THE ROLE OF IDENTITY IN POSTTRAUMATIC GROWTH AND PSYCHOLOGICAL ADJUSTMENT FOR ADULTS WITH CANCER

by

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A Dissertation Submitted to the Faculty of

The College of Education

in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

Florida Atlantic University

Boca Raton, FL

April 2009
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This dissertation was prepared under the direction of the candidate’s dissertation advisor, Dr. Linda Webb, Department of Counselor Education, and has been approved by the members of her supervisory committee. It was submitted to the faculty of The College of Education and was accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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ACKNOWLEDGEMENTS

I would like to acknowledge the help and contributions of many individuals without whom this research would not have reached completion. Dr. Paul Peluso for his guidance, editorial advice, for sticking it out through all the many versions and encouraging me as a mentor and friend. Dr. Linda Webb for lending her support at exactly the right time. Dr. Susan Chase for her insightful help with qualitative research. Dr. Alexis Miranda for his invaluable support. Dr. Patricia Maslin-Ostrowski for inspiring me and educating me in the rigor of qualitative inquiry. Dr. Ann Branaman for guiding my early efforts to understand identity and self in context. Dr. Len Sperry and Dr. Bill Nicoll for helping me shape the direction of this study in the early stages. I have nothing but gratitude to the faculty, staff and students of the FAU department of Counselor Education. My family whose belief in me inspired me. Dr. Valeria Fabj, who believed in me and this project even when I wasn’t sure, who encouraged me in my darkest hours, lovingly read every labored version, and gave freely of her infinite wisdom. My deep, sincere appreciation to all of my participants for their invaluable contributions and for sharing their experiences with a hope to help others. Not to be forgotten, my loyal dog, Cody, who faithfully bore witness to the entire project by my side every step of the way.
This mixed methods sequential research study was performed to explore the role of identity in posttraumatic growth and psychological adjustment for adults with cancer. One hundred nineteen individuals participated in an online survey which included items from Brief COPE, Mini-Mental Adjustment to Cancer (Mini-MAC), Brief Illness Perception Questionnaire (BIPQ), Sense of Coherence Scale – 3 items (SOC-3), Posttraumatic Growth Inventory (PTGI), Illness Intrusiveness Ratings Scale (IIRS), and Centrality of Event Scale (CES). A two-step cluster analysis divided the sample into two clusters based on the integration of cancer into identity: High Cancer Identity Cluster (cancer identity scores above $M$) with strong cancer identity and Low Cancer Identity Cluster (scores below the $M$) with a weak or absent cancer identity. HCIC yielded positive and negative subgroups. A discriminant analysis revealed which variables are
significant predictors of group membership: PTG factor New Possibilities (Wilks’ $\lambda = .781, F(1, 119) = 32.834, p = .000$), Psychological Adjustment factor Anxious Preoccupation (Wilks’ $\lambda = .863, F(1, 119) = 18.612, p = .000$), Illness Intrusiveness factor Intimate Relationships (Wilks’ $\lambda = .794, F(1, 119) = 30.348, p = .000$), and Illness Perception factor Perceived Life Impact of Cancer (Wilks’ $\lambda = .783, F(1, 119) = 32.412, p = .000$).

From the sample, 17 individuals and spouses/partners were interviewed to obtain a deeper understanding of the lived experience of cancer. Qualitative themes of suffering, woundedness, and uncertainty were found. Narrative data corroborated the quantitative data and contributed depth to the analysis. A new Cancer Identity Process Model was offered in which assimilative and accommodative efforts are informed by identity structures. Performing Normalcy is an assimilative process in which stressful life events such as cancer activate automatic behaviors guided by existing identity structures with the goal of regaining status quo. As dissonance grows over the inability to re-establish valued former identities, negative affect and intrusive rumination prevails. Individuals then utilize accommodative strategies in a process of Constructing Survivorship to either regain valuable aspect of former identities or to create equally valued new ones.
DEDICATION

Dedicated to my dad whose journey with cancer inspired me as it transformed him, to those who shared their time and stories to help me with this research, and to all who battle cancer.
THE ROLE OF IDENTITY IN POSTTRAUMATIC GROWTH AND PSYCHOLOGICAL ADJUSTMENT FOR ADULTS WITH CANCER

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CHAPTER 1
INTRODUCTION

There are two Lance Armstrongs, pre-cancer, and post. Everybody’s favorite question is “How did cancer change you?” The real question is how didn’t it change me? I left my house on October 2, 1996 as one person and came home another.

—Lance Armstrong (2001)

It’s Not About the Bike: My Journey Back to Life

“Identity is not a sudden and mysterious event, but a sensible result of one’s life story” (Gergen & Gergen, 1988; p. 19). Identity is defined as the subjective concept of oneself as a person and is subject to personal agency (Thoits, 2006) as it is ongoing development of a self-theory (Berzonsky, 1992). Erikson (1968) conceptualized identity as providing inner unity and a sense of integrative continuity over time. He also theorized that consistent, coherent identity provides a basis for dealing with daily life and with stressful events by assimilating and construing experiences. Individuals make sense of experiences and re-narrate events for coherence with narratives, or life stories, providing a vehicle for identity construction (McAdams, 1993; Mathieson & Stam, 1995; Neimeyer, 2006). It was once believed that self-concept was static, but now it is understood that sense of self is not only dynamic, but a guiding force for individuals’
lives (McAdams, 1993). Thoits (1999) posits that understanding more about the role of identity is critical to knowing why people are variably disturbed by stressful experiences.

Several researchers have noted identity changes in adults with cancer (Allen, 1998; Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., 2003; Bradley, Calvert, Pitts, Redman, 2001; Mathieson & Stam, 1995; Tower, 2000; Turton & Cooke, 2000; Zebrack, 2000). Diagnosis with cancer often shatters not only a client’s world and their belief systems (Calhoun and Tedeschi, 2006; Janoff-Bulman, 1992, 2004), but also their cohesive life narrative and sense of self (Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., 2003; Charmaz, 1991; Mathieson & Stam, 1995; Zebrack, 2000). The disease of cancer and its treatment are crises that can threaten identity by challenging a person’s integrity of self and biographical continuity between past and future self (Corbin & Strauss, 1988). This happens when basic assumptions about self and the world are shattered (Janoff-Bulman, 1992), when awareness of one’s own mortality becomes suddenly relevant (Brennan, 2001; Taylor, 1983), and when meaningful roles and activities are threatened by the intrusiveness of illness (Charmaz, 1991, 1995, 2002; Corbin & Strauss, 1988). Ultimately, traumatized individuals – such as those with cancer – adjust by seeking to reclaim a coherent, culturally-situated identity or “self-narrative” (Neimeyer, 2006). Given that identity can affect psychological adjustment and health behaviors (Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., 2003; Bowen, Hickman, & Powers, 1997), at the core of the survivor experience is an identity shift that is not only an outcome, but a global coping strategy that may affect the illness trajectory or adjustment (Abernathy, 2008; Allen, 1998; Berzonsky, 1992; Bradley, Calvert, Pitts, & Redman, 2001).
Psychological distress is a ‘normal,’ almost universal, response to a diagnosis of cancer that in some respects is mediated by an individual’s ability to maintain valued roles and successfully navigate identity threats created by illness and treatment. Distress is mitigated by the extent to which one interprets his or her ability to successfully manage the crisis as central to one’s identity or life narrative. Even rejection of an identity defined by cancer is a manifestation of identity renegotiation. While some researchers (Allen, 1998; Mathieson & Stam, 1995; Tower, 2000; Turton & Cooke, 2000; Zebrack, 2000) have identified patterns (themes or tasks) of identity reconstruction primarily through qualitative studies, there is little effort to correlate the patterns with empirical measures of psychological distress or adjustment. Therefore, the process of identity renegotiation has not been established, nor its relevance within the overall (coping) structure of the cancer experience.

Research on cancer patients has also recently begun documenting posttraumatic growth (PTG) or profound positive change in some adults with cancer (Calhoun & Tedeschi, 2006; Stanton, Bower, & Low, 2006). Some patients are embracing the “survivorship” identity arguably personified by Lance Armstrong, who claimed that surviving metastatic testicular cancer inspired him to win the Tour de France an unprecedented seven consecutive times and to establish a charity which seeks to empower other patients in their battle against cancer. This identity is characterized by a renewed appreciation for life and sense of purpose, and those embracing this identity often consider cancer a gift. Survivorship has become the dominant social model. Recently, the National Cancer Institute also formally adopted the newer meaning of the term: “An individual is considered a cancer survivor from the time of diagnosis, through
the balance of his or her life.” Popular literature has promoted this new model of ‘survivorship’ through a variety of self-help, inspirational, and spiritual books (e.g. Bolen, 1996; LeShan, 1994; Siegel, 1993).

One of the three domains identified by Tedeschi and Calhoun (1995) as relevant to PTG is change in perception of self; the other two are: change in the experience of relationships with others and change in the general philosophy of life. The research on surviving trauma suggests that part of successfully navigating the experience of trauma is a new sense of self. As individuals engage in meaning-making to regain coherence and comprehensibility (schema change), they re-narrate their stories, finding not only new meaning but a new sense of themselves (Brennan, 2001).

While a link between PTG and identity renegotiation might appear obvious, further research is needed to clarify the important elements. The research on PTG is at times inconclusive, confusing, and counter-intuitive (Stanton, Bower, & Low, 2006). While PTG is associated with strength, it is also associated with vulnerability. In fact, PTG may be accompanied by decreased well-being and greater stress (Calhoun & Tedeschi, 2006). Despite the almost exclusive emphasis on the positive aspects of PTG, it is necessary to remember that it is born from trauma – crisis, suffering, and an awareness of one’s own mortality. Therefore, contradiction is inherent and inevitable (Neimeyer, 2006). Since PTG is characterized by positive growth and psychological adjustment is characterized by minimization of psychological distress, a significant overlap was expected, but curiously, the research finds only a weak or inconsistent relationship between PTG and adjustment (Stanton, Bower, & Low, 2006). This relationship is deeper and more complex than it initially seems. It is indeed this complexity that hints at the
richness of the relationship. Yet insufficient attention has been given to this area with regard to cancer patients and the role that identity tasks may play in explaining some poorly-understood aspects.

Problem Statement

Much has been written about the psychological distress and other devastating effects of being diagnosed with cancer, including shattered assumptions and “loss of self” (Calhoun and Tedeschi, 2006; Charmaz, 1991; Janoff-Bulman, 1992; Mathieson & Stam, 1995; van der Kolk, Roth, Pelcovitz, Sunday, Spinazzola, 2005; Zebrack, 2000). More recently, it has been acknowledged that some people experience profound personal growth as a result of their cancer experience which results in, among other things, changes in the way one views oneself (Calhoun & Tedeschi, 2006; Stanton, Bower, & Low, 2006). Furthermore, several researchers have described the changes in identity among patients and survivors (Allen, 1998; Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., 2003; Bradley, Calvert, Pitts, Redman, 2001; Mathieson & Stam, 1995; Turton & Cooke, 2000; Zebrack, 2000), yet there are no published accounts of efforts to theoretically integrate this process with psychological adjustment and posttraumatic growth. Learning more about this process may illuminate some previously poorly-understood aspects of the disease experience. Since many of the same processes at work in reconstruction of identity are also utilized in PTG, e.g. meaning-making, it is reasonable to consider what role identity might play in mediating the relationship between psychological adjustment and PTG. It is surprising that so little attention has
been given to the ways in which alterations in concepts of self may explain the paradoxical findings (Heidrich, Forsthoff, & Ward, 1994).

Research Questions and Purpose of the Study

**Research Questions**

1. What is the role of identity in posttraumatic growth and psychological adjustment in adults with cancer?

2. What are the identity clusters (or profiles) that emerge when looking at measures of illness perception, psychological adjustment to cancer, posttraumatic growth, illness intrusiveness, centrality of event (to identity), and sense of coherence of adults with cancer or who have survived cancer?
   a. What are the differences on these measures among the clusters?
   b. What is the role of identity within these groupings?
   c. What is the nature of the relationship of these variables to adjustment?

3. What are the emergent themes that relate to identity in the narratives of adults with cancer?

**Purpose of the Study**

The purpose of this two-phase sequential mixed methodology study was to discover the role of identity for adults with cancer, particularly with regard to posttraumatic growth and psychological adjustment. Therefore, it was necessary to obtain statistical, quantitative results from a sample and the follow up with a smaller
representative group of individuals from the sample to probe or explore those results in more depth.

In the first phase, 119 participants completed quantitative measures used to evaluate with regard to a number of variables known to be important in the experiences of adult cancer patients: psychological adjustment to cancer, posttraumatic growth, illness perception, illness intrusiveness, and sense of coherence. Then clusters were derived which grouped the sample on the variable centraality of cancer to identity. Then phenomenological qualitative interviews were used to probe statistically significant quantitative results by exploring aspects of cancer identity within each cluster. The semi-structured interviews helped clarify the role of cancer identity in each of the clusters and identify experiences which result in a transformed identity.

This study stands at the juncture of three areas of research and contributes to our understanding of this experience from the patient’s perspective. Second, it permits us to explore how a patient’s identity shifts correlate to adjustment and posttraumatic growth. Third, this study provides guidance with regard to interventions for counselors to help their clients during an experience of cancer.

Definitions

Identity

Identity is defined as the subjective concept of oneself as a person, located in subjective psychological experience, and includes multiple levels of representation – individual, relational, and group levels of self-representation (Sedikides & Brewer, 2001). It is assumed that individuals’ actions and decisions are guided by identity motives and
attempts to maintain valued roles (Breakwell, 1988; Vignoles, Regalia, Manzi, Golledge, & Scabini, 2006). It is also assumed that identity is constructed through a complex interaction of cognitive, affective, and social interaction processes, within cultural and local contexts (Drury & Reicher, 2000). Finally, it is assumed that persons need to maintain internal congruence – an essential continuous self – with regard to identity, seeking behaviors and experiences that validate beliefs about self and re-narrating events that challenge them.

The use of the term *self* in the literature is somewhat confounding as it is often used as synonym for identity but other times distinctly. In this study, identity will represent an aspect of self. Studies about self-concept, self-evaluation, personal identity, and social identity can inform about the workings of identity (Breakwell, 1988). Thoits (1999) explains that she treats the terms *selves* and *identities* as equivalent because as people typically invest themselves in their identities, “private selves and public identities become two halves of the same coin” (p. 348).

*Psychological Adjustment*

Adjustment is defined as a response to a stressful event (an event which could trigger extreme emotions and actions and/or cause problems at work and home) that allows one to become more suitably adapted to that change, in other words, the absence of psychological distress. Therefore, adjustment refers to the psychological processes that occur over time as the individual, and those around them, manage, learn from and adapt to the multitude of changes which have been precipitated by the illness and its treatment. Adaptive coping, healthy emotion regulation, optimism, and self-efficacy have proven
important in adjustment to cancer. Adjustment is the adaptation that occurs as people work to cope with their disease.

**Posttraumatic Growth**

Posttraumatic growth (PTG) is defined as “positive psychological change experienced as the result of the struggle with highly challenging life circumstances” (Tedeschi & Calhoun, 2004). Therefore, PTG is more than mere survival or resisting damage from a traumatic experience, it is transformational change in adaptation, psychological development, and life awareness beyond pre-trauma levels. Tedeschi & Calhoun (1996) assert that PTG produces three groups of beneficial outcomes: changes in self-perception; changes in interpersonal relationships; and changes in philosophy of life.

**Adult with Cancer**

Adult with cancer is the preferred term because it does not define one primarily through an identity of illness or disability. However, the terms ‘patient’ and ‘survivor’ will also be used throughout this paper to avoid excessive repetition and to be consistent with the existing literature. For the purpose of this study, an ‘adult with cancer’ is one who was at least age 18 when diagnosed with cancer and who is either on active treatment or has completed treatment.

**Illness Perception**

Illness perception is an individual’s representation of illness or health threat. It is a continuous feedback loop of appraisal process and formation of illness/threat
representation that result in coping responses. Five dimensions have been identified: 1) identity—the label the person uses to describe the illness and the symptoms they view as being part of the disease; 2) consequences—the expected effects and outcome of the illness; 3) cause—personal ideas about the cause of the illness; 4) timeline—how long the patient believes the illness will last; and 5) cure or control—the extent to which the patient believes that they can recover from or control the illness (Leventhal, Nerenz, & Steele, 1984). This is conceptualized as a self-regulatory model. Changing patients’ illness perceptions has been found to improve recovery or outcomes in patients with myocardial infarction, diabetes, and AIDS (Leventhal, Nerenz, & Steele, 1984).

**Trauma Sequelae**

Trauma sequelae will be defined according to the *Diagnostic and Statistical Manual of Mental Disorders—IV–TR* (DSM-IV TR; American Psychiatric Association, 2004) criteria for posttraumatic stress disorder (PTSD). Trauma sequelae follow a traumatic event as defined in the DSM-IV TR and fall into three categories: 1) re-experiencing (intrusive distressing recollections, flashbacks, and nightmares), 2) avoidance (avoiding reminders of some aspect of the trauma, dissociation, sense of foreshortened future), or 3) arousal (hypervigilance, insomnia).

