn’t upset – nothing. All of a sudden he said, “Well, we think you might have lung cancer.” Boop! The curtains closed and I said, “Okay, I think I’m going home now.” Paid my 75 buck deductible and started home. And it really didn’t even hit me until I hit [a road by my house] (Geri, 60, lung cancer).

Avoidance as a coping strategy tended to be more deliberate and in the service of increasing well-being.

K: So, take me through what you were thinking and how you were feeling during all of this.
G: I, uh, I guess I kind of pushed it to the back. There were things that were more important... Um, they never said this, because they don’t like to say anything, but I assumed that uh, and I never really asked them, because I didn’t really want to know, that it was pretty progressive, the cancer. The surgery, the amount of surgery they took, because I had very little muscle or fatty tissue under my arms or any place like that, all the way across. And, uh, one side is a little more than the other, but uh, I figured that, I never asked. I figured what I didn’t know won’t hurt me, and if I really needed to know they would tell me. Maybe I’m hiding, I don’t know (Gloria, 67, breast cancer).
H: I don’t think about that a whole lot – I don’t dwell on it. (Helen, 78, colon cancer)

Although conceptually it may be problematic to classify both avoidance and acceptance under one category, it was often difficult to distinguish between the two. Sometimes participants described using avoidant strategies but labeled this as acceptance and other times it appeared that they were using a strategy that included elements of both acceptance and avoidance.

G: How do I accept it? By ignoring it. Well...accepting it is like, like I said before, not thinking about it. (Geri, 60, lung cancer).

K: And when people told you...you looked like a skeleton, how’d that affect you?
B: I just brushed it off. There was nothing I could do about it. So, why worry about it? I don’t worry about things I cannot change (Betty, 62, lung cancer).

Acceptance of one’s fate was expressed by all participants. Some participants seemed to be handling their situation better than others, but all stated that they had accepted that they were going to die from cancer. When discussing acceptance, participants often referenced how good their previous life had been, that they had been able to accomplish many of the tasks they had wanted to in their lives, and that they were now focused on living in the present tense.

I’m living everyday just like I was before it happened and uh, accepting whatever comes (Rachel, 73, lymphoma).

Humor

Many participants used humor in their interactions with others as a coping mechanism. In some situations the coping mechanism was used to increase well-being for the participant.

K: How did the loss of your hair affect you?
J: Well, I knew it was coming. They said it could happen. And I’m thinking, well you know, if it happens, I was never really that happy with the hair I had anyways, so. Like the doctor told me when we went, he says, ‘You know, you’re
going to lose your hair’ and I looked at him. I said, ‘Did you see how I burned this hair up, do you really think I’m gonna miss it? I’d like some new’. So he laughed (Joann, 62, breast cancer).

In this instance, Joann was using humor to cope with information she received about the likely possibility that she was going to lose her hair. By making fun of her hair she was able to minimize the possible negative impact the loss may have for her. Through humor she was able to detach from her appearance and discuss a possible positive consequence of the chemo – new hair.

Joann and other participants sometimes used self-disparaging humor in certain instances, particularly when interacting with non-cancer patients.

I learned you there’s just things that, like I can’t walk distances, and I think I have what I call chemobrain because I’ll like ‘huh, now what was I going to say?, where did I put that?’ [laughing] you know! That’s what I call, I tell the kids, my grandchildren, I said, ‘I think I’ve got chemobrain,’ and they say, they’re okay with that, ‘Nanny’s got chemobrain, she can’t remember.’

Yvonne had a double mastectomy and this was sometimes used as material for self-disparaging humor when she would interact with her children.

I mean, I think about my kids, you know. What will happen to them? But they see how I am about everything and I would take off my (starts lifting up shirt) and I would say, ‘Look, which is my back.’ It’s a joke. I make a joke because this is what I have to live with. I have to look at myself everyday (Yvonne, 60, breast cancer).

Disparaging humor is defined as statements intended to “elicit amusement through the denigration, derogation, or belittlement of a given target” (Ferguson & Ford, 2008, p. 283). Situated within social identity theory, disparaging humor can be seen as a tool to increase positive distinctiveness through social comparisons. Patients are often fighting or struggling
with their newly acquired membership into the group “cancer patient.” This label is often unwanted and is a serious threat to their pre-illness identity. Self-disparaging humor can help to restore positive distinctiveness from this outgroup. It is no coincidence that participants in the current study used this type of humor when interacting with individuals who were in the ingroup (“non-cancer patients”). The examples above show how some individuals use self-disparaging humor to positively separate themselves from the outgroup by making light of a situation that is oftentimes threatening to healthy individuals.

**Focus on Others**

Most participants expressed their concern for others during our interviews and they often described being more concerned for others than for themselves, possibly in an effort to take their mind off of their current situation.

*I wish she would accept it and but uh she’s beginning to a little more I think but uh I wish they all would so they all would help each other. I worry more about them than I do myself and what’s gonna happen to them and uh myself, you know and when I’m gone what’s gonna take place with them and of course I know God’s gonna be there to look after them too but…* (Wendy, 60, ovarian cancer).

Several participants engaged in behaviors directed towards helping others, again in an effort to focus on something outside of their illness experience.

*I found myself you know wanting to try and help other people. It helps to take things, take my mind off of me because I, I don’t really feel like I’m dying, I feel like I’m living.* (Rachel, 73, lymphoma).

For Rachel, helping others did not only help to distract her from her personal situation, it also helped her to feel like she was still alive, contributing to the world around her.
Interestingly, literature is beginning to emerge which supports the notion of generativity (a term coined by Erikson which describes the developmental desire for adults to transmit knowledge and meaning aimed at guiding the next generation) as an important element of dignity in terminally ill individuals (McClement et al., 2007). In fact, one component of Dignity Therapy, a therapy aimed at enhancing perceived dignity in individuals with terminal illness, is a generativity document. The generativity document is a transcribed interview with the patient that discusses what the individual wants their family to know, lessons they would like to pass on to their loved ones, and advice on the future, among other things. The data on this process are promising with 78% of individuals claiming that this type of document and therapy helps them reach a sense of heightened dignity.

In the Legacy Project, a study aimed at assessing the psychological and emotional outcomes of producing a tangible legacy memento for chronically ill older adults and their caregivers, researchers found that the Legacy intervention (3 sessions) was successful in reducing stress in the caregiver and reducing breathing difficulties and increasing religious meaning for care recipients (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008). Participants were particularly happy that their loved ones would be able to access the information in the Legacy memento after they had died. One participant who had chosen to record audio tapes stated, “The tapes can be saved and we’ve thought of that before because of the kids . . . The older they get the more nostalgic they get, and things like this will be priceless to them later on down the line” (Allen, 2009, p. 170).


Likening Cancer to Aging

Each participant was asked about the changes they had experienced because of their illness and treatment as well as how they were reacting to these changes. Interestingly, a subset of participants described changes in their personality, physical abilities, and social interactions as having been caused by cancer but later in these interviews they attributed the changes they were experiencing to the general aging process.

*I knew I was going to get old anyways (laughs) so, um I don’t think it’s really affected me in any way because I believe that if we grow old with grace we don’t look as old* (Betty, 62, lung cancer).

*I changed a lot because as I get older and things happen to me, I put certain things in perspective and I said, ‘You know as you get older, you must change and be a little humble’. Because I wasn’t* (Yvonne, 60, breast cancer).

It may be that participants associate illness with aging but it is also possible that attributing cancer-related changes to the general aging process is easier to handle because these changes were expected and are less threatening.

Social Comparisons

Downward social comparisons are often used to help bolster well-being by comparing the self with others who are less fortunate (Wills, 1981). This strategy is often used to achieve a favorable self-evaluation or a reformulation of identity into one that is more positive (Wood, Taylor, & Lochtman, 1985). According to the literature, downward comparisons are often enacted when there has been a significant threat to one’s sense of self (Wilson & Benner, 1971).

Participants in this study often made downward social comparisons with others in a variety of domains. One of the domains evaluated was response to cancer treatment.
If I can stay at home and uh, I know I got sick, but I didn’t get sick like some of them did. I was very lucky...Like I said, there’s always somebody out there worse than you. That’s one reason I don’t want to dwell on myself (Gloria, 67, breast cancer).

Participants often saw themselves as less sick or experiencing a lesser degree of problematic symptoms (e.g., hair loss, weight loss). Participants also saw themselves as having a better experience overall than others they had known with cancer.

G: Yes, I did see her several times but she really wasn’t, she wasn’t nearly as mobile as I am and I’ve had it longer so I feel very, very fortunate.
K: I was going to ask you how do you think your experience compares to hers.
G: Well, mine is much easier. You know, mine was really a whole lot easier (Geri, 60, lung cancer).