**Centrality of Event**

“Centrality of event is the extent to which a stressful event forms a reference point for personal identity and attribution of meaning to other life experiences life” (Berntsen & Rubin, 2006). In other words, it references how central an event is to a person’s
identity and life story. Trauma can become an anchor and a turning point. Therefore, trauma memory that is considered a central turning point in one’s life story is also a central component of personal identity. The integration of trauma then can inform understanding of identity transformation.

**Sense of Coherence**

The term “sense of coherence” describes internal congruence with regard to an individual’s global view of the world and the environment as comprehensible, manageable, and meaningful. Sense of coherence has three elements: comprehensibility (cognitive), manageability (instrumental/behavioral), and meaningfulness (motivational) (Eriksson & Lindstrom, 2005). Some researchers claim that sense of coherence can have a positive effect on health.

**Illness Intrusiveness**

Illness intrusiveness is defined as disruptions to life, activities, and interests that are created as a direct result of illness sequelae or treatment. Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al. (2003) describe illness intrusiveness as interference by disease and/or treatment with a person’s psychologically meaningful pursuits.

**Mortality Salience**

Mortality salience is a perceived threat to life that causes a person to confront their own mortality. Tennen and Affleck (1998) suggest that this disrupts the anticipated personal ‘trajectory’ of an individual’s life. Frank-Stromberg, Wright, Segalla, &
Diekmann (1984) note the cancer patients perceive an “amputation of the future.” After a life-threatening diagnosis, many people prepare for the possibility of death (Brennan, 2001). Individuals deal with the possibility of a foreshortened future experience an urgency to accomplish delayed dreams or goals.

Assumptions, Scope, Delimitations, and Limitations

Assumptions

Several theories also contribute to our understanding of the dynamics with these patients. Trauma theory reports that trauma yields a disrupted understanding of the world and one’s place in it, leading to “ego shock.” The resultant feelings of self-annihilation give salience to mortality or awareness of one’s own mortality (Janoff-Bulman, 2006) that yields a new appreciation for life and experience personal growth or transformation as a result of their experience (Calhoun & Tedeschi, 2006; Stanton, Bower, & Low, 2006). Finally, terror management theory adds that mortality salience often results in a need for close, meaningful relationships and in striving for symbolic immortality.

This acknowledgement of shifting identities is congruent with the current focus on the postmodern convergence of identities or multiplicity of selves. Also, it honors multiculturalism by appreciating that individuals have intersecting identities and can simultaneously belong to more than one demographic. Finally, it fits with Positive Psychology by seeking to identify strengths rather than pathologize persons living with cancer.
Scope

In the first phase of the study, 164 adults diagnosed with cancer were solicited from four counties in south Florida – Palm Beach County, Martin, St. Lucie, and Broward counties – to complete an online survey with a series of quantitative measures relative to their cancer experience. Then in the second phase, 17 individuals and their spouses/partners were recruited for an in-depth, semi-structured interview in order to gain representation from each of the clusters identified during analysis of the first phase and to learn more about the role of identity in adults with cancer.

Delimitations

This study was confined to persons diagnosed with cancer who were at least 18 years of age at the time of diagnosis.

Limitations

Soliciting at locations within four south Florida counties limited the sample to persons currently living in or around these counties. This may affect the generalizability of these findings to other populations. Also, individuals who are willing to participate in a study may differ from those who choose not to.

It is necessary to consider the threats to internal validity arising from the instrumentation and variability in participants’ responses which may occur due to a prior trauma history. Biases and characteristics of the researcher could also contribute to the internal validity of the study. Longitudinal research would be valuable to obtain a more
complete representation of the role of identity in posttraumatic growth and psychological adjustment of adults with cancer.

Significance of the Study

Cancer is the second leading cause of death and the cause of 25% of all deaths in the United States (American Cancer Society, 2008). Over the course of a lifetime, men are reported to have a 1 in 2 chance of being diagnosed with cancer, while the rate for women is estimated to be 1 in 3 (National Heart, Lung and Blood Institute, 2007). In 2009, 1.4 million Americans are expected to be newly diagnosed with cancer and 564,830 cancer deaths are estimated (National Heart, Lung and Blood Institute, 2007). Since survival rates are rising, the number of people surviving cancer is increasing. The number of cancer survivors has increased dramatically in the last twenty years, creating a significant population of cancer survivors – those who have finished treatment and those who are currently undergoing treatment. According to the National Cancer Institute (2004), approximately 10.8 million Americans with a history of cancer were alive in January 2004. Sixty-four percent of adults diagnosed with cancer in 2004 will be alive in five years (American Cancer Society, 2008). The National Heart, Lung, and Blood Institute (2007) estimated $219 billion in overall costs due to cancer in 2007.

Counselors are increasingly expected to be able to help clients navigate these new challenges and create new meaning from the events (Edwards & Patterson, 2006). Given the prevalence of cancer and the dramatic increase in survivorship, this issue is of vital importance to counselors and their clients. Therapists need to understand the process in order to assist clients to construct new roles and identities that have positive meaning.
Counselors are in a position to assist clients with cancer to construct an identity that enhances empowerment, self-efficacy, adjustment, PTG, and quality of life (Gray, Doan, & Church, 1990; Mok, 2001). Identifying predictors and mediators of this process may provide valuable insight into not only those diagnosed with cancer, but also for patients with other kinds of critical illness and survivors of other types of trauma.

Transition Statement

Chapter Two offers a review of the literature with regard to posttraumatic growth and psychological adjustment of adults with cancer. The literature on identity is also featured. Chapter Three presents a discussion of the methodology that was used to collect and analyze the data. This chapter focuses on mixed methodology, the value of both quantitative and qualitative research, and phenomenological methods.

Chapter Four presents the findings of this mixed methodology study. Essential themes and salient features are highlighted in this section. Chapter Five discusses and situates the findings within the realm of existing literature and introduces a new Cancer Identity Process Model. Implications for further research and clinical work are also provided in this chapter.
CHAPTER 2
LITERATURE REVIEW

Strategy Used for Searching Literature and Content of the Review

An extensive review of relevant articles and books was performed within psychology, social psychology, health psychology, counseling, rehabilitation counseling, psycho-oncology, behavioral medicine, medical sociology, medical anthropology, nursing, social work, and traumatology, using the search terms: cancer, patient, psychological adjustment, adaptation, psychological distress, sequelae, coherence, meaning-making, salutogenic, existential, perceived control, threat to life, mortality salience, death salience, identity salience, role strain, role conflict, real vs. ideal self, benefit-finding, self, identity, role, integration, coping, self-efficacy, resilience, empowerment, trauma, traumatic stress, stress-related growth, posttraumatic stress, posttraumatic growth, illness, health, wellness, identification, and adult development. Searches were performed using the following: Academic Search Premier, CSA, FirstSearch, OmniFile Full Text Mega Edition, Proquest, Proquest Dissertation Abstracts, and Google Scholar. Attention was also given to a few key sociological and anthropological writings as they related to culturally- and socially-contextualized identity. A cursory review of popular literature related to coping with and surviving cancer was performed to ascertain the type of materials most cancer patients might
encounter and that might influence their perceptions and expectations of a cancer experience.

Structure of the Review

The literature review draws on three distinct areas: illness and identity, psychological adjustment, and posttraumatic growth in adults with cancer. The first section reviews the literature regarding the role of identity in illness with particular attention to adults with cancer and discusses several representative models. The research on identity renegotiation, identity reconstruction, and identity reconstitution is summarized. This section also highlights the ways in which cancer can impact identity through a series of potential threats that challenge an individual’s cohesive identity, status, roles, and meaningful activities.

The second section focuses on psychological adjustment in adults with cancer with particular attention to those factors known to be relevant to identity, such as: psychological distress, illness perception, perceived control, self-efficacy, coping, quality of life, optimism, discrepancy between actual and ideal self, sense of coherence, social support, and meaning-making. The third section summarizes the literature relating to posttraumatic growth with emphasis on factors associated with increased PTG and aspects of PTG relevant to identity.

Cancer and Identity

Several researchers have detected a process of ‘identity renegotiation’ that occurs for adults with cancer when illness intrudes on maintenance of valued roles and
awareness of mortality becomes prominent (Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., 2003; Mathieson & Stam, 1995; Tower, 2000; Zebrack, 2000). Since identity can be viewed as a lens through which individuals construct meaning and cognitive appraisal, it is necessary to then consider how identity then influences psychological adjustment. Given that identity is dynamic and constructed through a complex interaction of cognitive, affective, and social interaction processes that are culturally contextualized, it is reasonable to consider ways that a traumatic event such as life-threatening diagnosis of cancer challenges roles and identity.

Identity Theory

In order to understand restructuring of identity, it is necessary to first be conversant with relevant identity theory, including the effect of stressful events on role-identities and valued roles. Some evidence is also presented about self-selected identity and health behavior. Also, some interventions are presented in which identity exploration is facilitated for traumatized adults.

Taylor (1983) suggested that life-threatening events trigger three themes: a search for meaning, mastery, and self-enhancement. Individuals consistently demonstrate a need to create meaning around events to make sense and regain coherence to their lives, thereby reestablishing the biographical continuity which is lost following a life-threatening diagnosis. Erikson (1968) described identity as subjective and including both a sense of self-sameness and stability over time. In this way an individual gains a sense of coherent identity despite different situations.
Severe or disabling illness disrupts the continuity which is so vital to the maintenance of coherent identity (Erikson, 1968). McAdams (1993) proposed that we learn about ourselves by the stories that we tell, and that, in fact, we create ourselves through conforming to our own mythic story. He also suggested that individuals make meaning of events in such a way to conform to existing life narratives which in turn inform understanding of self. Facing a life-threatening illness such as cancer can lead to an individual to reevaluate the meaning of her/his existence and her/his identity which in turn shapes how she/he approaches and deals with cancer.

Role-identities not only provide a sense of purpose and belonging, but define who we are and provide normative cues for behavior (Thoits, 2003). Competent role-identity enhances self-efficacy, and in fact, contributes to overall mental health (Thoits, 2003). When individuals successfully solve role-specific problems, identity is enhanced while events which are not successfully navigated can be identity-threatening (Thoits, 1991 & 1994). The impact of illness on valued roles determines the extent to which an individual’s physical, social, emotional, psychological, spiritual, and financial well-being is affected (Thoits, 2003). Distress occurs when an individual is unable to maintain valued roles which are salient to identity, and therefore the identity associated with those roles is undermined (Thoits, 2003). When there is a conflict between identity standards (how one believes one should act) and how one actually behaves, the individual will either seek to alter the situation or will “bring self-relevant meanings back in line with identity standards” (Thoits, 2003, p. 191).

Recent attention in the literature has been directed at “identity motives” which guide identity construction with pressure toward certain identity states and away from
others (Vignoles, Regalia, Manzi, Golledge, & Scabini, 2006). These motives are theorized to generally be outside the awareness of most people but can be inferred (Vignoles, Regalia, Manzi, Golledge, & Scabini, 2006), reflected in desires and future identities. These authors theorize that people will work to avoid negative emotions or marginalization and to achieve future selves that maximize satisfaction and self-esteem (Vignoles, Regalia, Manzi, Golledge, & Scabini, 2006). This is consistent with Taylor’s body of research (e.g. 1983) which describes positive adjustment as often illusory but self-enhancing. This also underscores the need to acknowledge the role of personal agency in identity as individuals reconstruct a wiser, more powerful sense of self (Thoits, 1999). Attention has focused also on the cultural contexts of identity motives to understand those influences, which is consistent with Foucault’s (1963) emphasis on contextualizing identity within a framework of societal power.

Researchers have found that identity can affect health behaviors, with the largest body of research related to ethnic identity (Bowen Christensen, Powers, Graves, & Anderson, 1998; Helms, 1990; Landrine & Klonoff, 1997). For example, Bowen, Hickman, and Powers (1997) report that women who self-identified as “African-American” are significantly more likely to report intention to have a mammogram than women who self-identify as “Black.” Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al. (2003) found that individuals going through bone marrow transplant who allow their cancer experience to define them are more likely to report psychological distress and disruption of psychologically meaningful pursuits than those whose illness does not define them. These individuals adopt a “patient” identity and are unable to return to normal even years after treatment. In other words, identity shapes meaning and
self-identification shapes appraisal, coping, and adjustment. Therefore, it is vital to obtain a deeper understanding of self-identity influence on health behaviors and psychological variables (Bowen Christensen, Powers, Graves, & Anderson, 1998). Illness models identify critical elements of adjustment or illness trajectories, while illness identity models demonstrate the influence of illness on identity and the impact of identity on the illness experience.

Newer therapeutic approaches for adults with cancer have recognized the need to move beyond cognitive behavioral approaches. Petersen, Bull, Propst, Dettinger, and Detwiler (2005) proposed a Narrative-Expressive Therapy intervention that is designed to address underlying stress and prevent PTSD. Their intervention seeks to promote coherence, meaning-making, and adaptation while also connecting patients with others. An art support group for adults with chronic illness has been used to help clients reconstruct positive identity through the use of art (Reynolds, 2003). To address the existential distress of adults with cancer and to promote a renewed appreciation for life Lee, Cohen, Edgar, Laizner, and Gagnon (2006) adapted a meaning-making intervention originally designed to help trauma patients come to terms with life-threatening critical injury. During the eight-session format participants were engaged in a collaborative process of exploration and self-discovery in which they were to consider the meaning of not only their illness, but the impact of their illness on their lives, their loved ones, their worldview, and their views of themselves to assist in integrating cancer and its implications (Lee, Cohen, Edgar, Laizner, & Gagnon, 2006). As the research continues to unfold, corresponding interventions will undoubtedly also evolve.
Identity Renegotiation

The impact of cancer far exceeds the physical symptoms of illness and treatment; it creates awareness of mortality and alters biographical continuity, all of which profoundly shape the performance of self. Corbin and Strauss (1988) proposed an identity reconstruction process for the 60 ill participants and their spouses who participated in their qualitative research. They posited that a major task of cancer is to re-evaluate one’s life story. They further suggested that transformed identity drives how we make sense of events and ultimately how we cope with them – that making sense of events is, in essence, making sense of our lives. They concluded that since identity is derived through our narratives, then re-storying results in a changed identity. They found that the chronically ill adults of their study were shaped by perceived changes that define the illness trajectory and driven by a need to regain a sense of wholeness which they link to biographic coherence. These researchers were among the first to describe how chronic illness, including cancer, was managed in diverse ways: by ignoring it, by maintaining illness as separate from one’s personal identity, by integrating it into one’s self and lifestyle, or somewhere in between.

Corbin and Strauss (1988) found that a singular episode of illness is conceptualized as bodily failure; however, the psychosocial demands of cancer require biographical revision, i.e. re-writing one’s life story but in the context of a radically circumscribed body. They (1988) also identified a process of identity renegotiation that begins at the time of diagnosis with challenges to biographical performance: “I might die” or “What if I can’t do the things I love anymore?” If illness intrudes into performance of valued roles, individuals again address the impact of illness on identity.
As they negotiate the demands of treatment and illness, patients seek a new sense of self that integrates a redefined biography. Corbin and Strauss (1988) suggested that ‘identity reconstitution’ is an integral component of the biographical work on the chronically ill and stage 3 of the four biological processes. They noted three steps to identity reintegration: 1. defining and redefining identity which begins with questioning and involves testing limits of the body resulting in values reorientation; 2. refocusing direction which involves replacing pre-illness performances with new ones that integrate limitations; and 3. integrating identity which is described as regaining a sense of wholeness.

Mathieson and Stam (1995) described the process by which adults with cancer engage in a process of identity renegotiation as part of their adjustment to illness. They interviewed 27 cancer patients and used a grounded theory analysis to derive the salient features of identity issues. They similarly found that patients re-negotiate identity by altering their self-narrative in order to regain a cohesive life story. Identity is renegotiated as a search for meaning begins and a new homeostasis is sought (Mathieson & Stam, 1995). This is consistent with narrative theorists who suggest that identity is created through biographical narrative (McAdams, 1993).

Threats to Identity

It is important to consider the ways in which an experience of cancer can challenge existing status, roles, and identity. This generally happens because of the traumatic shattering of existing assumptions, sudden awareness of one’s own mortality, and the intrusion of cancer on valued roles and activities. The individual must
successfully resolve these threats to identity to reduce psychological distress and to maintain a sense of coherence about her/his life (Mathieson & Stam, 1995). The impact of each threat depends on its salience to one’s identity (Thoits, 1999). Relationships change and body cues are a constant reminder. Individuals lose the status of a healthy person and become a person with cancer – with all the associated societal preconceptions and expectations. How they perform or internalize those roles shapes their identity. Even rejection of an identity defined by cancer is a manifestation of identity renegotiation.

King and Hicks (2007) found that individuals conceptualize not only future goals but future selves, a construct they call “possible selves.” In their studies of adults with significant life changes, they discovered grieving about lost goals but also about a memory of the self that would have been “if only.” The higher the salience of each possible self, the greater its importance and the greater the impact of the loss. They found that failure to disengage from lost goals positively correlates with decreased well-being. They also found that the self-reported happiest individuals were those who could easily recall and elaborate on lost goals and lost possible selves, but had disengaged from those goals and fully committed to the new ones with an expectation that good things lie ahead. These persons had also been able to develop a deep sense of gratitude. From their findings they concluded that being able to maintain a full, elaborate portrait of what is lost while not focusing on the loss yields “a richer, more complex self” (p. 630).

Moorey and Greer (1989) concluded that the trauma of cancer falls along two dimensions: threat to survival (‘sense of immortality is shattered’) and threat to the self-image (mental and physical abilities, personal and social roles, and physical appearance). According to Cohn and Lazarus (1979), illness threatens: “life; bodily integrity and
comfort; self-concept and future plans; emotional equilibrium as a result of the other threats; social roles and activities; and threats involving the need to adjust to new social or physical environments.” These threats to self-image or ‘threats to identity’ contribute to loss of status and identity, such as the sudden, unexpected awareness of mortality, loss of status as a healthy person, illness intrusiveness, body changes (e.g. alopecia, surgical scars, or amputation), and interacting with a disempowering biomedical culture.

Brison (1997) suggested that trauma generates threats to three aspects of self: 1. the embodied self, 2. the narrative self, and 3. the autonomous self. The embodied self includes the recognition that my body is me and a threat to the body is a threat to self. Threat to narrative self is manifested when trauma interrupts a continuous narrative and the resulting disorganized cognitive function inhibits coherent re-storying and therefore unity of self. This disruption to the biographical narrative also ruptures continuity of self in time by loss of future self. Trauma threatens autonomous self through challenges to agency such as dealing with sudden, unpredictable, uncontrollable events, and loss of belief in oneself as powerful or capable of handling threats, and loss of mastery.

Mathieson and Stam (1995) suggested that cancer results in “threats to former self-images,” such as “loss of productive functioning, financial strain, family stress, personal distress, and stigma,” and that these threats force a transformation in identity. Among adults with chronic illness, Charmaz (1991) found that the most significant predictor of impacted identity was illness intrusiveness, or the effect of illness on life activities and functioning, and an altered sense of self in temporal time.

For example, Rozmovits and Ziebland (2004) found that among survivors of colorectal cancer who required ileostomy the loss of the ability to control bowel function,
a skill associated with very early stages of childhood development, was also a loss of adulthood. In fact it often interfered with several roles associated with adulthood: ability to maintain employment or professional identity; loss of social and/or sexual identity; and compromises about privacy, dignity, and independence. These losses ultimately resulted in alienation and despair.

_Cancer as Trauma_

Like any life-threatening event, cancer can be a psycho-traumatic occurrence (Jonker-Pool, van Basten, Hoekstra, van Driel, Heuvel, & Schraffordt-Koops, et al., 1997). In 1994, the definition of a traumatic event for the diagnosis of Post-Traumatic Stress Disorder (PTSD) was expanded to specifically include (among others) the diagnosis of a life-threatening illness. Approximately 94% of people stated that the diagnosis of cancer was the most traumatic experience of their lives (Petersen, Bull, Propst, Dettinger, and Detwiler, 2005; Stanton, Bower, & Low, 2006).

In her discussion of what constitutes trauma, Janoff-Bulman (1992) noted that it is not the extreme nature of the event that defines a stressful experience as traumatic, but rather the internal experience of it. She noted that terror is the definitive response to trauma, characterized by internal disorganization and disintegration, shattered assumptions, and feelings of self-annihilation – in other words, everything that makes our lives intelligible, meaningful, and coherent. Trauma yields distress, a disrupted understanding of the world and one’s place in it (including lack of power and control), and provides salience to mortality (Calhoun & Tedeschi, 2006). These challenges to the assumptive world and psychological sense of coherence trigger “ego shock” (Campbell,
Brunell, & Foster, 2004) or a “loss of self” (Charmaz, 1991). Therefore, trauma is a rupture in the self-narrative that results in a threat to identity (van der Kolk, Roth, Pelcovitz, Sunday, & Spinazzola, 2005). Trauma survivors must adapt a more complex representation of themselves and the world, and relinquish a previous sense of security (Znoj, 2006). Experts agree that in order to successfully navigate trauma, survivors ultimately must renegotiate a coherent identity (Calhoun & Tedeschi, 2006; Mathieson & Stam, 1995).

Impact of event.

Having cancer is a potentially traumatizing experience and may induce traumatic stress reactions (Smith, Redd, Peyser, & Vogl, 1999). Given the intense and dramatic loss of control and safety cancer can cause, it is not surprising the number of studies which indicate a potential for trauma sequelae. There is growing evidence that the diagnosis and treatment of cancer may lead to persistent symptoms even without a full-blown posttraumatic stress disorder (PTSD) syndrome (Smith Redd, Peyser, & Vogl, 1999). In fact, some researchers have suggested that there is no value to relating the trauma of illness to a psychiatric diagnosis at all; they argue that it is more important to understand how illness is a source of stress for years to come (Kazak, Stuber, Barakat, & Meeske, 1996). Brewin, Dalgleish, and Joseph (1996) suggested that PTSD symptoms may be common because they are part of a normal adaptive process or continuum.

Meta-analyses by Ozer, Armitage, Bennett, Crawford, Demetri, Pizzo, et al. (2000) and Brewin, Andrews, and Valentine (2000) of predictor variables on PTSD in adult non-cancer samples yielded similar results. Ozer, Armitage, Bennett, Crawford,
Demetri, Pizzo, et al. (2000) found that while prior trauma, prior psychological adjustment, family history of psychopathology, perceived life threat during the trauma, posttrauma social support, peritraumatic emotional responses, and peritraumatic dissociation all had significant effect sizes, peritraumatic dissociative responses emerged as the strongest predictor of PTSD, whereas premorbid variables yielded the smallest effect sizes. A similar meta-analysis by Brewin, Andrews, and Valentine (2000) found that the severity of trauma and posttrauma-related indices (especially additional life stressors and a dearth of social support) were strong predictors of PTSD, even accounting for demographic variables.

Kangas, Henry, and Bryant (2002) performed an extensive review of the existing literature relating to adults with cancer and found that 0 – 32% develop PTSD. Further, their review found prior negative life stressors, a history of psychological problems, elevated psychological distress subsequent to the diagnosis, female gender, younger age at diagnosis, lower social economic status, lower education, avoidant coping style, low social support, and reduced physical functioning are reported by various researchers to be predictive of PTSD among adults with a history of cancer (Kangas, Henry, & Bryant, 2002). The findings with regard to medical variables were less decisive. For example, while some studies have found no association between type, severity, stage, and prognosis of cancer and subsequent PTSD, others identified an association with more advanced stages of disease, recency of treatment, and experiencing one (or more) cancer recurrences (Kangas, Henry, & Bryant, 2002; Stanton, Bower, & Low, 2006).
Mortality salience or existential terror.

Morality salience is a sudden awareness of the finitude of life resulting from a perceived serious threat. Existential terror is another way of defining the result of a perception of such a threat (Tower, 2000). After a life-threatening diagnosis, many people consider the full impact of confronting their own mortality and prepare for the possibility of death (Brennan, 2001). Tennen and Affleck (1998) suggested that this disrupts the anticipated personal ‘trajectory’ of an individual’s life while Corbin and Strauss (1988) noted life-threatening illness is an interruption in the continuity of past and future. Frank-Stromberg, Wright, Segalla, and Diekmann (1984) noted that cancer patients perceive an “amputation of the future.”

Awareness of life’s fragility changes health behaviors and stimulates re-evaluation of life goals and relationships, stripping away pretense. Taylor (1983) suggested that this may lead to either striving to complete long-standing goals or abandoning priorities which suddenly seem trivial. In their study of individuals with chronic illness, Whittemore, Chase, Mandle, and Roy (2002) found that ‘health within illness’ (p. 23), or living so that illness is no longer at the forefront, was linked to an awareness of the fragility of life.

Terror management theory posits that mortality salience, such as that experienced by many persons diagnosed with cancer, positively disposes one toward people or concepts that confirm their worldview and self-esteem, and often results in a need for close, meaningful relationships and in striving for symbolic immortality (Arndt, Greenberg, Schimel, Pyszczynski, & Solomon, 2002). Carstensen, Fung, and Charles (2003) found that reminders of mortality shift attention from future-oriented goals to
emotionally meaningful goals. Further, two studies by Fung and Carstensen (2006) evaluating social goals before and after September 11 attacks and the SARS epidemic in Hong Kong showed that reminders of mortality correlate with references for relationships that are close and meaningful. Perceived threat was positively associated with posttraumatic growth, and in fact, individuals with more traumatic life events report more benefits than those with fewer traumatic life events (Cordova, Cunningham, Carlson, & Andrykowski, 2001). This is consistent with other trauma literature (Tedeschi & Calhoun, 1996).

_Threat to image of future self._

A person’s identity is created in large part by their personal trajectory, by their understanding of the meaning of the past, and by the anticipated future (Tennen & Affleck, 1998 & 2002). Given the perceived ‘amputation of the future’ created by mortality salience, cancer is a threat to the image of a ‘future self.’ Brennan (2001) and Smith, Redd, Peyser, and Vogl (1999) noted that while cancer meets the definition of trauma posed in the DSM-IV, cancer is distinguished from many other traumata in that the threat is situated primarily in the future, not the past. A significant finding is the surprising increase in anxiety as the end of treatment nears and uncertainty looms due to the absence of medical support (Brennan, 2001). This may be accounted for in part by a well-known phenomenon – survivors’ apprehension about recurrence or relapse. In fact, worry about symptoms and fear of recurrence are so common (Somerfield Stefanek, M.E., Smith, T.J., & Padberg, 1999) that they are considered normal (Brennan, 2001). A survey of over 600 cancer patients in remission found that their most commonly reported
cancer-related problem was uncertainty and fear about the future (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992). Brennan (2001) suggested that an individual’s perception of illness and prognosis predicts their assessment of future threat and accurately assesses the traumatic impact of their disease experience. Trauma is also a disruption in continuity of an individual’s autobiographical narrative (Corbin & Strauss, 1988). Neugarten (1979) found that an individual’s assessment of whether an event is ‘on-time’ or ‘off-time’ (with regard to predictable life events) is crucial. For example, in older persons illness and disability are common, therefore predictable, and the threat is ‘universal’, whereas disability or life-threatening illness in a younger person constitutes ‘unique’ vulnerability. Charmaz (1994) found that attempting to retain or regain identities rooted in the past is problematic when those past identities are irretrievable, but can provide incentive to fight illness and death.

_Centrality of event._

“Centrality of event is the extent to which a stressful event forms a reference point for personal identity and for the attribution of meaning to other experiences in a person’s life” (Berntsen & Rubin, 2006). Individuals differ in regard to the degree to which an emotionally intense negative event becomes central to identity, life story and understanding of the world (Berntsen & Rubin, 2006). Berntsen and Rubin (2006) concluded that these individual differences are critically related to PTSD symptom profiles and “the extent to which a traumatic or stressful event forms a personal reference point for the attribution of meaning to other events, a salient turning point in the life story and a central component of a person’s identity and self-understanding” (p. 220).
In their study of 111 undergraduates, Rubin and Berntsen (2004) asked a series of questions and a standardized checklist for PTSD symptoms about the most stressful events in the participants’ lives. Compared to participants without a PTSD symptom profile, those with a PTSD symptom profile tended to agree more with the statements that the trauma was central to their identity and they reported that a greater sense of connections and similarities between the trauma and current experiences.

Trauma theories predominantly emphasize lasting trauma sequelae as an inability to process and integrate trauma with knowledge of self and the world (Berntsen & Rubin, 2006). Berntsen and Rubin (2006) suggested the opposite: rather than trauma sequelae representing a lack of integration, trauma may have become too central and over-emphasized in the life narrative and identity of the trauma survivor. They argued that situating trauma as a salient turning point in the life story may lead to oversimplification, and that enhancing internal consistency of the life story sacrifices the “multiplicity of meaning that normally characterizes our life narratives” (Berntsen & Rubin, 2006, p. 221). Participants may exaggerate those aspects of current life that can be explained by reference to the trauma and ignore contradictory aspects (Berntsen & Rubin, 2006). Therefore, a survivor may over-identify with the traumatic event (Berntsen & Rubin, 2006). In fact, Berntsen & Rubin (2006) cautioned that therapists working with survivors of trauma be alert to avoid the traumata from becoming a defining event in the person’s life.
Illness Intrusiveness

Illness intrusiveness represents the degree to which a person’s life and activities are disrupted by illness. Several researchers have found illness intrusiveness has a profound impact on identity of patients with illness. In Charmaz’s (1994) extensive qualitative research with chronically ill patients, she found that drastic, forced lifestyle changes can erode or collapse valued identities. Furthermore, Charmaz (1994, p. 238) stated that, as illness intrudes, “discoveries of self . . . are typically framed in loss.” Loss of one’s familiar manifestation of self yields feelings of sorrow, betrayal, and/or shame, yet it is this very loss that can produce a transformed self and deeper meaning of life (Charmaz, 1994). Charmaz (1994) suggested that some patients will go to great lengths to preserve existing or former public and private identities. These strategies must utilize considerations of timing and staging, and often these patients recruit others, such as spouses and family members, to assist them. These individuals work diligently and utilize impression management to mask evidence of illness.

Becker’s (1993) study of 64 individuals who experienced a severe stroke found that these patients tried to maintain continuity of life despite profound disruption. Failure to do so resulted in a series of strategies to maintain ‘fit’ between the former life and the current one. While all individuals sought to maintain continuity with previous identities, those who were successful were also more likely to successfully adapt to their life changes.

Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., (2003) reported that their study found illness intrusiveness impacts the self-concept of bone marrow transplant patients and the effects are amplified when patients experience “engulfment,”
defined as the period of time when patients are overwhelmed by their cancer experience. Illness intrusiveness that becomes engulfment leads to helplessness, hopelessness, and distress (Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., 2003). This represents dominance of identity by illness. In other words, it reflects an identity as a sick person. This is consistent with what Charmaz called ‘immersion’ that she found was predominantly characteristic of newly diagnosed persons or persons with significant life impairments as a result of their disease.

**Threats to Social Identity and Relationships**

Patients’ perceptions of illness are likewise critical to understanding their responses. Those perceptions are generated not only on a personal level but are also influenced by the social construction of illness on the societal level. Symbolic interactionist theory informs our understanding of this process. How others respond shapes not only the experience but the meaning of an event and our interpretation of its effect on our identity. Twaddle and Hessler (1987) suggested three distinct definitions related to the absence of health: *disease* to indicate the physical manifestations; *illness* to represent the psychological aspect of symptoms and emotions; and *sickness* relates to the social elements such as the interpretation of ‘sick role’ and self (Allen, 1998). Calhoun and Tedeschi (2004) suggested that there are both distal and proximal elements in play with regard to response to trauma; distal factors include pre-trauma characteristics (e.g. socioeconomic, culture/ethnicity, and gender-related variables) and fundamental schemas of life and self with proximal factors being represented by coping processes, narrative development, and schema change. Stanton, Revenson, and Tennen (2007) noted that the
research on this is scant and that much more work is needed on the intersection of cultural identity, acculturation, and socioeconomic status as they relate to disease-associated adjustment.

_Sick role._

As patients develop explanatory models or illness representations, they perform a role and construct an illness identity based on their illness perception and understanding of social construction of cancer (Petroni, 1969). Parsons (1951) suggested that patients perform a “sick role” that serves to exempt sick individuals from normal social roles and from responsibility for their illness, but also obligates them to try to get well and cooperate with the physician (Parsons, 1951). While Parsons’ theories have been painstakingly critiqued as reflecting the medical hegemony of the 1950s and 1960s (Zebrack, 2000), some elements have also more recently been revitalized (Shilling, 2002).

In addition to social and cultural pressures to conform to a “sick role,” patients are shaped by the healthcare culture itself as they are reduced to their diagnosis or disease status. The current system of biomedicine fosters a sense of inequality and sets clear hierarchical structures in which the patient is made passive while the medical professionals are made active (Atkins, 2005; McGregor, 2006; Morris, 1998 & 2000). Patients lose their former status and evidence of identity. Many have talked about the reductivist nature of being a cancer patient (Broyard, 1992; Frank, 1995; Morris, 1998). Alternately, others report responses to cancer are a rediscovery of the spirit in a direct
response to avoid the reductivist experience of being a cancer patient (Broyard, 1992; Frank, 1995; Morris, 1998).

Patients’ perception of the “sick role” may be a factor as they perform a role congruent to what they believe is expected of them: for example, if they believe stoicism is desirable, they may underreport symptoms and therefore, not receive appropriate treatment (Yabroff, Mandelblatt, & Ingham, 2004). It is, therefore, important to consider the meaning to a cancer experience given by our society and by patients as they construct and execute their performance of the “sick role” or illness identity (Parsons, 1951).