Participants even compared the level of instrumental and emotional support they were receiving during their illness, seeing others as receiving less of this support than they were. Teresa (66, breast cancer) described her experience of going to the hospital for treatment and seeing others whom she assumed were alone.

And, the most unfortunate thing (daughter) and I noticed um you know when we go sit over there waiting for appointments you see these people come in there they have nobody. No one driving them, uh well maybe a bus service or uh, but they are there and they are sick as a dog. One lady was sitting in a wheelchair there for a long time waiting to be picked up from somebody. I guess she just had treatment or an appointment and uh these people don’t have anybody to have their back. To ask these questions, they’re in a blur. So, we’re kind of a tag team and uh I think more people need advocates like that because I think they’re maybe pushing a treatment they might have gone in another direction had they understood. They may have had less um mental and emotional stress had someone explained exactly what this was.

As the quotes above show, these downward comparisons are made with a variety of targets. Participants compared themselves to other cancer patients that they either knew personally or did not know and to others who did not have cancer.
Wood, Taylor, and Lochtman (1985) found similar results in a study of 78 women with breast cancer. Over 60% of the sample reported using downward comparisons when evaluating how well they were coping and over 50% of the sample engaged in downward physical comparisons. Participants reported evaluating themselves against several sources including individuals in the media and those they knew personally who had and did not have cancer.

**Focus on Things under Control**

Some participants described a shift in focus during their illness experience. This shift drew more attention to what the participant could control and prevented her from thinking or worrying about those things that were not.

_"I don’t know. I just don’t worry about things. If it’s nothing I have control over, I don’t worry about it. Now if I fall off of a ladder, that’s something I could have controlled and I will you know say to myself, ‘Well, that was really stupid of you’_ (Geri, 60, lung cancer).

This shift in focus had an influence on the reformulation of identity, sometimes causing new information to be integrated into the patient’s identity.

_"You can do something; you can do something with your mind. You can do something with what’s working. Use what’s working. ...it’s like somebody will ask me, how are you feeling? And I said, ‘Well, my mouth is still working. We’re in good shape’. The mouth is working. When the mouth stops working, you know I’m in bad shape...I just think you can’t just sit there and let one thing defeat you when you have other things that you could be using. You know, your mind or your body – that’s my philosophy_ (Teresa, 66, breast cancer).

In this example, Teresa focused her attention on what she did have control over – her thoughts and words. These became more central to her post-diagnosis identity because they were aspects that were easily under her control, unlike some of the physical tasks for which she had to depend on others. She integrated new information about her physical body as well as her mental and
verbal abilities into her identity. In Teresa’s quote we also see a firm separation between self and body, a theme that several participants reiterated and which is explored in the next section.

**Separation of Self and Body**

Participants in this study sometimes divided the self from their body when discussing how they viewed themselves. Some participants referred to their body as an object (e.g., “it”). Mary (60, breast cancer) states, “I think it’s been through a hard time and I think it needs me to appreciate how hard it worked…treat it kindly because it’s been through hell and back.” Here we see the body referred to as “it” and the self referred to as “me.”

*Right now...well...my relationship with my body...I’m not very happy with it, but I can’t do anything about it. I’m not happy with the way it looks, I’ve got the stomach here, and my back is curved, uh...the stomach’s here because the back is curved and I can’t stand up straight. I’m in pain at times. I’m lucky my pain’s not that bad, plus they give me stuff for it. That’s all just...eh...I think that’s another reason I don’t like to go out, because of the shape of my body. I don’t mind people coming by here. I don’t like to go out, but I will go out. I just have to...I’m still in the process I guess of accepting it what my body looks like. I don’t look at mirrors much* (Gloria, 67, breast cancer).

Some individuals discussed only having control over the inner self and not their body. It was their hope that they could continue to keep that aspect of the self intact despite the changes that were happening to the physical self.

*I say, ‘Don’t let it change you’ and then you beat that disease in a lot of ways. You may not have, you know, you may die from it still but you still given it a good wallop and remain true to yourself and your belief* (Betty, 62, lung cancer).

Charmaz (1995) discusses this phenomenon in her studies of individuals with chronic illness. She describes it as an attempt to “allay disquieting feelings about themselves and their bodies” (p. 663). Thus, the goal is to create an acceptable identity in an effort to enhance well-being.
Spiritual Coping

There is a large literature base on spiritual coping strategies employed during illness, including cancer (for a review see Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006). Studies break down spiritual coping strategies into various categories, including social support and meaning making (Feher & Maly, 1999).

For some participants in the study, just having a belief in God was a sense of comfort when they were diagnosed with cancer.

*It didn’t phase me at all. I was used to being sick all my life. And when I found out I just put everything in the Lord. I believe in God* (Alice, 75, breast cancer).

Many participants believed that their bout with cancer was part of God’s plan for them and even though they were initially distressed by the news, they decided to trust in God’s plan for them.

*I believe in God and I thought, I felt all along, you know, my mother said when she got sick, ‘God never gives you anything more than you can handle’. So, that’s what I believe, you know. Maybe it’s a little rougher and you don’t like it but you know, that’s what God had planned for you and that’s it* (Joann, 62, breast cancer).

Oftentimes participants explained they were unsure about what God’s plan was for them but they were confident that the cancer was part of a larger picture that God was controlling.

*Man is not in control. He can only go so far and the Lord has the last word. And uh so that’s whose hands I’m in, in His hands, whatever He sees fit for me so be it* (Rachel, 73, lymphoma).

Participants also saw God as a resource during tough times, believing that God could provide them answers. Teresa, for instance, found comfort in her relationship with God when she was searching for a treatment course.
That’s where faith comes in. You know, because you’re being led every step of the way and what to do, if you’re out here in a maze and you’re in a spin and you’re listening to this doctor, that doctor, this drug, that drug, they don’t have time to listen to what you need to be guided to (Teresa, 66, breast cancer).

Oftentimes faith in God also aided in acceptance of difficult situations.

H: I’ve accepted it.
K: You’ve accepted it?
H: Mmmmm
K: What was that like at first?
H: Well, I thought about it, and got to thinking about it. And I just thought about the different treatments, and I said, “This is in God’s hands. He’ll handle it. Don’t you worry.” That was my thing. Don’t worry about it. Because if you worry, you don’t have no faith in God. He’s the one who is in control. The doctors are not in control, I’m not in control, He’s in control. And whatever He sees fit for me, it’s going to be. I can’t tell you God’s will. I can’t change it (Helen, 78, colon cancer).

As in other studies (Feher & Maly, 1999), most participants found some meaning in their cancer experience by using a spiritual framework.

God took something negative and made something positive out of it. And that’s what I think that my life is. I try to take a negative and make something positive out of it (Betty, 62, lung cancer).

Participants’ spiritual coping behaviors ranged from praying and talking to God to helping others. For all of the participants in this study, spirituality was a central part of their identity. Most participants reported the centrality of their faith to identity before they were diagnosed. Two participants reported a return to spiritual practices that they had not engaged in for several years prior to diagnosis.

Focus on the Positive/Minimize Negative

In addition to a shift in focus related to the mind/body split, participants also reported that they tended to focus on the positive aspects of life. Sometimes this involved refraining from
discussing negative events or topics, finding positive aspects in everyday life on which to focus attention, or simply downplaying negative aspects of the cancer experience.

I thank God for the time I’ve had. Whatever time I have with my daughters come down from New Jersey and my daughter here and I have time with my grandchildren, then that’s a gift (Joann, 62, breast cancer).

Some participants went to great lengths to keep the negativity out of their lives. Two participants mentioned either minimizing interactions with those who were negative or cutting off ties with these individuals all together.

So one time about a month ago she called her and fortunately I have, uh, caller ID. So I saw her name come up on the thing and I said, ‘I’m not talking to her’. Why should I? She’s an unhappy soul, I’m a happy soul. Don’t want anybody to bring me down. So I didn’t. I just ignored the call. She never called back. So… That’s the way it is (Geri, 60, lung cancer).

The overall goal of these actions was to increase well-being for the participant.

These findings are consistent with socioemotional selectivity theory (Carstensen, Isaacowitz, & Charles, 1999) which postulates that older adults shift their focus toward goals related to deriving emotional meaning. To aid in this process, older adults tend to focus on and recall more positive than negative information (Charles, Mather, & Carstensen, 2003; Mather & Carstensen, 2003).

Camouflage

When participants began experiencing appearance or physical changes they reported attempts to present as if they were not sick. This often involved camouflaging themselves with prostheses, wigs, or make-up.
Well, I used, ah eye brow pencils and stuff to make my eyebrows and still do now, and stuff. And then I wear my wig, you know, when I went out and ah it was like my normal, same color as my hair and the way I’d usually worn it cut, you know. And it was like that, it was just a miracle, everyone just thought it was my real hair so they really didn’t pay that much attention…(Wendy, 60, ovarian cancer).

Participants engaged in these behaviors usually to protect themselves from others comments or to protect others from being uncomfortable.

J: When we went, my son-in-law took us out for Easter was it, and I had a bandana, I wore a scarf because I thought, you know these people might feel uncomfortable. It was [Name of place], it was a big place, it was really nice, and you know everybody’s dressed to the nines and I thought well I’m not going to go without something on my head…I said, ‘Well you know what I don’t have to prove to anybody, but there’s people there that might have had somebody…’. I know it’s really weird, when my mother passed away from breast cancer, she lost all her hair.

K: So, that’s what influenced you to wear something?
J: Well, that day…I thought, yea I thought, maybe you know people…it’s Easter, and you know everybody’s out to eat and they’re relaxing, sometimes people get very nervous, or they don’t feel uncomfortable. So, I thought this was not fair to them, so, I just wore a scarf on my head.
K: How do you know, ah, other people become uncomfortable, did somebody say something, or?
J: No, it’s not that, I know when I was younger…and I’d see somebody without hair, and I knew, and I’d say, ‘Ahh’. I’d feel so bad for them, you know, oh my gosh she’s got, she must have cancer, some kind of cancer, she lost her hair, she’s so young and. You know, I think it’s everybody has that tendency to say, ‘ah, that poor thing’ so I don’t want, I don’t want that (Joann, 62, breast cancer).

Although most participants used some form of camouflage, individuals who had a prolonged bout with cancer or who had cancer that came back at a later point reported transitioning to a level of comfort with their changed appearance. They were less concerned about what others would say or think and more focused on their own comfort.

And, um, at first I was concerned and I always made sure I had my wig on. But those things are so hot that the minute I’d get in the car it was like (motions like she’s taking off the wig). Okay. But, um, it’s not bad now. I have one that I like
a lot. Its kind of shoulder length...So if I want to wear it, I wear it. If I don’t, I don’t. And people look but I don’t care if they look (Geri, 60, lung cancer).

Other studies have reported similar findings. For instance, Rosman (2004) reported that participants in her sample who had multiple reoccurrences of cancer sometimes refrained from wearing wigs because they had “nothing to hide.”

Summary

Participants used a variety of coping mechanisms throughout their cancer experience to deal with changes resulting from the illness or treatments. Even though the mechanisms themselves were different, in all cases the desired outcome was a positive sense of well-being. Some mechanisms were aimed at the creation or reformulation of identity post-diagnosis, including acceptance, humor, social comparisons, focus on things under control, separation between self and body, spiritual coping, and camouflage. Each of these mechanisms either helped the individual maintain aspects of their pre-illness identity or helped them to integrate new realities into their post-diagnosis identity.

Resistance Strategies

In the Merriam-Webster Dictionary, resistance is defined as “an act or instance of resisting: opposition.” Resistance strategies are often employed when someone believes they are being treated unfairly. For participants in this study, resistance strategies were aimed at challenging commonly held notions about individuals dealing with cancer. Their discourse about their own experience included many statements like, “I’m alive!’ That’s how I deal with certain things, you know, weight doesn’t mean anything, you know. Having no hair. I’m alive and happy to be alive” (Yvonne, 60, breast cancer). These comments were often in reaction to
the messages others were communicating to the participants. Participants actively fought against the notion that they were all but dead.

Participants also described resistance to the dominant rules for displaying illness. Even though many participants initially engaged in camouflage techniques, they eventually rejected them in favor of being comfortable. Gloria, for instance eventually decided not to wear prostheses.

_The only time I wore them was when I got out because clothes look nicer on you. And now, hey, I don’t care. I got out just like this without them_ (Gloria, 67, breast cancer).

_When I found out I had it the second time I said to hell with it. I’m not going through that again. If I lose my hair I lose my hair, and I’ll just wear a hat or whatever or go out bald, um, but I’m not gonna you know try and, I’m just, I’m just not gonna try and be something I’m not. I’m bald so, um, I’m not gonna flaunt it, but I’m not gonna spend an in-inordinate amount of time worrying about it_ (Mary, 60, breast cancer).

In response to others’ negative reactions to their presentation of illness, participants often chose to disregard others’ opinions.

_I don’t care how they respond. Everybody knows in the world that when you have cancer treatment you’re going to lose your hair. One way or another – it ain’t going to be there at some point_ (Geri, 60, lung cancer).

Betty (62, lung cancer) expressed pride about all that she had been through with cancer. She had just been told that she likely had cancer in her breast in addition to her lungs and that she may have to have a mastectomy. She responded, “_These don’t make you (pointing to her breasts). Don’t risk your life. Do something about it, and be proud of it. And don’t hide it._”

Participants used resistance strategies to fight back against the stigma that they experienced as a cancer patient. Other studies (e.g., Rosman, 2004) have found similar results,
particularly when participants felt that they were being unfairly stigmatized. These strategies clearly aid in the reformulation of a post-diagnosis identity, as the focus is less on conforming to conventional ideas about what an ill individual’s identity should be composed of, and more of a focus on what the ill individual finds important and can meaningfully incorporate into their sense of self.

Post-Diagnosis Identity

For the purposes of this study post-diagnosis identity refers to any self-concept that has been reformulated after diagnosis of cancer. Participants actively integrated and shed information as their situation changed. Changes to identity occurred because of a variety of variations that were inherent to the cancer experience. Unlike stage theories, the current model (see Figure 3) does not specify that individuals with cancer go through different stages of identity reformulation. Instead this reformulation impacts and is impacted by many factors, including pre-illness identity markers such as race, gender, and sexuality. Thus, this reformulation that takes place is highly individualized. Additionally, it is difficult to make the assertion that one type of identity reformulation is “better” or “healthier” than another and stage theories often risk pathologizing individuals’ development by suggesting that there is a universal developmental experience.

In this study, interviews were conducted with individuals who were rapidly approaching death. Assessment of their post-diagnosis identity was also conducted at one period in time. It is hard to determine how their identity was different before the time of the interview. It may be because of these two factors (closeness to death and cross-sectional examination) that most of
the participants described their identity as including aspects of cancer and these aspects of identity were even a source of pride, in some cases.

I’m like, ‘Well, if it’s gonna come out, it’s gonna come out, and I can’t, I can’t crazy glue it back in’. ‘Cause I know those two ladies were I go and both of them had been going for chemo for quite a while and this one’s third round of chemo. Like she had a year and two year off, and then she had um a flair up in her lung, so now she’s going, you know for chemo for that. It started out as breast cancer, and she said they think it’s gone up to the bone in the back by her brain, so, she’s says she’s waiting to see but I asked her, I said, ‘well, why do you wear a hot hat?’...I’m comfortable in my skin, I’m not trying, I don’t have to impress anybody and it isn’t like I went out and took an electric razor and said, ‘gee I’m gonna make a statement, I’m gonna shave me head’. And I just figure this way, it’s me (Joann, 62, breast cancer).

Participants also incorporated some of their camouflaging techniques into their identity as well. Using camouflage often gave these individuals an opportunity to express different sides of their identity.

K: Yeah, so what was the reason that you wore the wigs at first?
G: Well I felt that was what I was supposed to do. You know I mean, I had heard of people having cancer and you know I knew that a lot of people went bald not every body I didn’t the first time I was on [inaudible] but I didn’t go bald at all, well I shouldn’t say that I did go a little. But at least I had hair, this time swish (sound) gone. So I thought that was what I was supposed to do, so before I ever lost a hair on my head I went down to a wig shop and bought 2 of them. And um so I change them around I think that makes it fun too. You know let people see something different in you (Geri, 60, lung cancer).

In addition to incorporating new information and experiences into their identity, all participants also managed to maintain some of the aspects of their identity that existed before
they were diagnosed with cancer. One participant, who self-identified as a fighter for her entire life, was able to maintain that fighting spirit throughout her illness.

K: Uh huh. If they told you that there was a chance that you would die on the operating table – would you still do it?
B: Yes, I would.
K: What’s the reason for that?
B: Because I tried...Because I was fighting. I died trying. I died fighting. See if you give into it, #1 it will take you faster. And #2 you can’t, uh, you don’t enjoy the beautiful days that are left to you. You can’t enjoy beautiful music or your favorite shows on TV or your favorite soap operas. ‘Cause all you do is whine and cry and sulk. If you enjoy your days, what’s left, while you can, then you’ll feel better (Betty, 62, lung cancer).