Changes in presentation of self due to body changes.

Research has also emerged about the impact on identity experienced by some who have changes in their body due to cancer or cancer treatment, e.g. surgery, radiation or chemotherapy. We are embodied beings argued Merleau-Ponty (1976). It is through our bodies that we experience the world and interact with others, a fact that many do not recognize until illness makes it impossible to fully enact existing lives and roles. Physical bodies and selves are interdependent and bodily appearance, more than being an expression of self, is a part of the self. Further, we manage our appearance to control our presentation to others. Merleau-Ponty (1976) suggested that bodily experiences are a source of selfhood and argues that we cannot understand self or identity separate from the body. A change in our bodily experience due to changed physical appearance, however, might disrupt the union of the body and the self (Ucok, 2002).

In Ucok’s (2002) qualitative study of 18 women with breast cancer, she found that a changed appearance resulted in a disharmony of body and self. Most survivors in her
study reported that inability to integrate changed physical appearance as a part of themselves resulted in a “loss of self.” Minimizing visible differences to present a conforming appearance not only allowed survivors to maintain social interaction but allowed the women to maintain identity integrity (Ucok, 2002). While some survivors incorporated their changed appearance as a part of their selves, others demonstrated resistance by minimizing change to manage their image and restore a purposefully created sense of self. This is reminiscent of Goffman (1961) who spoke poignantly about ways in which individuals “resist the pull” (p. 121). Despite choosing different approaches, Ucok (2002) noted that all survivors in her study sought to maintain a “coherence of the self in moments of change and uncertainty.”

Ucok (2002) found two distinct phenomena with regard to changed appearance. Body changes could be distinguished by whether they are changes in the visual or tactile bodily experiences of cancer survivors. She found that physical changes not only transformed one’s experience of one’s own body, but also how one interacts with others. She also noted the profound impact of others’ responses to the body changes of the survivor and subsequently on the survivor’s social identity. She recognized that survivors who minimize visible differences in an effort to conform to the expectations of others were more able to maintain social interaction without disruption, whereas a survivor who is unable or unwilling to maintain a normal appearance is less able to maintain usual social interaction routines. In other words, this is a reflective process in which social interaction shapes the ways we view ourselves. In fact, among the women that Ucok (2002) studied, support from family members and friends was found to be critical in
helping survivors become more comfortable with body changes and resist the reactions of others to their image. (Ucok, 2002)

Hair loss is an almost universal side-effect of chemotherapy and was noted in particular by the women in Ucok’s study. Ucok (2002) noted that the women discussed hair loss as a visual experience and affects recognition by others and by one’s self. Hair is known to be an important part of identity and have social significance. In fact, with military inductees and prisoners of war, head shaving is used to foster the loss of individual identity (U.S. Army, n.d.). Ucok (2002) related that to these women loss of hair is more than just a change in one’s appearance but in self. The loss of breasts due to mastectomy, on the other hand, was not directly related to loss of self in terms of an inability to recognize one’s own self. It is a loss of self in terms of one’s intimate and tactile experiences (e.g. breast-feeding, hugging, love making etc.) in addition to the visual ones (Ucok, 2002).

Reactions of others.

Social support is known to play a significant role in adults with cancer. Ucok’s (2002) qualitative study of women with breast cancer found that interactions with significant others had a profound influence on “the reintegration of one’s body and self.” Yet cancer may restrict patients’ social activities and access to interpersonal resources when they are most needed (Brennan, 2001). Social constraints, a feeling of being misunderstood or alienated, are also known to play a negative role in the experiences of cancer patients (Lepore & Ituarte, 1999; Reynolds & Perrin, 2004).
Thoits (1991, 1994, 1999, 2003, 2006), who has written extensively regarding identity, acknowledges the contributions of Cooley, Mead, Blumer, and Styker with regard to symbolic interactionist notions of identity: that identity is socially constructed, and that we are defined in part by how others see us and mirror ourselves back to us. A symbolic interactionist stance emphasizes the social construction of self – that we learn about ourselves through our interactions with others. It is, therefore, easy to see the importance of understanding patients’ perception of others’ reactions. Social-cognitive processing (SCP) model focuses on recovery within an interpersonal context and notes that the social context of cognitive processing is particularly important for those with cancer. (Brennan, 2001)

*Valued roles.*

An individual with cancer all too often loses the identity of a healthy person and becomes a person with cancer due in no small part to changes in their roles and the responses of others. Maintaining valued roles and identities is more likely when strategies successfully minimize illness intrusiveness and illness visibility (Charmaz, 1994).

Kelly (1983) found that people derive meaning from investment in their roles in life. Several researchers in other forms of illness have identified the importance of valued roles. In patients with arthritis, Abraido-Lanza (2004) determined that role-appropriate helping relationships do not negatively impact self-esteem or self-efficacy, but illness intrusions or helping relationships that interfere with valued roles are related to distress and poorer adjustment.
Brennan (2001) suggests that for persons with cancer changes in social roles can challenge assumptions about self-worth, self-efficacy, and may interfere with valued roles. Work and professional identity enable individuals to engage in meaningful activity and to achieve self-actualization through competency and contribution to society (King, 2004). Loss of work and other valued roles can cause a perceived loss of adulthood (Rozmovits & Ziebland, 2004). Kelly (1983) found that leisure activities which are a source of social identity are central, meaningful, absorbing, and shared with valued others.

**Illness Models**

Several researchers have offered illness models a review of these models yields valuable insights into the impact of illness and treatment demands on the lived experiences of patients and the resultant influences on identity. Illness models from Fennell (2001 & 2003) identified a predictable phased trajectory with four distinct phases of adaptation for persons living with chronic illness: Crisis, Stabilization, Integration, and Resolution Phases. Progression is driven by an individual’s inability to return to life as it was before and culminates in the individual defining a new self as he/she integrates illness into a meaningful life. Alternately, Paterson’s (2001) Shifting Perspectives Model theorized that persons with chronic illness (like some patients with cancer) move perception between foreground and background depending on intrusiveness of symptoms, disease-related losses, threat to control, and other significant changes. While illness-in-the-foreground is driven by a focus on disease, suffering and loss – the body is primary, wellness-in-the-foreground is characterized by focusing on the self rather than the body as the “source of identity” (pg 23). Individuals with a wellness-in-the-foreground stance
do not lose awareness of their diseased body but seek to “create consonance between self-identity and the identity that is shaped by the disease, the construction of illness by others, and by life events” (pg 23).

Other illness-related models focus more specifically on the role of illness on identity. Clusters or profiles are common. These are distinguished by illness intrusiveness on life roles and activities, psychological adjustment, centrality of illness to identity, discrepancy of ideal vs. actual self, views of future self, and ability to either accommodate to or assimilate illness. Perception of time also appears to be critically important. Some studies have found identity profiles of cancer patients/survivors as linked to the illness trajectory (Tower, 2000), a specific medical event (Turton & Cooke, 2000), or the level of illness intrusion (Allen, 1998).

Integration

In research of patients with chronic or critical illness, nursing researchers have identified a construct they call integration which is defined as “synthesizing changing life circumstances into one’s life identity” (p. 262) or “as a human-environment interaction whereby new life experiences such as illness are reconciled with past and present identities and roles” (Whittemore, 2005, p. 261). Integration of an illness experience in self-identity results in improved psychological adjustment (Whittemore, 2005). Westra and Rodgers (1991) reviewed the relevant literature to that point and identified key attributes of integration as: process, combination, interaction, and unity. Integration is conceptualized as both an outcome and a process and, according to Westra and Rodgers (1991), is valuable in assessing patient outcomes.
Whittemore (2005) suggested that sense of coherence is a related concept that influences one’s overall life outlook, but is primarily an internal process while integration includes both internal and external processes associated with life events. Need for coherence is a driving force in integration as individuals seek to create meaning that renews continuity and homeostasis or a ‘new normal’ (Whittemore, 2005). Sense of coherence is primarily an internal process related to perceptions, attitudes, and emotional coping that influences one’s overall outlook on life. However, integration appears to encompass both, therefore, a positive sense of coherence might facilitate successful integration (Whittemore, 2005).

Integration has been studied extensively in patients with cardiac illness or diabetes and patterns have contributed to a model which identifies a sequential process, challenges, and influencing factors (Whittemore, 2005). Whittemore (2005) performed an extensive literature review in which she evaluated 36 empirical articles about integration and identified three specific subtypes of integration: role integration, social and community integration, and temporal integration. Role integration is defined as the disparity between stress and satisfaction in one’s primary roles. Social and community integration involves a sense of belonging with regard to relationships and activities of daily life. The temporal integration subtype addresses the disconnect individuals experience between the past and future and seeks to enhance the present, which Whittemore (2005) suggested can contribute to self-transcendence.

Whittemore’s (2005) model shows transitional experiences as 1. establishing a pattern, 2. embedding a pattern, and then 3. living a pattern. The first transitional experience includes both focused attention to living with illness in conjunction with
awareness of threat and vulnerability. Hernandez (1996) identified critical elements of this as total involvement with illness, reconciling emotions, and managing illness at the forefront (Whittemore, Chase, Mandle, & Roy, 2002).

A phase of integration involves self-exploration to find personal meaning in illness and increased attention to managing illness. In fact, a critical element of making durable lifestyle changes is exploring self and restructuring to support change. Personal strategies lead to changes in life patterns in which illness is no longer primary, illness intrusiveness is minimized, and attention to meaningful life events is recommenced. Other researchers (Fleury 1991; Medich, 1995) identified conscious awareness of, and commitment to, change among the common themes of integration. This also contributes to establishing patterns as routine (Whittemore, 2005). Trial and error allows idealized expectations to transform into reality; creating workable routines and experiencing positive outcomes reinforces changes and increases the likelihood of lasting change.

Cancer Identity Models

Finally, identity models have been offered that are specific to adults with cancer. Several researchers have noted distinct patterns and clusters of identities among cancer survivors but the significance of identity is only just beginning to be understood. Bradley, Calvert, Pitts, & Redman (2001) suggested that it is from the illness identity that coping strategies evolve. In a qualitative study of women who had completed treatment for early-stage gynecological cancer, the researchers found that development of an illness identity formed from the women’s illness representations was important in understanding patient responses (Bradley, Calvert, Pitts, & Redman, 2001). For example, women who failed to
note symptoms prior to diagnosis were more ‘shocked’ by the diagnosis, were prone to fear symptom-free recurrence, and sought more medical reassurance. They failed to regard being symptom-free as indicative of being cancer-free (good health) and were unable to return to a ‘healthy’ identity. In fact, they “argue that the illness identity of gynaecological cancer perpetuates a vulnerability to cancer recurrence” (Bradley, Calvert, Pitts, & Redman, 2001; p. 511). This illustrates the power of a renegotiated identity.

_Cancer trajectory models._

Illness trajectory is a term often used by physicians to describe the medical course of illness. The actual course of illness moves up and down, twists and turns as it goes through time. The work required to keep illness on course can only be known by living with illness (Corbin & Strauss, 1988). Corbin and Strauss (1988) used ‘illness trajectory’ to describe the combination of the impact of the course of illness as well as the role of the individual in shaping the course of illness (Loescher, Welch-McCaffrey, Leigh, Hoffaman, & Meyskens, 1989; Mullan, 1985; Turton & Cooke, 2000).

The cancer survival trajectory offered by Loescher, Welch-McCaffrey, Leigh, Hoffaman, and Meyskens, (1989) includes: 1. living cancer-free for years beyond diagnosis and treatment; 2. having lived a long cancer-free period but now dying rapidly of late recurrence; 3. having lived cancer-free but now developing a second primary cancer; 4. living with intermittent periods of active disease; and 5. living after expected death. Mullan (1985) identified six stages of cancer: discovery and diagnosis, treatment, remission or cure with return to daily activities, recurrence, spread, and terminal disease.
Similarly, Turton and Cooke (2000) offered a model of cancer identity evolution that mimics the illness trajectory: “cancer patient,” “incurable cancer patient,” “terminally ill cancer patient,” and “dying cancer patient.” They associated each of these with a particular medical event: diagnosis, secondary diagnosis, tertiary diagnosis, and entering the dying phase.

Weiner and Dodd (2001) suggested that uncertainty shapes the trajectory for cancer patients. The authors had originally theorized that living with cancer would result in discernible phases or stages of illness but soon found that instead the physical status of the patient and the socio-psychological implications of cancer and treatment were the central themes at all points. Their interviews with 100 cancer patients and their families at three different time periods led them to describe nine processes at work in these individuals: 1. Pacing or cutting back on activities; 2. Becoming a professional patient; 3. Seeking reinforcing comparisons; 4. Engaging in review of symptom onset (often includes blame of self or anger at healthcare professionals); 5. Setting goals to keep oneself moving forward but not looking past that goal; 6. Covering up to avoid looking weak in front of others or to avoid being labeled a hypochondriac; 7. Finding a safe sanctuary; 8. Choosing a supportive network; and 9. Taking charge – choosing treatment options which enhance both a sense of control and defiance of the healthcare team.

In a four-year longitudinal study of 363 women with breast cancer, Helgeson, Snyder, and Seltman (2004) found four distinct trajectories of change. The most common trajectory was slight but steady improvement, but smaller subsets yielded different findings. One subset started out very high and remained high, another showed decline, and another showed rapid increase and then remained steady. The presence of personal
resources — such as self-image, optimism, perceived control, and social resources — such as social support — were linked to different paths. More advanced age was found to be associated with lower levels of physical functioning and vice versa. Physical functioning appeared predictive of mental functioning.

Tower (2000) presented a model of cancer survivor transformation with six stages, each a building block for subsequent stages: 1. initial conditions; 2. diagnosis; 3. treatment; 4. transition; 5. integration; 6. continuous growth. Stage 1 is characterized by “alienation as an agent of transformation.” Tower stressed the dissatisfaction and feeling of being trapped into a life one does not want, and suggested that cancer is an unconscious way to escape. Stage 2’s theme is the existential terror created by diagnosis. Stage 3, on the other hand, incorporates five themes: the horrors of medicine, time for reflection, letting go of control, redefining positive attitude, and time for love. What Tower actually describes is the loss of identity and valued roles (e.g. independent, in-control, bread-winner, Type A) driven not only by the sudden salience of mortality but also by the physical pain and misery of treatment. Further, he described a distinct, abrupt rupture of one’s biographical narrative, particularly with regard to time: there is ‘before cancer’ and ‘after diagnosis.’ Tower suggests that it is the annihilation of life before that makes room for renewal, reorganization, and reconstruction of life and identity.

Stage 4 of Tower’s model includes three themes: depression and stress, positive stress, and growth strategies. This period of dynamic struggle is socially isolating and emotionally troubling. Tower suggested that “death imprint” is the catalyzing factor for growth. Stage 5 is called Integration and represents two themes: Adjustment/Accommodation or Growth and Transformational Growth. Tower posited a
theoretical Stage 6, Continuous Growth, which he admitted he had no evidence for but argued that continual striving is consistent with Maslow’s stage of self-actualization.

Cancer survivor identity.

In his study of 53 adult survivors of leukemia and lymphoma, Zebrack (2000) identified a “cancer survivor” identity that he noted was characterized by easy recall of feelings and events around the cancer experience, lingering vulnerability, and ongoing concern about mortality. He stated that due to the changes in roles, cancer survivors see themselves differently in relation to the world, which therefore affects not only their self-image, but also their sense of well-being or quality of life. In other words, woundedness is a common construct that is central to the development of a new identity that incorporates a paradox of strength through brokenness.

Zebrack (2000) found that overall adjustment (which he refers to as ‘achievement’) is predicted by the degree to which patients can maintain valued roles, stabilize the life trajectory, and manage dissonance about self-concept (or maintain coherence about identity). Self-concept mediates the impact of stressful events on valued aspects of self and influences the regulation of meaning (Pearlin, 1989; Zebrack, 2000). He noted that the important elements of adjustment are reconciling ideal and actual experiences, managing role-specific disruptions, and experiencing positive interactions with others. Maintaining or regaining valued social roles is critical in minimizing distress and maintaining a sense of control that will enhance the likelihood of long-term adjustment and overall well-being (Clark & Stovall, 1996; Zebrack, 2000).
Allen (1998), who interviewed 30 cancer patients and drew upon her own experience as a participant observer, identified a model that integrated models by Twaddle and Hessler (1987) and Charmaz (1991). She found six profiles: 1. cancer as total immersion: the cancer person; 2. cancer as immersion and intrusion: the newly diagnosed person; 3. cancer as intrusion: the cancer survivor; 4. cancer as intrusion and interruption: the impaired survivor; 5. cancer as interruption and intrusion: the intact survivor; and 6. cancer as interruption: the person who had survived cancer (Allen, 1998). Further, she identified that a patient’s need to return to normal drives the trajectory of patients from immersion to intrusion or interruption.