Another participant who identified as a caregiver was able to creatively maintain some of her caregiving abilities. Even though she was no longer able to clean the house or physically take care of her husband and son, she found a way to maintain her role as caregiver.

Yeah, um I’ve tried to prepare things, to get things ready to [unintelligible] when I am gone, like we already got funeral arrangements prepaid you know and taken care of and already got a tombstone for us and he wanted me to write down the obituary I wanted put in the paper and I’ve done that, that’s hard to do. It’s hard to do, but I’ve done that to help him out and I’ve got my clothes, my burial clothes out and things and ah trying to make it easier for him and [son] you know (Wendy, 60, ovarian cancer).

The reformulation of identity post-diagnosis included both aspects that were central to identity pre-illness and new characteristics that were often associated with cancer or the illness experience. In all cases, this new post-diagnosis identity took into account physical limitations.

Impacts on Quality of Life

What effect, if any, does this reformulation of identity have on quality of life? A study by Clarke and Black (2005) examined individuals’ quality of life and sense of identity after a stroke. They found that those individuals whose identities were based on physical or mental...
abilities that had been lost or affected by the stroke reported lower quality of life than those whose identities were based less on the functioning affected by the stroke. Additionally, some individuals reported that they went through an adjustment period following the stroke. During this period they sought out ways to retain activities and roles that were crucial to their identity. Even if the activities or roles that they were able to maintain were achieved in a modified form this still produced an increase in quality of life.

The results of the current study mirror those found by Clarke and Black (2005). Some participants were less affected by the physical changes they had experienced due to cancer. This was usually due to the fact that central aspects of their identity were not affected by the disease. Rachel, a 73-year-old woman with lymphoma, felt that a central aspect of her identity was helping other people, usually by listening to them.

*I guess I would like to be thought of as maybe uh somebody that’s helpful, uh concerned about issues and things and I’m a good listener about people’s problems and uh other family members and friends and loved ones. I, I uh I guess I had that role even before I got sick, as being a good listener because a lot of people came to me with a lot of different problems and we would talk about them and I hoped that when they got through talking they had a better attitude or better understanding but I still try to do that uh it’s important to me to try and be helpful to other people.*

Because she was able to continue doing this after she had been diagnosed with cancer her quality of life was less affected by the changes she experienced. She described herself as “reasonably happy.”

It was more common for participants to report more substantial affects on their identity due to the cancer experience.
Here again, loss of, sense of loss of being independent. Or, being able to make your own choices and follow through on your own. I can’t follow through on my own on anything. Just like before, I would have put those cabinets together, they’d have been up and ready, I’d have had two more going over here and um, wouldn’t have had to bother anybody. But now I have to wait, wait for the convenience of someone else, or, you know, because I have to be respectful of their time. You know, and their...so having to wait is a big thing for me, but, you know, here again you have to adjust because people’s lives have changed, too (Teresa, 66, breast cancer).

Most individuals were able to creatively find ways to maintain aspects of their identity that were important to them.

Uh well, you say uh like this week or last week no this week, we made a 15 bean soup and my daughter’s never made dry beans from scratch. Okay, so this was learning to make 15 bean soup week. (laughs). So I supervise and I say, “Well, okay, I can’t get in there and do it so she’s got to be my hands, and she’s got to be my stamina, but I can teach, you know, so, it’s good news, bad news (Teresa, 66, breast cancer).

In essence, an individual experiences a higher quality of life if she is able to engage in activities and roles that are a meaningful part of her identity. Cancer does not necessarily have to eliminate the opportunity to create a meaningful identity, as these participants have shown. Instead, creative adjustments can lead to a sense of purpose and stability in identity, which helps the individual to maintain a relatively positive quality of life.

There is a well-established literature on how certain types of coping can directly affect quality of life in cancer patients (e.g., Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Stanton et al., 2000). Thus, the proposed model depicts a mediation effect of post-diagnosis identity on the relationship between coping mechanisms and resistance strategies and quality of life.
Feedback Loop

As the quotes above demonstrate, women in the sample reconceptualized themselves throughout their illness in response to continuous changes in their environment, bodies, and relationships. Further evidence for the continuous changes they experienced in identity are provided below.

Participants often discussed how their conceptualizations of their identity changed in response to the physical changes. Teresa, for instance, described a fundamental change in herself in response to the multiple changes she experienced.

Here again, it’s the limitations thing. You’re, you’ve had to learn to live a whole different existence when you’re hit with uh physical problems and disease. The old me before any problems would have been just all over the place… I was able to multitask, you know, able to go through a lot of things but, this me – just thinking about multitasking is tiring. So definitely the me has changed (Teresa, 66, breast cancer).

This change in her identity, however, did not occur at once. Instead she had to learn to deal with each physical change as it happened. Sometimes she was able to move around better or have more energy than other times, which affected her self-perception.

In addition, several participants had cancer for an extended period of time or even had reoccurrences. These experiences were sometimes qualitatively different.

Well, it happened so quickly it was afterwards. Going through everything. And really, I gave it a lot of prayer and thought. I, um...didn’t...I think it hit me a little harder this time than it did the first time. Because, well, like I said, when it came back like this it surprised all of us, because I was past the 5 year thing. I was 8 years. But, I was a little older and I knew that, uh...it could do that, but like I said I was shocked, because I wasn’t thinking about that. Like I said, I had things planned, things we were going to do, you know...and that’s the thing that’s upset me the most (Gloria, 67, breast cancer).
K: Yea, so what was the reason that you wore the wigs at first?
G: well I felt that was what I was supposed to do. You know I mean, I had heard of people having cancer and you know I knew that a lot of people went bald not every body I didn’t the first time I was on [inaudible] but I didn’t go bald at all, well I shouldn’t say that I did go a little. But At least I had hair, this time swish (sound) gone (Geri, 60, lung cancer).

Here Geri and Gloria described differences during their experience with cancer. Gloria had cancer at two different points in her life and was finding the second experience much more difficult to adjust to while Geri had two different rounds of treatment, which affected her body and impacted her identity differently. For instance, during the first round of treatment, Geri did not have to think about her appearance in the same way that she did during her second round because she only lost her hair during the second treatment.

All participants reported a change in their cancer experience over time whether it was changes in interactions with others as the illness progressed, changes in their physical appearance or abilities, changes in their awareness of death, or changes in quality of life. These changes often caused or were caused by changes in their identity, showing the dynamic and fluid nature of the experience of self-perception.

Secondary Aim

The secondary goal of this project was to examine positive aspects of the cancer experience. Most participants offered positive outcomes on their own but all were able to name at least one positive aspect of the cancer experience when directly asked. Participants most often focused on positive changes in their relationships with others. Oftentimes this came in the form of deepening current relationships, as Helen (78, colon cancer) stated, “Of course my
family has always been a big part of my life, but, uh, I would say I’m closer to my family than I have been in the past."

Participants reported having a different outlook on life that they thought was positive. Most explained that they appreciated the experiences they were having.

You begin to appreciate life a little better, uh, and you have to take it a day at a time, like I said and you find yourself doing a lot of things different, really, uh you understand things better. Uh, and you have uh, a little more sympathy for other people and their feelings than you had before (Rachel, 73, lymphoma).

Others thought that they became better people because of their experience with cancer.

K: Good. What do you think are some positive things that have come out of this experience?
Y: I’m closer to the Lord. Oh yes, I was a hell cat! And I got pretty humble.
K: okay, what do you mean?
Y: Well, put it this way. If you look at me too hard I go off. ‘What’s your problem?!’, you know?... I’m very opinionated (Yvonne, 60, breast cancer)

Like Yvonne, some participants felt that they had changed their personalities for the better. Additionally, some felt that they had become nicer to others, particularly if they had physical problems.

G: Like I said before I’m a better person. When you’re feeling good and everything...you, uh...tend to be a little more selfish. I don’t know. I hope ...I’m a more caring person than I was.
K: Caring about other people?
G: Yeah. What they think, how they feel...I try to be. I’d rather think about them than me. Like I said, there’s always somebody out there worse than you. That’s one reason I don’t want to dwell on myself. I’d rather be caring about somebody else, find out...I always ask people about their families and whatever when they come, try to get to know the different people, the caregivers. And they’re not supposed to talk to me, either, about their private lives, but...it helps to take the patient’s mind off themselves (Gloria, 67, breast cancer).