**Illness Identity Models**

Charmaz (1983, 1987, 1991, 1994, 1995, 2002, 2006, 2007) has produced a significant body of qualitative research with chronically ill patients and has written extensively about loss of self and subsequent reconstruction of self. In her research, Charmaz found that loss of self (disrupted identity) is precipitated by awareness of illness intrusiveness, and she concluded that it is, in fact, that challenge to identity which invokes a transformed self and deeper understanding of life. Charmaz found that individuals reframed themselves and their lives by the intrusion of illness on their lives. Charmaz (1983; 1991) offered a model that delineates patients with chronic illness in three ways: those who experience illness as intrusion, those who experience illness as immersion, and those who experience illness as interruption. Her model accounts for the salient factors of illness intrusiveness on the life and identity of the patient and patient perception of self in time.
Charmaz (1987) argued that people strive toward preferred personal and social identities. She also identified a hierarchy of identities among chronic illness patients that consists of levels: supernormal social identity in which “extraordinary feats are common in the conventional world;” restored self which is a “reconstruction of previous identities prior to illness;” contingent self which is “a potential but uncertain identity because of the possibility of future illness;” and salvaged self which is “retaining past identity based upon a valued activity or attribute while becoming physically dependent”. Progressive deteriorating illness results in individuals “reducing identity goals and aiming for a lower level in the identity hierarchy” (Charmaz, 1987, p. 285).

Nochi’s (2000) qualitative study of individuals with traumatic brain injuries (TBI) found that coping and adjustment were derived from self-narratives. These individuals reorganized their life-stories to incorporate a time-perspective and attention to the social and physical context of the individual. These re-conceptualized self-narratives resulted in five categories: “the self better than others,” “the grown self,” “the recovering self,” “the self living here and now,” and “the protesting self.” They viewed themselves differently; self-narratives were intact either “in spite of TBI” or to be worthwhile “because of TBI.”

Yoshida (1993) interviewed 35 patients with traumatic spinal cord injury in order to identify the impact of this event on the participants’ identities. A pendular model was suggested in which identity reconstruction is depicted as a pendulum that swings back and forth between the disabled and nondisabled aspects of self (Yoshida, 1993). In this model, identity is conceptualized as fluid and dynamic, continuous, evolving, and dual-directional. This model challenges the view of adjustment as linear but confirms the relationship of adjustment to identity. Yoshida (1993) identified five predominant
identity views: 1. former self; 2. supernormal identity; 3. disabled identity as total self; 4. disabled identity as an aspect of the total self; and 5. middle self. Identity reconstruction is conceptualized as both a process and an outcome.

Psychological Adjustment in Adults with Cancer

Individuals with cancer can demonstrate anxiety, depression, or regressive behaviors that can interfere with quality of life and treatment outcomes (Sperry, 2006). They also experience a loss of productive function, stigma, financial stress, and family strain (Mathieson & Stam, 1995; Moos & Schaefer, 1984). Discussions of cancer tend to be around diagnosis, treatment, and coping (Kudler, 2005). The literature on patient adjustment includes: psychological distress, illness perception, perceived control, self-efficacy, coping, quality of life, optimism, discrepancy between actual and ideal self, sense of coherence, social support, and meaning-making among others (Sharpe & Curran, 2006). In an extensive review of the literature, Stanton, Revenson, and Tennen (2007) found three themes to the issue of heterogeneity of adjustment to illness: “(a) chronic disease requires adjustment across multiple life domains, (b) adjustment unfolds over time, and (c) there is marked heterogeneity across individuals in how they adjust to chronic illness.”

Self as Mediator (discrepancy between actual and ideal)

Heidrich, Forsthoff, and Ward (1994) studied cancer patients’ use of self as a mediator of adjustment. They use theoretical perspectives of Rosenberg (1986) that suggest that the adaptive capacity of the self could be useful in exploring how
expectations regarding the self are related to adjustment to illness. Rosenberg’s (1986) conceptualization of the self as dynamic (malleable) and multidimensional provides a meaningful approach to investigating differences in adaptation. Participants in the research were studied with regard to their ideal self and their actual self. They concluded that a discrepancy in the two constructs results in psychological distress, and patients are, therefore, motivated to maintain congruence. Taylor (1983) and others (Wood, Taylor, & Lichtman, 1985) have suggested that cognitive control (e.g. self-enhancing evaluations and thoughts) in response to a stressful event is correlated with better adjustment; that adjustment is illusory for the express purpose of self-enhancement.

**Psychological Distress**

A meta-analysis of the literature from 1980 to 1994 revealed that psychological distress in cancer patients manifests most commonly as depression; there was no significant difference between adults with cancer and adults without cancer with regard to anxiety (Van't Spijker, Trijsburg, & Duivenvoorden, 1997). This is consistent with the finding that while many adults with cancer report no psychological difficulties (Rodrique, Behen, & Tumlin, 1994), about one-third report global adjustment difficulties such as depression or anxiety. Psychological distress in cancer patients appears to be significantly correlated to being recently diagnosed, illness intrusiveness, and disruption of valued roles (Rodrique, Behen, & Tumlin, 1994). However, Folkman and Moskowitz’s (2000) review of the literature on coping found that psychological distress is not exclusive of positive affect. In fact, Calhoun and Tedeschi (2006, p. 11) postulate a curvilinear model to PTG in which those with substantial psychological impact suffer
primarily negative responses and are unlikely to find benefit, and those with strongest capabilities would not be significantly affected and therefore have no need to make meaning or seek benefit. Other studies have shown that women with breast cancer at the low and high end of the distress scales benefit the least from a support group.

Brennan (2001) theorized that the huge range of individual variation in how people respond to overwhelming events, such as a cancer diagnosis, is reflective of: 1. differing cognitive models of self; 2. differing social contexts through which to experience events; and 3. individual styles of responding to discrepancy or incompatibility with assumptions. Brennan (2001) also stated that heightened arousal, denial-avoidance, and intrusive thoughts and images, while symptoms of trauma, may also be elements of normal adaptive coping processes. In the early stages of coping with trauma, avoidance may help by decreasing stress and permitting gradual recognition of threat; later, approach promotes assimilation into “an integrated self-structure” (Brennan, 2001; p. 9).

**Illness Perception**

Recent attention has been directed to goodness-of-fit or reality-matching which has been supported by the research and represents an understanding that individuals’ beliefs are important in adjustment to illness (Sharpe & Curran, 2006). Illness representations are multidimensional with five related, but conceptually and empirically distinct, components from self-regulation theory: identity, timeline, cause, serious consequences, and curability/controllability. The identity component reflects the illness label and perceived symptoms associated with the illness. The timeline dimension refers
to a person’s beliefs about the relative chronicity of the illness. An individual’s attribution of cause of the illness to different factors makes up the cause component, while perceptions of the potential of the illness to have a serious impact on an individual’s lifestyle and well-being comprise the serious consequences dimension. The curability/controllability component reflects an individual’s assessment as to whether they have the personal resources to control the illness and beliefs in the effectiveness of treatment. A revised measure of illness perception (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002) divided controllability into treatment control and personal control, and added emotional representation and causal attribution – dimensions from Leventhal’s self-regulation theory. Perception of timeline or personal position in temporal time is important (Charmaz, 1991; Hofmeister, 2004; Ricoeur, 1992).

**Self-efficacy**

According to Bandura (1982), whose extensive study of the construct of self-efficacy significantly advanced the research and refined our understanding, self-efficacy is a sense of mastery and a self-judgment of one's ability to successfully execute tasks in a specific domain. Bandura (1982, 1997) later identified agency and control as critical components of self-efficacy. Self-efficacy is also a vital feature of self-regulation and has proven important in understanding and predicting medical compliance (King, 2004). Cvengros, Christensen, and Lawton (2004) found that patients do best when they have some sense of perceived control. King (2004) argued that self-efficacy is important in the development of feelings, action, and thought. It has also been suggested that self-efficacy is a correlate of sense of coherence (Surtees, Wainwright, Luben, Khaw, & Day,
Hamilton’s (1998) analysis of language by bone marrow transplant patients in an on-line list-serv found that direct and indirect reported speech which portrayed the patient as “a strong self-advocate and the physician as contributing to that positive image of the patient, either directly or indirectly” was related to participants’ “construction of identities as survivors rather than victims.”

Osowiecki and Compas (1998) found that cancer patients’ coping responses differ as a function of their perceived control. Ferraro, Barreto, and Toledo (1994) found in their study of 69 women with breast cancer that perceived control was the single most important factor in mental adjustment to cancer. The research of Thorne and Paterson (1998) represented patients as active agents in attaining desired outcomes. While patients who participate in their own health care seem to fare better than those who do not (Laine, 1997), the research is not conclusive.

In contrast to personal agency, many adults with cancer instead find a sense of powerlessness, and loss of control and status that accompany interaction with the health care system (Bolen, 1996; McGregor, 2006). Many patients complain about communication with physicians and health system inconsistencies (Donovan, Hartenbach, & Method, 2005). It is known that physicians have a significant influence on patients and their decision-making process (Foucault, 1963; McGregor, 2006). Patients explain that they are expected to comply without questioning and believe that their insights are not welcomed.

However, despite a systemic move toward patient empowerment, some patients express a preference for passive acceptance of physician-determined treatment (Maly, Leake, & Silliman, 2004). While some physicians engage in power-sharing, many
patients feel overwhelmed and unprepared to make such critical, technical decisions. However, Stiggelbout and Kiebert (1997) found that some patients prefer to adopt a passive role, not wanting to choose a course of action, leading Laine (1997) to hypothesize that being more active leaves patients no one to blame when things go wrong. This creates a paradox in the current drive for patient empowerment and engagement to shift patients from the role of patient to partner (Thorne & Paterson, 1998). Perhaps not all patients equate decision-making with self-efficacy. In her qualitative study of mid-life career women who survived cancer, Hofmeister (2004) noted that in her study survivors viewed themselves as self-efficacious by focusing on maintenance of dignity and integrity rather than autonomous decision making.

Achieving patient compliance is a constant concern. Non-compliant patients are deemed difficult: impediments to their own survival (Sharf, Stelljes, & Gordon, 2005; Thorne & Paterson, 1998). Patient refusal is an extreme on the continuum of adherence or compliance. Sharf, Stelljes, and Gordon (2005) studied patients who refused physicians’ recommendations for either diagnosis or treatment of lung cancer and found that patients had reasons for their choices that they believed were valid including “distrust of medical procedures, memories of unfortunate past experiences of self or others, complaints of inadequate information, as well as criticisms of physician competencies and other negative aspects of the health care system. By emphasizing doubts about medical authority, the response of refusing diagnostics or treatments takes on a logic of its own” (Sharf, Stelljes, & Gordon, 2005, p. 632).
Coping Style

Cancer demands intense psychological coping as a response to the unpredictable, life-threatening, and potentially traumatic experiences (Jonker-Pool, van Basten, Hoekstra, van Driel, Heuvel, Schraffordt, et al., 1997). Lazarus and Folkman (1984) defined coping as cognitive and behavioral approaches to management of external and internal demands that strain or exceed the resources of the individual. It is an active adaptation that occurs through an ongoing reappraisal process (Paterson, 2001). Coping is not a static process and shifts with development of the disease or intrusion of symptoms. Thoits (1999) suggested that some changes in identity salience may be coping strategies.

Jarrett, Ramirez, Richards, and Weinman (1992) argued that patients' cognitive and behavioral coping responses to cancer may explain a large proportion of individual differences in psychological adjustment. Cancer patients who responded with high levels of optimism and self-esteem correlated with decreased levels of psychological distress (Stiegelis, Hagedoorn, van der Zee, Buunk, & van den Bergh, 2003). In patients with advanced cancer Brennan (2001) found problem-focused coping to be more favorable and associated with lower psychological distress than emotion-focused coping. Over time, however, active coping appears to be less favorable as patients have to adapt to a changed life perspective and active coping to solve problems is nearly futile. In patients with a diagnosis of advanced cancer, problem-focused coping was found to be more beneficial than emotion-focused coping (Brennan, 2001). Van't Spijker (2001) also found that an active coping style is related to lower psychological distress early in the cancer experience when uncertainty is at its peak and active coping provides a sense of control. Patients nearing death have little use for active coping.
Brandtstädter and Renner (1990) distinguished two types of coping: assimilation and accommodation. Assimilative coping entails active attempts to correct disappointing life circumstances to get back the previous life situation; in other words, to return to life the way it was. Accommodative coping involves revising standards for self-assessment and personal goals to promote adjustment to a changed life. In accommodative coping, goal discrepancies are removed by downgrading or rescaling life goals or activities (Brandstädter & Rothermund, 2002). They suggest that these coping styles are not mutually exclusive and at times may function simultaneously. Also, there can be variability in the degree to which a person utilizes each of the modes. Luszczynska, Mohamed & Schwarzer, (2005) suggested that assimilative and accommodative coping strategies may predict specific aspects of finding benefits in cancer. They found that self-efficacy beliefs were strongly predictive of coping strategies. However, while self-efficacious patients may be more engaged in utilizing assimilative, active coping, they also adjust to life changes and seek opportunities for success, which is definitive of accommodative coping.

Berzonsky (1988) suggested an assimilation/accommodation process model to understand the role of identity in management of daily life. Cognitive and behavioral components are central to Berzonsky’s model. A continuous stream of information is incoming from our ‘social and physical reality’ to which our ‘identity structures’ provide cognitive schemata and scripted behavior changes to deal with any experience. Most situations utilize assimilative processes which are relatively automatic, not employing cognitive processing or re-structuring. If assimilative efforts are unsuccessful, however, the resultant dissonance requires that cognitive processing adapt new schemata and
behaviors guided by the identity structures which ensure consistency of self and ultimately, biographical continuity.

Kudler’s (2005) model is similar to assimilation/accommodation, but more organically represents the experience of cancer survivors. Her study of women surviving cancer lead her to suggest that individuals surviving an illness the magnitude of cancer respond by trying to fill the void while coping with tremendous uncertainty – she calls this *Performing Normalcy*, working to regain status quo. She described the liminality caused by profound vulnerability. She also described women’s attempts to make meaning of their survival which results in what she calls *Constructing Survivorship*, working to achieve something positive when one cannot return to the original status quo. She suggests that Constructing Survivorship is about the subjective experience of confronting illness while attempting to restore balance for self and others with an ultimate goal of creating a ‘new normal.’ She further suggests that both processes occur simultaneously.

*Sense of Coherence*

Seeking a renewed sense of coherence may account for cancer patients’ attempt to make meaning of events and regain a disrupted identity. Csikszentmihalyi’s (1990) theory of flow suggests that when one’s feelings, intentions, and thoughts are focused on the same goal, harmony or coherence emerge, and it is then that the self can grow. Antonovsky (1987, p. 19) used the term sense of coherence (SOC) to describe a concept he defined as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and
explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement.”

He also claimed that the way people view their life influences their health (Eriksson & Lindstrom, 2005). Surtees, Wainwright, Luben, Khaw, and Day (2006) found in fact that cancer patients with higher SOC had lower mortality.

In trauma recovery, SOC is believed to be the individual’s means of reconciling discrepancy in shattered assumptions and rectifying disharmony. McAdams (1993) conceptualized coherence as created through dynamic narratives which render meaning and subsequently shape a narratively-derived identity.

SOC has proven to have enduring value as a way to understand adjustment. Gustavsson-Lilius, Julkunen, Keskivaara, and Hietanen (2007) found less distress among cancer patients and their partners who have strong SOC. Znoj (2006) posits that sense of coherence is a measure of resilience. A thorough review of the research about SOC revealed that it is important in predicting positive outcomes in a long-term perspective but tends to increase with age (Eriksson & Lindstrom, 2005). Lev-Wiesel and Amir (2006) cited research in which sense of coherence is viewed as a trait (Antonovsky, 1979) or a correlate of resilience (Almedom, 2005), and research that conceptualizes it as more dynamic and subject to influence. For example, Wolff and Ratner (1999; Lev-Wiesel & Amir, 2006) found that social support mediates long-term negative effects and increases a sense of coherence.

The search for coherence may be confounded by the inherent powerlessness of patients within the biomedical framework. The patient’s knowledge of his/her own body and symptoms is often subjugated to the technical knowledge provided by the medical
profession: knowledge about the disease, not the patient’s experience of the illness becomes primary (Foucault, 1963; McGregor, 2006).

Social Support

Social support has been portrayed as critically important in understanding cancer patients’ individual adjustment and coping. In fact, it has been suggested that social support can extend life and minimize mortality. In a study by Devine, Parker, Fouladi, and Cohen (2003) of 53 patients with metastatic cancer, social support was found to be a mediating variable for adjustment and quality of life. High social support was negatively correlated with intrusive thoughts/avoidance, psychological distress and was positively correlated with mental health quality of life. They concluded that high levels of social support translated into opportunities to cognitively process the cancer experience. Social support can directly affect benefit-finding by enhancing coping and thus changing the threat of stress (Bandura, 1997).