M: Um, I have much more compassion for people in wheel chairs, in canes, on canes, and there are a lot of those people. Um, which I’d never paid that much
attention to before. Um, so much more compassionate for those who have a handicap.

K: Mmhmm yeah, anything else that you can think of?

M: (sigh) Well, um, I think I’m more trusting in God that even if this doesn’t go the way I want it to (Mary, 60, breast cancer).

Participants reported a deepening of their relationship with God, which they reported was a positive change since being diagnosed with cancer. “Well, I’ve gotten a lot closer um with a lot of my family members and stuff and with my hospice people and, and I think closer with God and, and things like that I, I think” (Wendy, 60, ovarian cancer).

Lastly, participants reported a deepening appreciation for life, likely due to the nearness of death.

I think I’m more aware of life and ah I think life has more meaning to me now than it did before. And of course, you know, my family has always been a big part of my life but, uh, I would say I’m closer to my family than I have been in the past (Helen, 78 colon cancer).

Summary

In summary, the interviews with hospice patients helped to shed light on the ways in which identity is impacted by the cancer experience, including physical changes and social interactions. These interviews also provided the framework for a model of post-diagnosis identity reformulation and how this newly developed identity can impact the individual’s quality of life. The model has a variety of clinical implications for care at the end-of-life for women with advanced cancer and provides an intersection for the literature in psychiatry, social and lifespan developmental psychology, feminist theory, nursing, and medicine dealing with identity and illness.
CHAPTER 5

DISCUSSION

Discussion of Findings

The results of this study suggest that patients with cancer are engaged in a reoccurring
process of negotiating and reformulating a personal identity that takes into account the ever-
changing situations they experience as a result of cancer. The model that emerged from the data
(see Figure 4) shows how identity is connected with quality of life, a construct often studied in
end-of-life research. The impetuses for a shift in identity are the body in flux, changes in
interpersonal interactions and relationships, and an awareness of approaching death. This
discussion section will explicate the study findings, how they relate back to the research
question, and will provide theoretical insight into changing identity from other bodies of
literature.

The question guiding this study was: “What is the nature of self-perception in terminally
ill older women with cancer?” This question was approached by seeking out older hospice
patients with cancer for insight into this phenomenon. The participants provided candid
descriptions of their struggles with the physical changes they experienced from their illness and
treatments, ranging from fatigue to loss of mobility to appearance changes. These physical
changes were difficult for the participants to handle because of the devaluation of ill and dying
persons in our society. Others would provide reminders of this devaluation by making remarks
about the individual’s changing appearance or functioning, would stare, or even tell the patient
that they were uncomfortable with her appearance. These comments were often experienced as hurtful and insensitive.

![Figure 4. Model of Post-Diagnosis Identity Development](image)

The devaluation of the sick body did not only appear from others. These negative views of the sick and dying were internalized by the participants who described themselves as “ugly” and “unattractive,” particularly when appearance changes occurred. This internalized view was most often described in reference to lack of hair, which some participants experienced as a result of the chemotherapy. During the initial phases of active treatment, the participants engaged in regulatory practices to “fix” the problem of presenting as ill by camouflaging themselves. These practices included use of prostheses, wigs, make-up, and even movement restriction. Movement restriction was used when participants were feeling particularly ill and did not want to show themselves to the public in this way.
We can understand the problems a sick body poses to society if we examine feminist theory. In recent years there has been a postmodern push within feminism to examine the body, the materiality of existence and the site at which power is expressed. Many of the feminist theories of the body have in some way incorporated Foucauldian notions about the body and power. In Bordo’s (1993) examination of Foucault, she highlights his use of modern power which is “non-authoritarian, non-conspiratorial, and indeed non-orchestrated; yet none the less [it] produces and normalizes bodies to serve prevailing relations of dominance and subordination” (p. 252). Thus, power is not something an individual or group can possess. This power is not random but is derived from different origins that ultimately lead to the construction of the body. Socially “appropriate” representations of the self, according to this analysis, are achieved through self-surveillance and self-correction in an attempt to bring the self closer to the “norm.” Thus, subjects are constantly monitoring themselves in an effort to present themselves as “normal.”

At least initially after diagnosis and in the early stages of illness, participants were clearly monitoring themselves, presenting themselves to the public as close to “normal” (in this case non-sick) as possible. For example, Joann did not like to wear anything on her head because of how hot it made her but she conceded and did so in certain public places. 

*But if I have to, then I’ll wear, you know I’ll wear something bandana on my head… When we went, my son-in-law took us out for Easter was it, and I had a bandana, I wore a scarf because I thought, ‘you know these people might feel uncomfortable’* (Joann, 62, breast cancer).
When signs of the illness could not be hidden in any interactions, participants often chose to whom they showed the signs of illness. Yvonne lost teeth because of the treatments she was receiving and modified her behavior accordingly.

*Y:* Yeah! I mean, I was eating, and they were breaking. What didn’t break, they were shaking, so I had to go to the dentist and get most of them pulled out, and this one now is...although it’s fixed, it’s like leaning inside the other one so I feel I’m going to have to do something. That’s why I didn’t go for my partial, I wanted to finish chemo first before, so I’m waiting to see, when everything come out of my system, if I need to pull the rest and get a full plate on top. I tend not to smile as much as I used to because of the missing teeth.

*K:* Are you self-conscious about that?

*Y:* Sometimes. Depends on what company I’m in (Yvonne, 60, breast cancer).

Foucault focused on the regulation of the body which is trained and shaped by “prevailing forms of selfhood, desire, masculinity, and femininity” (Bordo, 1993, p. 14). Bordo argues that female bodies have become what Foucault termed “docile bodies,” which are bodies whose energies are expended on transformation and improvement and who are particularly vulnerable to external regulation. She explains that female bodies are normalized through the practices of diet, exercising, make-up, and feminine dress. Ultimately, women’s energies are more focused on self-modification with the inherent understanding that women’s bodies are not good enough and need constant improvement.

I would argue that this same principle can be applied to the sick or dying body. The dominant model of selfhood is one of self-sufficiency, independence, and invulnerability. Sick bodies challenge this assumption and are subject to external regulation much the same way female bodies are. Sick bodies are normalized through the process of camouflage or movement restriction. Sick bodies are often engaged in behaviors that mask or hide the illness from the
public’s eye, often for fear of being reduced to the illness. Although this study only examined women’s experiences, it is also possible that male bodies that are sick or dying are treated in a similar fashion. However, the data in the study cannot speak to this hypothesis and it is a question for future research to answer.

We can gain insight into the disruption that the sick body embodies if we look at the theoretical work on pregnant bodies in public space (Longhurst, 2001). The pregnant body is inherently problematic because it “transgresses the boundary between inside and outside” (p. 81). Longhurst interviewed several pregnant women who explained that they increasingly withdrew from public spaces the more evident their pregnancy became. Longhurst argues that they restricted their movement because of possible seepage and dominant negative discourses about pregnant women’s bodies.

According to Longhurst (2001), one of the reasons pregnant bodies are threatening is that there is always a possibility that they may leak. Bodily fluids can be understood as disruptive if we examine Grosz’s (1994) analysis on all bodily fluids.

Body fluids attest to the permeability of the body, its necessary dependence on an outside, its liability to collapse into the outside (this is what death implies), to the perilous divisions between the body’s inside and outside…They attest to a certain irreducible ‘dirt’ or disgust, a horror of the unknown or the unspecifiable that permeates, lurks, lingers, and at times leaks out of the body, a testimony of the fraudulence or impossibility of the ‘clean’ and ‘proper’. They resist the determination that marks solids, for they are without any shape or form of their own. They are engulfing, difficult to be rid of; any separation from them is not a matter of certainty, as it may be in the case of solids. Bodily fluids flow, they seep, they infiltrate; their control is a matter of vigilance, never guaranteed (p. 193-194).
In Longhurst’s interviews, participants reported altering their daily schedules around avoiding displays of ‘leaking.’ Vomiting, lactating, and water breaking were some events that the women particularly feared. They would often describe these events as “revolting.” This description is not surprising given the dominant discourse on pregnant embodiment. A study on public attitudes towards breast feeding indicated that a significant number of individuals find breastfeeding in public places “shameful” (Scott, Binns, & Arnold, 1997).

Grosz’s (1994) examination of bodily fluids is also relevant to the sick body. Participants in this study, for instance, often had trouble with continence and vomiting. Like the pregnant women, these participants kept themselves out of the public eye when they were having problems with leakage and were engaged in self-monitoring when they were out in the public eye. For example, Joann (62, breast cancer) refrained from being close to her granddaughter because the chemo leaked from her skin.