Functional support, the quality of relationships with others, matters more than structural support, the mere presence of others (DiMatteo, 2004). Luszczynska, Mohamed & Schwarzer (2005) found that for adults with cancer social support was not predictive of personal growth or acceptance but only affected perceived positive changes in family relations. This is consistent with the findings of Tedeschi and Calhoun (1996).

With trauma there is also a profound, debilitating sense of isolation or disconnection from others that inhibits social support (van der Kolk, Roth, Pelcovitz, Sunday, & Spinazzola, 2005). Additionally, in a study of long-term cancer survivors, Bush, Haberman, Donaldson, and Keith (1995) found that 96% reported that a perception
that support deteriorates over time. This can be particularly problematic when illness precludes independence or necessitates dependence on others.

Cancer patients often report negative social experiences. Talking about trauma facilitates processing for many people but negative responses to disclosure lead to avoidance, intrusive ideation, inhibited cognitive processing, and increased distress (Cordova, Cunningham, Carlson, & Andrykowski, 2001). Lepore, Miles, and Levy (1997) found that among patients with breast or colon cancer, intrusiveness three months post-diagnosis was correlated with negative affect in only those individuals with high social constraints. Social constraints are defined as "any social condition that causes trauma survivors to feel unsupported, misunderstood, or otherwise alienated from their social network when they are seeking social support or attempting to discuss their trauma" (Lepore & Ituarte, 1999, p. 168). Social constraints are associated with greater avoidance and intrusiveness. Discrepancy between the type of support desired and the type of support received creates incongruence.

Corbin and Strauss (1988) observed that the work of illness, or illness management, is largely a dyadic process. Charmaz’s (1994) qualitatively study of 20 men with chronic illness found that most married men perceived enormous affirmation of valued identities while validated identity supports were less available to unmarried men. The married men reported feeling not only supported, but also that they mattered. Charmaz argued that wives provided continuity for their husbands between past and present by remaining actively involved in the present circumstances. Men were more likely than women to link future to past selves.
Posttraumatic Growth in Adults with Cancer

There is a growing body of literature describing the posttraumatic growth reported by many cancer survivors (Calhoun & Tedeschi, 1998; 2004; 2006; Stanton, Bower, & Low, 2006). A recent review of the literature found that most cancer patients report growth or benefit from their cancer experience (Stanton, Bower, & Low, 2006). In fact, cancer patients have often reported that, irrespective of their prognosis, their lives had been changed for the better (Antonovsky, 1987; Stanton, Bower, & Low, 2006). Jonker-Pool, van Basten, Hoekstra, van Driel, Heuvel, and Schraffordt et al. (1997) attributed this to the inherent existential questions that result from a cancer diagnosis.

Posttraumatic growth (PTG) is a term created by Tedeschi and Calhoun (1995) to describe a phenomenon of positive changes following a traumatic event, i.e. a precipitating stressor of ‘seismic’ magnitude (Calhoun & Tedeschi, 1998). They have identified three components to PTG: change in perception of self; change in the experience of relationships with others; and change in the general philosophy of life. Basic assumptions and values are challenged; new meanings emerge (Ackerman & Maslin-Ostrowski, 2004). Selves are made and unmade through crisis (Ackerman & Maslin-Ostrowski, 2004).

It is accepted that creation of meaning and developing coherence is helpful to cancer patients in coping and is crucial to posttraumatic growth. Recovering from trauma involves seeking new meaning and coherence, finding new connections and re-writing our basic assumptions on the most fundamental level – our sense of ourselves and our world (Janoff-Bulman, 2006, p 83). Neimeyer (2006) suggested that PTG is a function of narrative reconstruction. It is in the struggle for meaning not from the trauma itself, that
growth occurs, and culminates in a transformation in views of self, others, and philosophy of life (Calhoun & Tedeschi, 2006). Ultimately there is a new sense of self that integrates the experiences and develops as more vulnerable and less naïve (Calhoun & Tedeschi, 2006).

Stanton, Bower, & Low (2006; p 151-155) summarized a significant number of studies to determine correlates of PTG in adults with cancer, but the results were inconclusive: PTG is positively associated with both high SES and low SES; PTG is found to be associated with minority status as well as showing no significance relative to minority status; similar inconclusive findings were noted with age, gender, marital status, and social support, perceived cancer stressfulness, time since diagnosis, disease type and severity, type of surgery, type of treatment, cancer-related medical visits, neuroendocrine functioning, immune functioning; pain, optimism, neuroticism, self-efficacy/self-esteem, psychological distress, psychological well-being, positive affect, quality of life, threat sensitivity, incentive sensitivity (Stanton, Bower, & Low, 2006). Significance has been found in the area of social context and some elements of coping.

**PTG and Adjustment**

The research on PTG is at times contradictory, confusing, and counter-intuitive with regard to its relationship with psychological adjustment. Since psychological adjustment is characterized by minimization of psychological distress and PTG is characterized by positive growth, a significant overlap was expected, but curiously, Stanton, Bower, and Low (2006) reviewed 15 studies of psychological distress in cancer patients and found an inconsistent relationship between distress and PTG. This
paradoxical finding led Stanton, Bower, & Low (2006) to conclude that PTG has a limited effect on psychological adjustment. In fact, PTG may be accompanied by decreased well-being and greater stress (Calhoun & Tedeschi, 2006). Several factors have been considered to explain why some people experience PTG and others do not, to predict who is likely to benefit, and to identity how to facilitate this process for all survivors. Coping, perceived threat to life, self-efficacy, social support, sense of coherence, perceived control, illness representations, and demographic factors have all been examined for their role in how cancer patients adapt but fail to account for the variance (Stanton, Bower, & Low, 2006).

Despite the almost exclusive emphasis on the positive aspects of PTG, it is necessary to remember that it is born from trauma – crisis, suffering, and an awareness of one’s’ own mortality. Therefore, contradiction is inherent and inevitable. It is the loss of the assumptive world that creates fertile ground for a new climate of meaning, value, and commitment (Janoff-Bulman, 2006). Paradoxically, healing from trauma involves incorporating both the good and the bad (Janoff-Bulman, 2006). While PTG is associated with strength, it is also associated with vulnerability. The newfound strength emerges from frailty, powerlessness, and loss. Vulnerability is transformed into awareness, disillusionment into appreciation, and unpredictability into preparedness. The gains are on the foundations of loss, inextricably tied to the pain of trauma. Znoj (2006) cautions that resolution of trauma does not equate to restitution of former well-being.
Coping

Similarly, Stanton, Bower, & Low, (2006) found inconclusive or contradictory findings with regard to many elements of coping and PTG: approach-oriented coping, planning, logical analysis, positive reappraisal coping, acceptance coping, acceptance coping, seeking social support, emotional approach coping, avoidance coping, denial/behavioral disengagement, escape/avoidance, distancing, distraction/seek alternative rewards, substance use, humor, religious coping, self-blame. The only clear evidence was for problem-focused coping and contemplating reason for cancer.

According to Calhoun and Tedeschi (1998) positive change in the aftermath of trauma and confrontation of mortality is predicated in constructive rumination in which one engages in contemplation of changes in an attempt to find meaning and revise life goals. Meaning making is the process of reconstructing narrative coherence and autobiographical continuity. Making meaning of trauma is distinguished as occurring in two ways: ‘meaning as significance’ (Janoff-Bulman & Frantz, 1997) and ‘meaning as comprehensibility’ (Janoff-Bulman & Berger, 2000). Meaning as significance is described as awareness of vulnerability and personal value while meaning as comprehensibility involves making sense of an event.

Calhoun and Tedeschi (2006) also found that cognitive processing is an important aspect of coping. They found particular importance in rumination which they suggest has two elements: intrusive and deliberate. Intrusive thoughts were distinguished by time since event and were more related to growth in the areas of spirituality and appreciation for life while deliberate rumination was found to be related to meaning-making and benefit-finding. In his studies with bereaved parents Znoj (2006) found evidence for the
importance of managing emotions in development of PTG. The coping strategies of intrusive and deliberate rumination seem to translate to Antonovsky’s (1987) notions of ‘comprehensibility’ and ‘meaningfulness’ while emotion regulation corresponds to ‘manageability,’ all key concepts of sense of coherence.

Janoff-Bulman noted that while successful coping is necessary for PTG, it is not sufficient (2004). As previously discussed, Tedeschi and Calhoun (2006) posited a curvilinear relationship between coping and PTG in which the least traumatized and the most traumatized are the least likely to develop PTG. Brennan (2001) suggested a simple explanation: that symptomatology identified as pathological – avoidance and re-experiencing – are actually the individual processing the trauma to integrate it into their existing schemata (self-schema).

King (2004) reviewed dozens of theories and models that strive to explain the ways in which people find meaning in life experiences and deduced three common to all: belonging (relationships), doing (meaningful engagement in activities), and understanding oneself and the world. Using these key concepts as an analytic tool, she created a constructivist, developmental model of meaning of life experiences which included five principles: 1. multiple, intertwined, fundamental meanings of human experience; 2. indeterminacy of cause and effect; 3. individual differences in preferences for ways of attaining meaning; 4. importance of commitments in life; and 5. life-long adaptation and changes in meaning. In other words, she found that people create meaning from experiences to maintain coherence to life and that meaning arises through creating structure in everyday life that consists of ways to engage self and the world. She
theorized that understanding the creation of meaning is important to counselors in devising effective treatment plans for clients.

*Increased Threat, Struggle, Adversity = Increased PTG*

Calhoun and Tedeschi note that a ‘seismic event’ is a necessary prerequisite to PTG (1998). It is long known and widely accepted that adversity brings strength: “What doesn’t kill me, makes me stronger.” ‘Fighting spirit’ has been acknowledged as potentially valuable in surviving cancer. Significantly, Thornton and Perez (2006) found that for men with prostate cancer, PTG was not related to quality of life, and in fact, the highest levels of PTG were found in men with the lowest quality of life. Similarly, Tomich and Helgeson (2004) found that among women with breast cancer those with more severe disease perceived more benefit than women with less severe disease. This is consistent with other studies. In fact, Thornton and Perez (2006) theorize that PTG may be adaptative coping in persons experiencing distress as a result of their cancer experience.

*Benefit-finding*

Benefit-finding is a coping process generally accepted to be highly correlated with PTG. Carver and Antoni (2004) performed a longitudinal study of 230 early-stage breast cancer patients in which they found that initial benefit-finding was predictive of positive emotion, higher perceptions of quality of life, lower distress and depression at follow-up four to six years later. In contrast, Tomich and Helgeson (2004) found that among women with breast cancer early benefit-finding (in interaction with the stage of
disease) was predictive of more negative affect 3 and 9 months later. Two other primary differences emerged – women of lower socioeconomic status and who were non-white perceived more benefit.

_Social Context_

Studies of PTG in adults with cancer confirm social context as important to personal growth but as inconclusive as to which aspects are most relevant. However, according to the meta-analysis performed by Stanton, Bower, and Low (2006), the following areas of social context are significant for adults with cancer: marital support, contact with PTG model, and prior talking about cancer (Stanton, Bower, & Low, 2006).

Married breast cancer survivors were found to be more likely to report PTG than unmarried women (Carpenter, Brockopp, & Andrykowski, 1999). Thornton and Perez (2006) found that for men with prostate cancer, PTG was associated with emotional support, pre-surgery negative affect, and positive reframing.

PTG in partners was higher in those were less educated, partnered to employed patients, had higher pre-surgery cancer-specific avoidance, and employed positive reframing (Thornton and Perez, 2006). Weiss (2004) found that PTG in husbands of women with breast cancer was correlated with greater marital commitment and exposure to wife’s PTG. Weiss (2004) even suggested that PTG may be “contagious” (p. 266). Explanation for the fact that a husband’s PTG is predicated on his wife’s includes acknowledgement of research that men are dependent on their wives for emotional support.
Cordova, Cunningham, Carlson, and Andrykowski (2001) found that social constraints (the extent to which significant people in an individual’s life restrain expression of trauma-related thoughts and feelings) and satisfaction with social support were not predictors of PTG. However, the degree to which a woman had talked with people in her social context about her breast cancer was a significant predictor of PTG in the Cordova, Cunningham, Carlson, and Andrykowski (2001) study.

Posttraumatic Self

Trauma survivors report a loss of self as trauma is also a lack of coherence in the self-narrative. They must adapt a more complex representation of self and the world, and relinquish the original sense of security (Znoj, 2006). Neimeyer (2006) asserted that one of the goals to surviving trauma is to reconstruct the self-narrative in such ways that “enlarge and deepen the survivor’s identity” or as Janoff-Bulman (2006) conceptualized, reconstructed narrative (or schema change) yields a new sense of self. Neimeyer (2006) posited that posttraumatic growth is the result of narrative repair. Many studies illustrate how individuals living with illness use narratives to create meaning and “remake the self in relationship to illness” (Barker, 2002). Calhoun and Tedeschi have found that reconceptualization of self is one of the three cornerstones of PTG (2006). Znoj (2006) speculated that trauma can activate developmental processes in response to “inconsistencies in one’s representation of the self and between the perceived world” (p. 193).

Individuals who have survived prior trauma and have regained a sense of coherence may be resistant to subsequent traumas (Janoff-Bulman, 2006). Janoff-
Bulman attributed this to “psychological preparedness” that creates better adjustment to subsequent trauma. These survivors may not experience the same profound assumptive loss and cognitive reprocessing that result in transformed views of self, others, and philosophy of life (Calhoun & Tedeschi, 2006). In other words, subsequent stresses may be less likely to qualify as traumatic and have traumatizing impact. Znoj (2006) reported that following life-threatening crisis, people become more resistant to depression and develop “a cognitively buffered self” (p. 177).

Cancer survivors who are able to derive meaning from their experience are more likely to shift priorities, accept their mortality, and adjust well to life after cancer (Ersek & Ferrell, 1994; O’Connor, Wicker & Geronimo, 1990; Taylor, 1993 & 1995). Likewise, Taylor, Lichtman, and Wood (1984) found that patients who were able to find meaning in the experience, and who “felt a sense of control and restored self-esteem, were emotionally better adjusted than those who lacked these perceptions.” In turn, they suggested this may promote self-esteem and maintenance of optimism about the future. One possible explanation for PTG is that those patients are focusing on their personal strengths and assets rather than the cancer’s threatening nature, enhancing self-efficacy and empowerment (Znoj, 2006) which is congruent with the research of Taylor (e.g. Taylor & Brown, 1988 & 1994) and others who found that most people maintain or create positively biased perceptions of themselves.

Summary

As more people are being diagnosed with and surviving cancer, the role of counselors becomes increasingly important. While a great deal of attention has been
given to the psychological distress that was presumed was universal to all cancer patients, research has discovered that not only is that scenario the minority, but most patients report finding benefit in the experience. Other research has identified the importance of identity on other variables. Also, the role of social and cultural influences is well-documented but only recently being considered as factors that affect adjustment and PTG in patients. This mixed methods study will advance the understanding of the interactions between contextualized identity and the discrepancy in adjustment and PTG. This study will enhance our knowledge of the valence of illness and trauma, ultimately yielding valuable information for counselors working with these clients. This move is congruent with the recent focus on Positive Psychology, as researchers shift gaze from pathology to strength and resources. There has also been recent acknowledgement that wellness can exist within illness and this research fits nicely within that conceptual framework.
CHAPTER 3

METHODOLOGY

Statement of the Problem

Although several researchers have identified a process of identity loss and reconstruction (Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., 2003; Bradley, Calvert, Pitts, Redman, 2001; Corbin & Strauss, 1988; Mathieson & Stam, 1995; Zebrack, 2000) with distinct profiles for adults with cancer (Allen, 1998; Tower, 2000; Turton & Cooke, 2000), there have been no quantitative attempts to derive these profiles. Further, although distinct differences have been observed quantitatively with regards to psychological adjustment and posttraumatic growth, there have been no studies which explore the relationship of identity to these constructs.

Purpose

The purpose of this two-phase sequential mixed methods study is to learn about the role of identity in psychological adjustment and posttraumatic growth in adults with cancer. Toward that end, I obtained statistical, quantitative results from a sample and then followed up with a smaller sample to probe and explore those findings in more depth. In the first phase, quantitative research methods explore variables known to be significant in research on adults with cancer such as: psychological adjustment to cancer, posttraumatic growth, illness perception, illness intrusiveness, integration of trauma into identity, and
sense of coherence to find clusters of individuals. In the second phase, qualitative interviews were used to probe significant findings by exploring the relationship between aspects of identity, posttraumatic growth, and psychological adjustment.

Research Questions

1. What is the role of identity in posttraumatic growth and psychological adjustment in adults with cancer?

2. What are the identity clusters (or profiles) that emerge when looking at measures of psychological adjustment to cancer, posttraumatic growth, illness perception, illness intrusiveness, integration of trauma, and sense of coherence of adults with cancer or who have survived cancer?
   a. What are the differences on these measures among the clusters?
   b. What is the role of identity within these groupings?
   c. What is the nature of the relationship of these variables to adjustment?

3. What are the emergent themes in the narratives of adults with cancer that relate to identity?

Conceptual Framework

This attempt to explain the relationship between the identity renegotiation of adults with cancer and their psychological adjustment and posttraumatic growth places the experience within varied streams of meaning. I have drawn on literature from disciplines that explore illness experiences and have been informed by trauma literature, identity theorists, and terror management theory. Significantly, this research also
considers the impact of social and cultural construction of illness on a patient’s sense of self.

Significance

This study stands at the juncture of three areas of research and contributes to our understanding of this experience. First, it allows us to explore how cancer patients’ identity shifts within their illness experience. Second, it contributes to understanding the relationship of identity to adjustment and posttraumatic growth (PTG). Third, it contextualizes patients in the dominant social and cultural framework to promote consideration of the social influences on adults with cancer, including the importance of valued roles and identity motives.

This study provides guidance with regard to interventions for counselors to help their patients in a cancer experience. Understanding the process of patient identity reconstruction is valuable to therapists working with this population, and likely helps counselors assist clients construct an identity that enhances empowerment, self-efficacy, adjustment, and PTG (Gray, Doan, & Church, 1990; Mok, 2001). Identifying elements of these relationships provides insight into not only those diagnosed with cancer, but survivors of other types of trauma as well.

Research Design

This study utilized mixed methods of quantitative and qualitative to explore and generate theory about the process of identity renegotiation in adults with cancer, and its relationship to adjustment and posttraumatic growth. A sequential mixed methods design
was utilized that incorporated both quantitative and qualitative components to confirm and cross-validate findings.

The first phase was quantitative and involved collection of survey data from adults who are either in treatment for cancer or have completed treatment for cancer. Surveys are used to identify broad trends in a population (Creswell & Clark, 2007). Several assessment instruments, variables such as coping strategies, illness beliefs, illness intrusiveness, sense of coherence, and integration of cancer to identity were measured to discern which factors are most strongly associated with the posttraumatic growth and psychological adjustment of adults with cancer. Physicians, medical centers, and local service agencies that specifically serve adults with cancer were solicited to participate and a sample of 164 people were recruited for a survey that incorporated seven instruments: Brief COPE, Mini-Mental Adjustment to Cancer (Mini-MAC), Brief Illness Perception Questionnaire (BIPQ), Sense of Coherence Scale – 3 items (SOC-3), Posttraumatic Growth Inventory (PTGI), Illness Intrusiveness Ratings Scale (IIRS), and Centrality of Event Scale (CES). Participants who had the same partner/spouse since diagnosis were asked if they would be willing to be contacted for a follow-up interview. A cluster analysis was performed to identify groupings of individuals with similar identity scores.

Then qualitative phenomenological interviews were used to probe significant results by exploring aspects of identity within a smaller, purposeful sample of partnered adult cancer patients/survivors. Interviews are used to probe multiple participant meanings and understand a lived experience from a participant’s point of view (Creswell & Clark, 2007). Forty-five survey participants provided contact information at the
completion of the survey indicating that they have been partnered since the time of diagnosis and were willing to learn more about an in-depth interview opportunity. Each one of them was sent an email to invite them to learn more about a follow-up interview. Twenty-seven responded to seek more information and 17 were eventually interviewed with their spouses/partners about the patient’s sense of self and identity changes during the cancer experience. Qualitative data were used to enhance description of the results and the identification of salient themes (Creswell & Clark, 2007).

A clustered phenomenology approach was used for the qualitative portion of the study and drove the shape of the interviewing; this method requires ongoing data analysis so that collection methods can shift in response with the data as it evolves. Data collection continued until saturation was achieved. Saturation is defined as the point at which no new conceptual insights are being added (Charmaz, 2006).

Characteristics of Mixed Methods Research

Mixed methods models are designed to combine the best of both quantitative and qualitative to obtain a more complete understanding of the issue than either method alone (Creswell & Clark, 2007). The weaknesses of each model offset the strengths of the other. Mixed methods model are preferred when one method alone is insufficient to understand the factors at work. The methods both contribute uniquely to overall understanding of the phenomenon and create complementarity.
Justification for Type of Design

Research on identity changes in individuals with cancer or other illness has been primarily done through qualitative inquiry. At this time, no published studies have reported a mixed methods approach to examining the role of identity in psychological adjustment and posttraumatic growth in adults with cancer. The intent of this study was to learn about the role of identity in adults with cancer particularly in regard to psychological adaptation and posttraumatic growth. With the wealth of information now available about PTG and adjustment in adults with cancer, it is essential to use methods which consider those factors now known to be important. Therefore, identity clusters were quantitatively derived from a sample of adults with cancer and then these clusters were qualitatively explored for distinctions.

The use of a mixed methods design allows for complementarity of methods and expansion of results through increased breadth, scope, and range of inquiry (Greene, Caracelli, & Graham, 1989). The two methods were used to corroborate each other and the data were integrated during the interpretation phase. At that time, convergence or lack of convergence was noted. Sequential strategy is well-validated and substantiated (Creswell, 2003). Methodological triangulation in which multiple methods are used decreases bias, allows for convergence, and increases construct and content validity (Greene, Caracelli, & Graham, 1989).

Qualitative methods are especially suited to finding meanings attached to experiences or events (Creswell, 2007) which is particularly important for this type of research. Exploring how individuals cope with cancer, make meaning of events, re-shape identity, and then how identity transformation affects psychological adjustment and
posttraumatic growth requires consideration of the patient’s lived experience. The value of qualitative research in the field of counseling has been reaffirmed as important in deriving the richness of lived experience, in exploring phenomena in the ‘natural environment,’ and in examining processes rather than outcomes variables (Berrios & Lucca, 2006). Merchant and Dupuy (1996) posited that narratives are the primary form by which experiences take on meaning and narratives are best accessed through interviewing. Phenomenological interviewing is designed specifically to access the lived experience of the participants which is particularly suited to persons living with illness or disease (Corbin & Strauss, 1988). The clustered phenomenological approach of this study was designed to elicit unique meaning from each of the quantitatively derived clusters.

The literature abounds with various theories to account for individual variation in coping and adjustment, but most are cross-sectionally derived. This study attempts to avoid this problem by purposefully soliciting participation from the larger sample with the intention of representing different phases within the cancer trajectory – thus theoretically sampling throughout the process.

**Visual Model and Procedures for the Design**

Figure 1. Visual Representation of Mixed Methods Design of this Study
Researcher’s Perspective

The study researcher is a Caucasian woman in the Counselor Education doctoral program in the College of Education of Florida Atlantic University. I am a licensed Mental Health Counselor, with over 20 years experience, 15 of which have been spent working with clients dealing with critical and chronic illness, such as cancer and HIV/AIDS. Due to my extensive clinical experience I have personal and professional beliefs and biases that I have attempted to keep at a minimum in this study. I used my experience and clinical judgment to guide the development of the research methodology and interview protocol, but tried to remain open to new interpretations of the data.

Data Collection

*Data Collection Methods*

Physicians, medical centers, and local service agencies that specifically serve adults with cancer were solicited to participate and 164 people who met the eligibility criteria were recruited for an online survey that incorporated seven instruments: Brief COPE, Mini-Mental Adjustment to Cancer (Mini-MAC), Brief Illness Perception Questionnaire (BIPQ), Sense of Coherence Scale – 3 items (SOC-3), Posttraumatic Growth Inventory (PTGI), Illness Intrusiveness Ratings Scale (IIRS), and Centrality of Event Scale (CES).

Willing participants were directed to a website where an informed consent was presented to them with risks of participation, confidentiality statement, and an overview of the objectives of the study. They were also informed that the online survey is encrypted for confidentiality. Each participant placed his/her initials in a box to indicate
their willingness to proceed. They were informed of their right to withdraw from participation at any time with no negative consequences for themselves. It was explained that participation in this portion of the study was expected to require a time commitment of 10-20 minutes. Participants were presented with check boxes for their answers. Once they completed the surveys, those participants who reported that they have been with the same partner/spouse since diagnosis were asked if they would be willing to be contacted to learn more about possible participate in an in-depth interview on the same topic. If affirmative, they were asked to provide contact information.

In this study, the quantitative instruments assisted in defining the groupings of individuals for the qualitative interviews which were used to explore how adults with cancer cope with threats to identity, and transform identity to accommodate limitations or changes.

**Setting and Sample**

Participants, or co-researchers, were recruited from physicians, medical centers, and local service agencies that specifically serve adults with cancer. To be eligible, each person had to have been diagnosed with cancer and must have been at least 18 years old at the time of diagnosis. The participants were newly diagnosed, on treatment, finished with treatment, or have relapsed.

Seventeen participants and their spouses/partners were recruited from the larger quantitative sample, but purposefully chosen to represent each of the two identified clusters derived from the analysis of the quantitative data. As has been done in a few
studies, spouses/partners were also interviewed concurrently to allow for triangulation of data.

Information was obtained regarding: sex, age, age at diagnosis, race/ethnicity, social class, marital/partnered status, diagnosis, treatment, residual impairment(s), and any relapse, recurrence or secondary malignancy.

Intervi
ers

This study utilized semi-structured interviews with 17 participants who have been diagnosed with cancer and their spouses/partners. Interviewing allows for a depth of data not possible through surveys or other means. I utilized an interview guide with items derived from the preliminary pilot study and the results from the quantitative data analysis. The interviews took 90 – 185 minutes with each person/couple. The interviews took place in the participants’ home or an acceptable alternative chosen by the participants. Sixteen interviews were audio-taped with the express permission of the participants (one couple declined). Each participant chose an alternative name for confidentiality.

Limitations

Soliciting through South Florida physicians, medical centers, and service organizations has limited the sample to persons currently living in these counties. This may or may not affect the generalizability of these findings to other populations. The results may not apply as well to unpartnered individuals. Also, patients who were willing to participate in a study may differ from those who choose not to participate.
Instrumentation

*Empirical Assessment*

Individuals were asked to complete assessment surveys: Brief COPE, Mini-Mental Adjustment to Cancer (Mini-MAC), Brief Illness Perception Questionnaire (BIPQ), Sense of Coherence – 3 Items (SOC-3), Posttraumatic Growth Inventory (PTGI), Illness Intrusiveness Ratings Scale (IIRS), and Centrality of Event Scale (CES).

*Brief COPE*

The Brief COPE (Carver, 1997) is an instrument designed to measure and assess coping and coping styles. It is an abbreviated form of COPE and has been used extensively in research regarding coping. This scale has two items per coping factors: active coping, self-distraction, denial, substance use, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, self-blame, use of instrumental support, and use of emotional support. Cronbach α exceeded .60. Brief COPE has been used in research with women with breast cancer and in research with hurricane survivors. Permission was obtained for use of this instrument.

*Mini-Mental Adjustment to Cancer (Mini-MAC)*

The Mental Adjustment to Cancer (Mini-MAC) was designed to provide information about adjustment to cancer (Watson, Greer, Young, Inayat, Burgess, & Robertson, 1988) on the following five dimensions: Fighting spirit, anxious preoccupation, helplessness/hopelessness, fatalism, and avoidance. Ratings are on a 4-
point scale from “definitely does not apply to me” to “definitely applies to me.” The original sample for the scale was 400 patients with cancer in Great Britain. High correlation was found between the scores of patients and their spouses. The following are sample items from the Mini-MAC: “I feel that life is hopeless” and “I see my illness as a challenge.” It includes cognitive appraisal as well as emotional reactions, covering the range from maladaptive to adaptive. Cronbach’s $\alpha$ ranged from .50 to .86 and correlation coefficient of test-retest was .68 to .88. Recent factorial analyses by Watson and Homewood (2008) led them to conclude that Fighting Spirit on the MAC represents positive adjustment while the factors of Fatalism, Avoidance, Helplessness/Hopelessness, and Anxious Preoccupation combined represent negative adjustment. Permission was obtained for use of this instrument.

Posttraumatic Growth Inventory (PTGI)

The PTGI (Tedeschi & Calhoun, 1996) was developed to measure posttraumatic growth following trauma. The PTGI consists of 21 items with the following five factors: relating to others (7 items), new possibilities (5 items), personal strength (4 items), spiritual change (2 items), and appreciation of life (3 items). The internal consistency of these factors ranged in alpha from .67 to .85. While the PTGI was originally validated on undergraduate college students, it has subsequently been used with several populations of adult cancer patients. Participants rate items on a 6-point Likert scale, ranging from 0 “did not experience this change as a result of cancer” to 5 “experienced this change to a very great degree as a result of cancer.” As in other studies, the items on the PTGI were modified to refer to cancer rather than a generic crisis. In an undergraduate sample PTGI
psychometrics were reported to be very good (Tedeschi & Calhoun, 1996). In a study with adult cancer patients, coefficient alphas for the PTGI total score (.95 and .96) and for the subscale scores (Relating to Others [.91 and .92], New Possibilities [.84 and .88], Personal Strength [.81 and .89], Spiritual Change [.88 and .89], Appreciation of Life [.88 and .83]) were very good. Test-retest reliability ranged from .65 to .74. Permission was obtained for use of this instrument.

Brief Illness Perception Questionnaire (BIPQ)

The BIPQ is a shortened version of the IPQ designed to assess illness perceptions quickly (Broadbent, Petrie, Main, & Weinman, 2006). This is especially useful for researchers with a lengthy protocol of other measures and serves to reduce the burden on research participants. Other advantages of the BIPQ are brevity and speed of completion for patients, particularly useful for ill and elderly populations (Broadbent, Petrie, Main, & Weinman, 2006). Easy interpretation of scores is another benefit to researchers (Broadbent, Petrie, Main, & Weinman, 2006). Items include: “How much does your illness affect your life?” and “How long do you think your illness will continue?” Each item is scored on a likert scale of 0 to 10, with 0 being not at all and 10 being an extreme amount, worded variably per item but appropriate to the content of the question. The BIPQ showed good test–retest reliability, between .49 and .75 at the p<.001 level and concurrent validity. Permission was obtained for use of this instrument.
Sense of Coherence Scale-3 Items (SOC-3)

The SOC-3 was initially developed in Sweden (Lundberg, 1997; Lundberg & Nyström Peck, 1995) and was used by Surtees, Wainwright, Luben, Khaw, and Day (2006) in a 6-year study with a large population of cancer patients – 20,323 participants, ages 41 to 80 years, in the European Prospective Investigation into Cancer Study in the United Kingdom. Participants complete a three-item questionnaire designed to assess each of the SOC component constructs by single questions:

1. Do you usually feel that the things that happen to you in your daily life are hard to understand? (comprehensibility)
2. Do you usually see a solution to problems and difficulties that other people find hopeless? (manageability)
3. Do you usually feel that your daily life is a source of personal satisfaction? (meaningfulness)

On this scale, response choices for participants are yes, usually (scored zero); yes, sometimes (scored one); and no (scored two). With scoring for comprehensibility being reversed, the three items are summed to provide a total SOC Scale score of 0 to 6, with a higher score representing a weaker SOC. This three item measure has been found to be similar to the original 29-item SOC measure (Lundberg & Nyström Peck, 1995; Surtees, Wainwright, Luben, Khaw, and Day, 2003). Due to the simplified design of a single question representing each dimension, internal reliability was low (Cronbach’s $\alpha = .39$), but this scale had high intercorrelation ($r=0.96$, $p<0.001$) and significant correlation ($r=-.67$, $p<0.001$) with SOC-29 which had Cronbach’s $\alpha$ of .93. The sample mean and
standard deviation were 1.83 and 1.16, respectively (Lundberg & Nyström Peck, 1995; Surtees, Wainwright, Luben, Khaw, and Day, 2003).

**Centrality of Event Scale (CES) – 7-item cancer version**

The Centrality of Event Scale is designed to measure the extent to which participants have integrated a traumatic event into their identity or how “central an event is to a person’s identity and life story” (Berntsen & Rubin, 2006, p. 219). Items from this instrument included: “I feel that cancer has become part of my identity” and “I feel that cancer has become a central part of my life story.” Participants are asked to rate the seven questions on a scale of 1 to 5 with 1 being *totally disagree* and 5 being *totally agree*. Berntsen and Rubin (2006) shortened the original 20-item scale to seven items since there was such high reliability, keeping the questions which were most highly correlated with the sum of the other questions. The 7-item scale was reported to have a Cronbach’s α that ranged from .87 to .92. The 7 item CES correlated with 20 question version with .96. A 7-item version of this scale specific to cancer was made available from the authors. It is identical to the seven item version except that the word *event* has been replaced with *cancer*. Permission was obtained for use of this instrument.