…but the kids, they’re funny, my granddaughter, one granddaughter…my youngest down here, she was out of the house and she’ll say ‘air hug!’ cause I can’t hug her… I’m always afraid whatever I have in my system, you know. ‘Cause nobody can use the bathroom for two days after I have my chemo. Yeah, it comes out, in, all over the place. It comes out in my, my skin smells like chemo too. I, you know, like something, like an old rag that’s burning…yup, that’s it!

In a similar study on cancer patients, Waskul and van der Riet (2002) state:

…one patient sobbed, quite understandable, when telling about an incident in which she accidentally defecated in her bed while a work colleague was visiting her. As almost anyone can understand, an inability to control basic human functions, especially “creature releases”…such as urination and defecation, seriously threaten a patient’s dignity and violate one of the most basic foundations of adult personhood. When a patient loses control over these basic body functions the assault on selfhood is catastrophic (p. 499).
Bordo (1993) points out that Foucault’s ideas of power include room for resistance to this power (at least in his later work). Bordo gives the example of a woman who, in an attempt to lose weight, engages in an exercise regimen which results in more muscle mass. The woman realizes that she now has more physical strength and begins to use this strength at work. Although she initially engaged in a specific behavior in an effort to fit into a “normal” bodily presentation of a woman, one of the unintended results was that she became physically empowered – an attribute not usually associated with femininity.

Many participants in the study were actively engaged in forms of resistance to the ideas of a “normal” body. Particularly when patients had multiple bouts of cancer they were less concerned about their appearance and would venture out into public spaces with no hair, no make-up, or with medical devices that would mark them as ill (e.g., oxygen tanks, walkers, wheelchairs). They would also resist being labeled simply by their illness. The participants often stated, “I am still alive” and many of their behaviors, thoughts, and emotions were present and future-focused. They reminded others who sometimes acted as if they were already dead that they were alive and were actively making plans for the future, however long that might be. Individuals who did not treat the patient as she wanted to be treated were cut out of the patient’s life when possible. Doctors were fired or loved ones were asked, usually in gentle ways, to reframe the way they were thinking about the patient. In this sense, the participants in the study were challenging the dominant concept of what a sick or dying individual looks like by becoming empowered, active, as independent as possible, and verbal about their wishes and needs. Socioemotional selectivity theory supports the idea that individuals will limit their social
interactions to those that support emotion regulation when time left to live is perceived as limited (Lang & Carstensen, 2002).

Participants experienced various challenges throughout the course of their illness, regardless of the length of it. Many participants felt that their previous quality of life, sense of dignity, and their self-concept were threatened. The new changes they experienced because of physical alterations, changing relationships and interactions, and awareness of impending death combined to disrupt concepts and experiences that had been relatively stable pre-diagnosis. Ideas about quality of life and dignity tended to change as physical functioning shifted. A quality of life that was once unacceptable became acceptable and bearable because the participant’s frame of reference had changed. They were able to find meaning in their lives, even when their physical capacity decreased.

Threats to pre-illness identity were particularly difficult for participants to cope with during the course of their illness. Their physical limitations often made it difficult to maintain their previous role as mother or wife and often challenged characteristics that had previously been fundamental to their identity, such as being independent and active. Participants dealt with all of the encroaching changes in a variety of ways that suited their individual needs, identities, and situations. Many of these coping strategies were aimed at the creation of a sense of stability through identity reformulation.

One of the more interesting coping strategies that participants employed was separating the body from the mind or the self. This strategy was often employed during the initial phases of the illness, possibly because the idea of incorporating the diseased body into one’s identity
was too threatening. Individuals who engaged in this coping strategy found it difficult to keep a clear separation between the body and the self because changes in physical status continued to occur throughout their illness, providing reminders that they were not separate from their bodies. Social interactions provided yet another reminder of this, as others would comment on the participants’ appearance or diminishing physical functioning. Thus, the strategy was a futile attempt at separation between the body and self.

The Möbius strip model of corporeality, proposed by feminist scholar Elizabeth Grosz, helps us to understand why the separation between the mind and the body can never be truly realized for these patients. She states,

The Möbius strip has the advantage of showing the inflection of mind into body and body into mind, the ways in which, through a kind of twisting, or inversion, one side becomes another. This model also provides a way of problematizing and rethinking the relations between the inside and the outside of the subject, its psychical interior and its corporeal exterior, by showing not their fundamental identity or reducibility but the torsion of the one into the other, the passage, vector, or uncontrolled drift of the inside into the outside and the outside into the inside (p. xii).

If we conceptualize an individual as holistic, including both, but neither the mind nor the body, then we can conceptualize the physical changes that terminally ill patients experience as fundamental changes in the person. These physical changes are inseparable from the mind and thus create a substantial change in the person – in their identity and stability.

Indeed, we see that at times participants were connecting to their illness, configuring it as part of their identity, incorporating their body regardless of its condition into their identity. Arthur Frank (1991), a sociology professor, documented his own struggle with serious illness and eventually came to an understanding that the self and the body were the same.
I am a bodily process, but I am also a consciousness, with a will and a history and a capacity to focus my thoughts and energies. The bodily process and the consciousness do not oppose each other; what illness teaches is their unity (p. 87).

Although coping mechanisms were often aimed at increasing or maintaining quality of life for the participants, sometimes the coping was directed towards development of a post-diagnosis identity. Such a reformulation allowed participants to construct a sense of self that took into account changes occurring in their lives because of cancer. The post-diagnosis identity included concepts that were previously central to the individual’s identity, although these concepts often had to be modified based on the participant’s abilities. Establishing stability and continuity in one’s sense of self (from pre-illness to post-diagnosis) aided in increasing or maintaining an acceptable quality of life.

The post-diagnosis identity was constantly in flux for the participants because so much of their day to day lives were also shifting due to illness, treatments, social factors, and environmental factors. Although one’s identity often changes throughout the lifespan, these changes usually do not include the progressive loss of functioning that accompanies the dying process. It is within this unique situation that we can see the factors that contribute to disruption of one’s previous identity, the coping strategies used to deal with such a challenge, and the resulting reformulation of identity despite significant physical changes.

Situating Results within Existing Literature

What is unique about this project is that the data support findings from a variety of fields including social and lifespan developmental psychology, psychiatry, death and dying, feminist theory, philosophy, nursing and medicine. The model developed from the data piece together
the findings from these fields to create an inclusive and holistic picture of what the experience of advanced cancer is like for older women receiving hospice care. End-of-life work is necessarily interdisciplinary and the model developed in this study provides support for such a notion. In the next sections, the ways in which the current project confirms and/or differs from some of the findings in the literature are explored.

Social Psychological Literature

The social psychological literature on the self has drawn attention to ways in which self-concepts and identity are influenced by social factors. The theories of symbolic interactionism, social identity theory, and stigma theory are some examples. The data from the current project support several of the theoretical positions in these theories. First, the data provide support for the idea that one’s sense of self is dependent on social interactions with others and thus is always in flux. In the study, participants reported changes in their identity as a result of others’ verbal and nonverbal communication with them. Sometimes the social interactions were positive and provided a buffer against distress because of physical changes. Other times these interactions contributed to a sense of identity loss.

Second, the findings provided partial support for Charmaz’s (1995) theory on adaptation to chronic illness (see literature review for a discussion of this theory). Consistent with this theory, participants in the current study experienced a disruption of the unity between the self and the body and a sense of lack of control over the body. Participants reacted in similar ways to those in Charmaz’s study – by attempting to separate the self from the body, hiding appearance changes, and shifting identity goals. However, the last stage in Charmaz’s theory
proposes that individuals “surrender” to the sick body and to do so they must relinquish control over their body, stop fighting their illness, and acknowledge that the self and the body are inseparable. Although some participants did accept their physical limitations they did not necessarily “surrender” (i.e., meet the three conditions Charmaz lists for surrender to occur). In fact, many of the participants were much more active in their reconceptualization and coping strategies than the term surrender implies. They were constantly taking in new information about their body and their environment and actively making cognitive adjustments to their self-concept. They often shifted from viewing the body and self as separate and viewing them as unified, yet at the same time they had accepted that they were terminally ill and that this had become part of their everyday lived reality. The process of accepting illness and incorporating it into identity, at least in the case of terminal illness, appears to be much more fluid and active than the concept of “surrendering to the sick body” implies.

Many of the participants in the study showed an awareness of and resistance to social categorization into the group “cancer patients” consistent with social identity theory and stigma theory. The participants experienced stigma in social interactions and at least initially tried to distinguish themselves positively from this outgroup by presenting as non-sick or using tools such as humor to set themselves apart from the commonly held notion of the cancer patient (i.e., someone who is depressed, passive, dying).

*Lifespan Developmental Literature*

The data in this study are also relevant to the developmental literature. There is a general view outside of gerontology that growth and development of personality or identity ceases or
significantly slows in old age. The data in this project provide evidence that identity continues to develop until the point of death. Additionally, much of the data is consistent with socioemotional selectivity theory (Carstensen, Isaacowitz, & Charles, 1999) which states that when an individual perceives a limited amount of time left in life (either because of illness or age), their focus tends to be on deepening relationships and emotion regulation (i.e., focusing on positive aspects of life, while minimizing negative). Indeed, the participants in this study reported both a deepening of relationships and a shift to focusing on positive experiences. Individuals who perceive a limited amount of time left to live also engage in pruning of their social network so that more time can be spent focusing on deepening several relationships instead of maintaining a large number of social ties. Consistent with this idea, most participants in the current study reported a deepening of their close relationships.

Death and Dying Literature

The data from this project do not support the stage theory on death and dying (Kübler-Ross, 1969). Although many participants did report periods of denial, depression, anger, and acceptance, experiences were not clear cut and did not follow a stage-like pattern. Participants also reported engaging in other types of coping strategies and having experiences that did not fit into one of the five stages of dying (e.g., separating body from self). However, participants did report retaining hope even when the situation was bleak. Sometimes this was hope for a few more weeks or months of life or hope that the individual’s legacy would live on through their loved ones. Additionally, participants communicated that they were still alive, despite having a terminal diagnosis, a message that Kübler-Ross tried to communicate through her work.
Dorbratz’s work on self-transacting dying received partial support from the data in the current project. The data did not appear, however, to support her seven patterns of self-transacting dying because most of the participants possessed characteristics of several of the patterns. For instance, everyone in the study acknowledged the inevitability of approaching death (consistent with the becoming-self) but may have also had characteristics associated with other patterns such as the transcending, reconciling, or avoiding selves. However, the data did partially support her notion of integrating forces that affect the dying process. Individuals often had experiences related to the categories of integrating forces (e.g., interpreting meaning, bodily feelings, and adjusting expectations) that varied from positive (e.g., management of bodily feelings) to negative (e.g., agonizing bodily feelings).

Other Literature

The ways in which the current data relate to other literature, including feminist theory and philosophy, have been discussed earlier in the discussion section. Additionally, the literature on the physical experiences of cancer patients was supported by the interviews conducted for this project. Most of the patients experienced fatigue, weight loss, mobility impairment, and body image concerns. Some patients experienced alopecia and pain as well. The mental health of the participants in the study was difficult to determine because it was not formally assessed. However, it appeared that participants experienced some anxiety and depressive mood from time to time throughout the illness.
Researcher’s Social Location

All research is in part influenced by the researcher’s social location, values, and beliefs. It is important to note these factors so that the limitations and merits of the work can be assessed by outsiders.

I conducted all of the interviews myself and thus, my social location is directly pertinent to the discussion of the data. I am a young, White woman from a working-class background, who is enrolled in a public university in pursuit of a doctorate. The question relevant to this discussion is: How did these factors impact data collection? In particular, because the research relationship always includes an element of power, we should examine how these factors impacted the research relationship and thus the data.

Being a young student seemed to lessen the power differential between me (the researcher) and the participants. Most participants mentioned that they were interested in helping me achieve academic success by participating and they were often shocked to see a young person take interest in older adults or those who were dying. Being a woman, in some ways, probably also impacted the data collection. Some of the women showed me scars on their chests or cancer in their breasts, which may not have happened had I been a male student. I do believe that a male student could have gotten similar data but the amount of physical exposure may have been different. While I cannot be sure exactly how my social location affected the data collection, it is an important aspect of the research process that should be explored in each study.
Limitations

This study has several limitations that should be noted. First, the sample was relatively small and homogenous. It was difficult to recruit members of minority groups because they were enrolled in hospice to a lesser degree than Caucasian women. Thus, even though there did not appear to be ethnic or racial differences in experiences, it is difficult to assess this question without more diversity in the sample. Second, although theoretical sampling was used when possible, the sample is largely one of convenience. It is difficult to judge the limitations to the current model of post-diagnosis identity formulation because the types of patients recruited into the study could not be selectively chosen to test the applicability of the model to specific types of patients. Additionally, patients were selected by hospice staff to participate. It is unclear how they made their selection of patients. It is plausible that the happiest patients or the least negative patients were selected by the staff, which would have implications for the data collected. One way to address this in future research is to specifically ask hospice staff to recruit patients who are not having a good experience or who seem to be negative. Third, data from two participants was minimal. One participant only was able to complete a half hour of the interview due to physical and emotional concerns while the other participant, who was bedbound, was very short in her replies, leaving little material to work with. It is likely that the physical issues that they were experiencing hampered the interview, although what they reported was consistent with the model proposed in this study.
Implications

There are several important implications that arise out of this project. One of the implications relates to care provided by the medical community. Because cancer patients’ identities, sense of dignity, and quality of life are at least partially affected by their interactions with others, including healthcare staff, staff should strive to lessen the potential negative impact that their interactions can have on patients. The patients in this study were explicit about the types of behaviors that made their experiences more positive including: being spoken to like a living, capable adult; being given information about their condition and possible treatments; being treated like a human being who is more than just illness; being listened to; and receiving treatment and interactions that are consistent with the patient’s individual worldview, psychological, social, and physical needs.

This project also opens up the possibility of intervention work that could help advanced cancer patients with identity work that deals with changes based on advanced illness. A possible intervention could be one that helps the patient identify important aspects of their identity and helps them retain those roles or attributes in ways that are physically manageable for the patient. This type of intervention would help the patients find a sense of identity stability throughout the illness process, provided that intervention sessions were held throughout the progression of the illness to deal with new physical and environmental changes.

This project also calls into question the application of the “Look Good, Feel Better Program” (http://www.lookgoodfeelbetter.org/) for older women with terminal cancer. The program is a free public service aimed at “help[ing] women offset appearance-related changes
from cancer treatment.” The program provides help with make-up application and provides information on strategies to deal with hair loss and is sponsored by the American Cancer Society. The problem with this program is that it perpetuates the stigmatization of ill and dying bodies (particularly women’s bodies) by encouraging these bodies to look “normal” instead of providing options for resistance to societal norms.

Although some of the participants initially engaged in camouflaging techniques, these often caused discomfort. Many participants came to the realization that they were trying to present as something that they were not and refrained from engaging in camouflaging behaviors as their illness progressed. If incorporating advanced cancer into one’s identity helps to create a positive quality of life because it reduces tensions between a previously held self-concept and the lived reality of the cancer experience, then camouflaging techniques may hamper efforts at this integration. A more fruitful service may be to provide individuals with access to previous or current cancer patients who have experience with facing stigma because of the disease and who have successfully integrated cancer into their identities in a positive way (e.g., peer-support groups). This service would provide patients with information on what to expect from others when physical changes take place, allowing time to develop strategies to deal with unpleasant interchanges while protecting self-esteem. It would also allow patients to have a visible model of how one can incorporate cancer into one’s identity in a positive manner.

This study also has implications for recruitment of participants from hospice sites. Recruitment was easier and more efficient at the hospice with the largest census. In addition to having access to more patients, this hospice also had a research team on site. Because the team
was familiar with the research process, they were seemed more comfortable with the recruitment process. Some of the Alabama hospices that had smaller census and no research team indicated that they had reservations about letting me have access to their patients because they were concerned about their well-being. This is understandable given that this population is vulnerable. If researchers do want to access hospices with lower enrollment, one suggestion would be to volunteer with the hospice or make some other personal contribution which would allow the staff to get to know that researcher on a personal basis. In my experience, such activities make for a greater likelihood that the hospice will grant the researcher access to their patients.
CHAPTER 6
CONCLUSION

Summary

Utilizing a grounded theory approach, the experiences of older women with advanced cancer were examined to determine how their identities changed throughout their illness experience. Twelve women over the age of 60 were recruited from hospices in and around Tuscaloosa, AL and Tampa, FL. The data provided information on how patients redefine themselves after a terminal diagnosis. These data were incorporated into a model of post-diagnosis identity which details the pathways from physical and social changes and awareness of one’s impending death to the reformulated identity and the effects this has on quality of life.

Individuals in the study reported experiencing changes in their physical body and social lives as well as a new awareness of mortality. These changes threatened the patient’s previously held sense of self, their sense of dignity, and their quality of life. Patients engaged in a variety of coping mechanisms and resistance strategies in response to these threats, which ultimately led to a reformulated identity that included aspects of cancer as well as components that had been important to the patient’s previously held self-concept. Establishing a reformulated identity that included aspects of the lived reality of the cancer experience helped patients achieve a more positive quality of life.

The model developed in this project is unique in that it provides an intersection between literatures from several different fields related to end-of-life issues. It incorporates notions of social psychological and lifespan developmental theories, data from the medical literature,
feminist and philosophical theories, data on death and dying, and the literature on mental health issues in illness.

Future Directions for Research

Future research should examine the applicability of the proposed model in other populations, including men and minority patients. These data will be important to further elucidating any individual differences in the experience and further development of identity during advanced cancer. This model may also be applicable to other forms of terminal illness in addition to cancer and future studies could evaluate its validity in these populations. For example, in the case of heart disease, fatigue is often reported but there are fewer appearance changes. Future research could evaluate how well this model applies to diseases such as these where threats to identity may be less pronounced but still present. In the case of dementia, it would be difficult to gather data from patients about their perspectives on identity changes and reformulation due to the decline in cognitive functioning. However, data from caregivers may provide a way to measure the proposed model or data from those in early stages of dementia or with mild cognitive impairment might provide a glimpse into identity issues within this population.

Other future projects should focus on the development of interventions that can aid patients with identity reformulation in the face of serious illness, without perpetuating stigmatization of illness and death. These interventions hold the promise of communicating to patients that others acknowledge that they are still living, breathing human beings and that their
quality of life is important. These interventions also hold promise to begin to dismantle the stigmatization of the old, sick, or dying body.
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Table 1. Patterns of Self-Transacting Dying (Dobratz, 2002a)

<table>
<thead>
<tr>
<th>Pattern</th>
<th>Characteristics</th>
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</thead>
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<tr>
<td>Transcending-Self</td>
<td>Union with death, awareness of impending death, peaceful</td>
</tr>
<tr>
<td>Becoming-Self</td>
<td>Direct actions/cognitions towards capturing as much as possible from situation before death, acknowledge the inevitability of death (but still disconnected from it)</td>
</tr>
<tr>
<td>Reconciling-Self</td>
<td>Focus on maintenance of psychological equilibrium and reaching out to others, possibility of death not directly acknowledged, focus on finishing business, dependent on others for support</td>
</tr>
<tr>
<td>Anguishing-Self</td>
<td>Experience of physical, spiritual, social, or psychological suffering that impedes social-psychological processes, no meaning found within illness, fear of death although it may be desired</td>
</tr>
<tr>
<td>Avoiding-Self</td>
<td>Avoid self-disclosure, no acknowledgement of problems, concerns, needs</td>
</tr>
<tr>
<td>Relinquishing-Self</td>
<td>Experience of such physical limitations that reactions are impeded, possible desire for abandoning life</td>
</tr>
<tr>
<td>Repressing-Self</td>
<td>Protect inner self from dying through psychological means, unable to integrate inner and outer realities</td>
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Based on:

Table 2. Demographic Characteristics

<table>
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<th>VALUE</th>
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<td>Min = 60, Max = 78</td>
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<td>4 African American</td>
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<td>DIAGNOSIS</td>
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<td></td>
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Table 3. Demographic Variables by Site

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<td>INCOME ADEQUACY: How hard is it for you to pay for basics like food, housing, medical care, and heating?</td>
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APPENDIX: Guiding Questions for Interviews

*Question Removed in Next Question Set
†Question Added to Question Set

10/22/07 (n=3)

Interview 1

1. What was your childhood like? Your adolescence? Adulthood?*
2. Were you married? Did you have children?*
3. Did you work outside of the home? For how long? What was that experience like for you?*
4. During your adolescence and adulthood how did you view your body? What types of thoughts or feelings did you have about your body?
5. How did you perceive yourself during adolescence? Adulthood? (e.g., What type of person were you?)*
6. Did anyone influence the way you felt about yourself or your body during adolescence? Adulthood?
7. When and how were you told you had cancer? What was the prognosis?
8. What type of cancer were you diagnosed with?
9. What type of treatments, if any, did you pursue? How did those affect you?
10. What physical changes have you noticed throughout the progression of the disease? What physical changes did you notice throughout your treatments?*
11. Did your treatments require prolonged stays in the hospital? How was your stay in the hospital during these times?
12. How did doctors and medical staff interact with you?
13. How did friends and family interact with you during this period?
14. Did any of your interactions with others affect how you felt about yourself after your diagnosis?
Interview 2

1. How do you think of yourself now?*
2. Has your perception of yourself changed since you’ve been diagnosed? If yes, when did it change? How did it change?
3. What types of changes in your physical appearance have you noticed since you’ve been sick, if any?*
4. How would you describe your relationship with your body now? Has your relationship with your body changed since you’ve been diagnosed with a terminal illness?
5. What types of changes in your personality have you noticed since you’ve been sick, if any?
6. What types of changes in your interactions with others have you noticed, if any?
7. Have other people, especially loved ones, treated you differently or the same since diagnosis? How?
8. When you think of who you are as a person right now, what are some of the qualities that stand out?
9. In thinking about how you see yourself right now, are there any other questions you think I should have asked?
10. Is there anything else you’d like to add?
Interview 1
1. Where did you grow up?†
2. What was it like growing up in your family?†
3. During your adolescence and adulthood how did you view your body? What types of thoughts or feelings did you have about your body?*
4. Did anyone influence the way you felt about yourself or your body during adolescence? Adulthood?*
5. Did anyone in your family have cancer? If yes, how has your experience compared to theirs?†
6. When and how were you told you had cancer? What was the prognosis?
7. What type of cancer were you diagnosed with?
8. What type of treatments, if any, did you pursue? How did those affect you?
9. What physical changes have you noticed throughout the progression of the disease? What physical changes did you notice throughout your treatments?
10. Did your treatments require prolonged stays in the hospital? How was your stay in the hospital during these times?
11. How did doctors and medical staff interact with you?
12. How did friends and family interact with you during this period?
13. Did any of your interactions with others affect how you felt about yourself after your diagnosis?
14. What losses have you experienced, if any?*†

Interview 2
1. Has your perception of yourself changed since you’ve been diagnosed? If yes, when did it change? How did it change?*
2. How would you describe your relationship with your body now? Has your relationship with your body changed since you’ve been diagnosed with a terminal illness?*
3. What types of changes in your personality have you noticed since you’ve been sick, if any?
4. What types of changes in your interactions with others have you noticed, if any?
5. How have other people, especially loved ones, treated you differently or the same since diagnosis?*
6. When you think of who you are as a person right now, what are some of the qualities that stand out?
7. In thinking about how you see yourself right now, are there any other questions you think I should have asked?
8. Is there anything else you’d like to add?
Interview 1

1. Where did you grow up?
2. What was it like growing up in your family?
3. Would you describe yourself as a spiritual person? Describe how spirituality in your life.
   Has this helped you cope with your illness? If so, how?†
4. Did anyone in your family have cancer? If yes, how has your experience compared to theirs?
5. Do you have any other health problems besides cancer? When did those start? How have those affected your life?†
6. What does a good quality of life mean to you? A bad quality of life? How would you describe your quality of life now? How did your ideas about quality of life shape your treatment decisions, if at all?†
7. What does dignity mean to you? Do you feel like you have a sense of dignity now? Were there times during your illness when you lost that sense of dignity? If so, explain. What helps you maintain a sense of dignity?†
8. When and how were you told you had cancer? What was the prognosis?
9. What type of cancer were you diagnosed with?
10. What type of treatments, if any, did you pursue? How did those affect you?
11. Are there any things you were unable to do as a result of your illness or treatments? Did you regain the ability to do these things? If not, how do you cope with this? If so, what was that experience like for you?†
   a. Did you ever have any other points in your life that you were ill or limited in what you could do? Describe those to me.†
12. Did your treatments require prolonged stays in the hospital? How was your stay in the hospital during these times?
13. How did doctors and medical staff interact with you?
14. How did friends and family interact with you during this period?
15. At any point in your illness have you felt like a burden to other? If so, describe this to me. If not, what do you think prevented you from feeling this way?

16. Did any of your interactions with others affect how you felt about yourself after your diagnosis?

**Interview 2**

1. Do you think you look physically different than before you were diagnosed with cancer? If so, how? When do you think this change occurred?

2. What types of changes in your personality have you noticed since you’ve been sick, if any?

3. What types of changes in your interactions with others have you noticed, if any?

4. When you think of who you are as a person right now, what are some of the qualities that stand out?

5. In thinking about how you see yourself right now, are there any other questions you think I should have asked?

6. Is there anything else you’d like to add?