**Illness Intrusiveness Ratings Scale (IIRS)**

The Illness Intrusiveness Ratings Scale (IIRS) is a 13-item scale that measures illness and/or treatment disruptions to lifestyles, activities and interests on 13 domains of life important to quality of life (Devins, Dion, Pelletier, Shapiro, Abbey, Raiz, et al., 2001; Devins, Bez, Mah, & Loblaw, 2002). On a 7-point Likert rating scale which
represents not very much to very much, participants rate the degree to which their illness and/or its treatment disrupt: health, diet, work, active recreation, passive recreation, financial situation, relationship with spouse, sex life, family relations, other social relations, self-expression/self-improvement, religious expression, and community and civic involvement. Total scores can range from 13–91. Total scores and three subscales (corresponding to relationships and personal development, intimacy, and instrumental life domains) can be generated. Among the many patient populations for which IIRS has been validated, reliability is consistently high (Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., 2003; Schimmer, Elliott, Abbey, Raiz, Keating, Beanlands, 2001). A study of individuals undergoing bone marrow transplantation validated the IIRS with cancer patients (Schimmer, Elliott, Abbey, Raiz, Keating, Beanlands, et al., 2001). In that study, reliability (coefficient alpha) was 0.89, internal consistency (coefficient alpha) ranged from 0.80 to 0.90 and test–retest reliability over 3 weeks, 6 weeks, and 9 months averages between 0.70 and 0.75 when circumstances of disease and treatment remain unchanged (Schimmer, Elliott, Abbey, Raiz, Keating, Beanlands, et al., 2001).

Permission was obtained for use of this instrument.

Traumatic Stress

Additionally, two yes-no questions assessed whether the cancer experience constituted a traumatic stressor. According to the Diagnostic and Statistical Manual of Mental Disorders-IV-TR (DSM-IV-TR; American Psychiatric Association, 2000), an event qualifies as a traumatic stressor if it both (a) "involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others," and (b) "the person's
response involved intense fear, helplessness, or horror” (American Psychiatric Association, 2000, p. 467). The two questions used in this survey are: “Do/Did you perceive being diagnosed with and treated for cancer as a threat of death or serious injury or a threat to your physical integrity?” and “Given your experience with cancer, has your response ever involved intense fear or helplessness?”

Measures for Ethical Protection of Participants

Ethical considerations for any researcher include avoidance of marginalizing or disempowering participants (Creswell, 2003). Respect for the participants has been foremost in the design and implementation of this study. It has been considered that participants may be a vulnerable population and safeguards have been instituted.

The purpose of the study was provided to the participants in each of the two major phases. During each of the major portions of the study participants were informed in writing that thinking and responding about stressful events may pose a risk and that a licensed therapist was available to them for discussion if needed. A phone number was provided for the participants to account for that potentiality. In the interview portion of the study, interviewees were informed that talking about stressful events may pose a risk of uncomfortable feelings, and that at any time they may stop the interview, decline to answer a particular question, or withdraw from the study with no negative consequences to themselves. Interviewees were asked to sign a prepared consent form for the interview and initial online for the survey to assure their understanding of the risk of participation and confirm their willingness to participate. Signed informed consent preceded initiation of any interviewing. All participants were asked for permission to audio-record using a
digital recorder and for the interviewer to be allowed to take notes during the interview. Interviewees were asked to select an alternate name for anonymity and confidentiality was assured. Also, participants were phoned following the interview to determine whether any harmful effects have been noted or new insights gained. The interview recordings were placed on the researcher’s computer, to which the researcher alone has access, and were password-protected and encrypted. Finally, every effort was made to fully represent the ‘voices’ of the participants with integrity.

Data Analysis

Quantitative

Quantitative analysis using SPSS began once data collection of the surveys was completed. Given that researchers have universally found groupings around identity in adults with cancer (Allen, 1998; Beanlands, Lipton, McCay, Schimmer, Elliot, Messner, et al., 2003; Charmaz, 1991; Corbin & Strauss, 1988; Mathieson & Stam, 1995; and Tower, 2000), cluster analysis was a natural choice for analysis of this data. Cluster analysis is used to derive homogenous constellations of objects by partitioning them into subsets based on inter-object similarities to maximize between-group difference while minimizing intergroup differences (Kaschigan, 1991). Correlations were obtained for the variables quantitatively derived, and Chi-square was used to determine goodness-of-fit or independence.
Qualitative – Phenomenology

The objectives of the qualitative analysis were to define the properties of each identity category, and to identify conditions - including resources and social contexts - under which individuals adopt or utilize various identities. To fully derive the lived experience of the participants, I read and re-read the interview transcripts to discern significant statements which contributed to understanding the central phenomenon. I grouped the statements into themes and then wrote in-depth, exhaustive descriptions of the themes with verbatim statements as evidence (Creswell, 2007). Therefore, I analyzed narratives to develop codes, categories, and themes as they emerged from the data. I also used analytic and self-reflective memos to document and enhance the analytic process and deepen understanding. (Charmaz, 2007).

Interviews were transcribed as soon as possible following the interviews and data analysis was ongoing throughout the entire research process. Interviews with patients were coded similarly, as were partner interviews and finally, couple interviews. Themes common to all participants were sought, but themes that only emerged with spouses/partners or couples were likewise noted. Therefore, not only similarities but also differences were identified.

This study appears to have face validity as the underlying theory and assumptions are consistent with the existing literature and with my clinical experience as a therapist working in the area of oncology for the past ten years.
Pilot Study

A pilot study was performed for the qualitative component involving interviews with three current/former cancer patients and their spouses. Interview questions were centered on changes in self-perception, roles, priorities, and relationships since the time of diagnosis and throughout treatment. The interviews revealed some common themes as well as some that were more specific to each couple. The common themes for patients were: 1. response of others; 2. illness intrusiveness; 3. awareness of strength; 4. lingering sense of vulnerability; 5. seeking normalcy; 6. valued roles; 7. shifting priorities; 8. survivorship; 9. mortality salience; 10. sense of becoming more authentic; and 11. sense of accelerated development/pace. For partners, the themes were similar but also included helplessness, feeling their needs are not legitimate, and observations on spouses. Couples’ themes include: differing perspectives, united front, and unbreakable bond.

Another theme that requires further exploration is that events amplify self-perception and relationship patterns. These findings were used to create an interview guide for this study.

Summary

Understanding more about the lived experience of adults dealing with their own mortality, treatment side effects, and working to make sense of events requires an approach which is flexible yet comprehensive. This sequential two-phase mixed method design quantifies key elements of the cancer experience, allows the researcher to determine measurable aspects of identity clusters, and distinguishes key factors within those clusters. The quantitative and qualitative methods each have strengths and together
create a complementarity which is important in appreciating the nuances of this lived experience.
CHAPTER 4
PRESENTATION AND ANALYSIS OF THE DATA

This chapter presents the findings of this two-phase sequential mixed methods study examining the role of identity in posttraumatic growth and psychological adjustment for adults with cancer. Toward that end, a survey was performed using quantitative instruments to obtain results from a sample and then followed up with a smaller sample to qualitatively probe or explore those findings in more depth. In the first phase, quantitative research methods were used to explore variables known to be significant in research on adults with cancer such as: psychological adjustment to cancer, posttraumatic growth, illness perception, illness intrusiveness, integration of cancer into identity, and sense of coherence to find clusters of individuals. In the second phase, qualitative interviews were used to probe significant findings by exploring the relationship between aspects of identity, posttraumatic growth, and psychological adjustment. The first section of this chapter describes phase 1 of the study which was a survey and the second section describes phase 2 which is qualitative and involves an interview with a representative sampling. Finally, an analysis of the data provides a synthesis of both quantitative and qualitative findings. The research questions are as follows:
1. What is the role of identity in posttraumatic growth and psychological adjustment in adults with cancer?

2. What are the identity clusters (or profiles) that emerge when looking at measures of illness perception, psychological adjustment to cancer, posttraumatic growth, illness intrusiveness, centrality of event (to identity), and sense of coherence of adults with cancer or who have survived cancer?
   a. What are the differences on these measures among the clusters?
   b. What is the role of identity within these groupings?
   c. What is the nature of the relationship of these variables to adjustment?

3. What are the emergent themes that relate to identity in the narratives of adults with cancer?

Quantitative Results

An online survey was developed which included items from seven instruments: Brief COPE, Mini-Mental Adjustment to Cancer (Mini-MAC), Brief Illness Perception Questionnaire (BIPQ), Sense of Coherence Scale – 3 items (SOC-3), Posttraumatic Growth Inventory (PTGI), Illness Intrusiveness Ratings Scale (IIRS), and Centrality of Event Scale (CES) – 7 item Cancer Scale. Participants were recruited through cancer service organizations such as Leukemia & Lymphoma Society. Answers were scored according to each individual instrument and subscale. Additionally participants were asked for disease specific and demographic information: cancer diagnosis, age at diagnosis, on or off treatment, whether or not cancer-free, any residual impairment, current age, marital/partnered status, whether partnered since time of diagnosis,
race/ethnicity, socioeconomic status, sex, and sex of partner. Each person was also asked two trauma questions consistent with the DSM-IV-TR: 1. “Do/Did you perceive being diagnosed with and treated for cancer as a threat of death or a threat to your physical integrity?” and “Given your experience with cancer, has your response ever involved intense fear or helplessness?” Participants were also invited to provide written comments on any topic related to their cancer experience. Finally, participants who reported that they have been partnered with the same person since the time of diagnosis were offered the opportunity to provide contact information in order to be contacted for a possible follow-up interview.

Sample Description

The final sample that participated in the online survey included 164 individuals. All but two agreed to the written consent; the two that did not provide consent were excluded. Two participants were excluded from the study because they reported that they were not 18 or older at the time of their cancer diagnosis. Cases with missing data were excluded from analysis. The final number of individuals who completed the survey and were include in the analysis was 119 (72.6%). Of the final 119, 19 (16%) were men. The age range overall was 18 to 83, with an average age of 52 (SD=12.049). The range of age at diagnosis is 18 to 78 with an average age of 45 (SD=12.958). The types of cancer represented include: acute and chronic leukemia, breast cancer, lung cancer, cervical cancer, ovarian cancer, vulvar cancer, testicular cancer, prostate cancer, thyroid cancer, colorectal cancer, esophageal cancer, appendix cancer, renal cell carcinoma, melanoma, multiple myeloma, osteosarcoma, polycythemia vera, brain tumor, and lymphoma.
Forty-one participants (34.5%) indicated being on treatment, and 20 (48.8%) of those report being cancer-free. Eight (6.7%) individuals reported not being on treatment and not being cancer-free. An additional 70 participants reported being cancer-free and not on treatment. Survey participants who are off-treatment (78) were asked about residual impairment and 67 (85.9%) reported having such problems as menopause, erectile dysfunction, deafness, bowel and/or urinary incontinence, immune suppression, amputation, disfigurement, bone pain, scars, neuropathy, pain, and memory loss.

Eighty-five (71.4%) persons reported being currently married or partnered, and 77 (90.6%) of those reported being with the same partner since the time of diagnosis. With regard to self-defined socioeconomic status, the following were reported: Low 1 (0.8%), Low to Middle 10 (8.4%), Middle 54 (45.4%), Middle to Upper 45 (37.8%), Upper 9 (7.6%). Regarding ethnicity, 108 (90.8%) identify as Caucasian, 5 (4.2%) identify as Hispanic, 3 (2.5%) as multiracial, 2 (1.7%) as African-American, and 1 (0.8%) as Asian.

**Correlations**

<table>
<thead>
<tr>
<th></th>
<th>Cancer Identity</th>
<th>Trauma</th>
<th>Illness Intrusiveness</th>
<th>Adjustment</th>
<th>PTG</th>
<th>SOC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Identity</td>
<td>1.000</td>
<td>.454**</td>
<td>.551**</td>
<td>.622**</td>
<td>.508**</td>
<td>-.230**</td>
</tr>
<tr>
<td>Trauma</td>
<td>1.000</td>
<td></td>
<td>.366**</td>
<td>.446**</td>
<td>.195*</td>
<td>-.143</td>
</tr>
<tr>
<td>Illness Intrusiveness</td>
<td>1.000</td>
<td></td>
<td></td>
<td>.428**</td>
<td>.360**</td>
<td>-.252**</td>
</tr>
<tr>
<td>Adjustment</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
<td>.347**</td>
<td>-.372**</td>
</tr>
<tr>
<td>PTG</td>
<td></td>
<td></td>
<td></td>
<td>1.000</td>
<td></td>
<td>.153*</td>
</tr>
<tr>
<td>SOC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.000</td>
<td></td>
</tr>
</tbody>
</table>

**. Correlation is significant at the 0.05 level (1-tailed).
**. Correlation is significant at the 0.01 level (1-tailed).
Bivariate correlational analysis was performed to determine the strength of the relationships of each variable to the others as shown in Table 1. The variables of cancer identity (from CES-7 item cancer scale which measures the centrality of cancer to one’s identity), illness intrusiveness (from IIRS), adjustment (from Mini-MAC), PTG (from PTGI), and SOC (from SOC-3) are included. Cancer identity is measured by the self-ratings of participants to items such as: “I feel that cancer has become part of my identity” and “I feel that cancer has become a central part of my life story.” For this correlation, the score on the Mini-MAC represents the overall score including the five factors: Fighting Spirit, Avoidance, Anxious Preoccupation, Helplessness/Hopelessness, and Fatalism, and does not distinguish between the negative and positive items. The Brief COPE and the Brief Illness Perception Questionnaire (BIPQ) are excluded since those scales are not meant to be scored as a totality but instead provide scores on various factors. For example, the Brief COPE contains nine factors with a mix of both positive and negative coping represented.

The correlation between cancer identity and adjustment was strong and statistically significant \((r = .622, p = .000)\) as defined by Cohen (1988). Therefore, 39% of variance is accounted for my adjustment, and Cohen (1977) reported that even 10% of variance has practical significance. A strong correlation was also found between cancer identity and Illness Intrusiveness \((r = .551, p = .000)\), for 30% of the variance, and PTG \((r = .508, p = .000)\), for 26% of variance. Cancer identity and perception of trauma – the extent to which the individuals perceived cancer to be a threat to life or physical integrity, and the extent to which the response was characterized by intense fear or helplessness – were found to be moderately correlated \((r = .454, p = .000)\) for 21% of the variance.
Perception of trauma was also moderately correlated with Adjustment ($r=.446, p=.000$) and Illness Intrusiveness ($r=.366, p=.000$). A moderate correlation was found between PTG and Illness Intrusiveness ($r=.360, p=.000$). A weak correlation was found between perception of trauma and PTG ($r=.195, p=.016$).

**Cluster Analysis**

Cluster groups were developed using $z$ scores of the variables psychological adjustment to cancer, posttraumatic growth, illness perception, illness intrusiveness, integration of cancer into identity (cancer identity), and sense of coherence. The $z$ scores ensured standardization of the variables. A two-step clustering process was used to identify relevant sub-groups. The first step determined the number of subgroups that characterized the data. The second step examined the conceptual value and meaning of that solution.

Cluster analysis was used to determine group membership as cluster analysis identifies groups that share within-cluster homogeneity and between-cluster heterogeneity on selected variables. Individuals within clusters are similar in some way and different from individuals in other clusters. All variables were converted into $z$ scores to avoid unequal weighting of the variables due to differing scales on the various instruments.

The Two-Step Clustering Method was used because of the ability to determine the optimal number of groupings. Since no missing values are allowed, cases with missing values were deleted. In the first step, the BIC (Schwarz’s Bayesian Criterion) was calculated for each number of clusters within a specified range and used to find the initial
estimate for the number of clusters. In the second step, the initial estimate by an agglomerative hierarchical clustering method was refined by finding the largest increase in distance between the two closest clusters in each hierarchical clustering stage. Log-likelihood used to calculate the probability based distance between two clusters is related to the decrease in log-likelihood as they are combined into one cluster. In calculating log-likelihood, normal distributions for continuous variables and multinomial distributions for categorical variables are assumed. Two clusters were determined to be the best fit for the data.

Hierarchical clustering was also performed to confirm the clusters for best fit. This method is capable of producing a sequence of partitions in one run. For the purposes of this study and based on the literature 2, 3, 4, 5, and 6 clusters were chosen as possible solutions. Each case begins as a single cluster and similar clusters are successively merged. Careful attention was given to the coefficients as small coefficients indicate that fairly homogeneous clusters are being merged while large coefficients indicate that clusters which contain quite dissimilar members are being combined.

However, validation of a cluster analysis requires subjective decision-making by the researcher (Romesburg, 1984) and the qualitative analysis failed to confirm the uniqueness of each cluster or the similarity of group members to each other with regard to cancer identity, which is the variable of greatest interest. Therefore, another two-step cluster analysis was performed using only the variable of identity. This yielded two groups: Cluster 1 had a membership of 59 and Cluster 2 had 60 members. The first group centroid was 29.90 (SD=3.473) and the second was 17.20 (SD=5.392). The primary effect was to sort the total sample into two groups: Cluster 1 with group membership of identity
scores above the mean (>23.5), and Cluster 2 with identity scores below the mean (<23.5). Therefore, Cluster 1 represents High Cancer Identity Cluster (HCIC) grouping which demonstrates a strong association with cancer identity as defined by scores on CES, while Cluster 2 represents a Low Cancer Identity Cluster (LCIC) group and a weak or absent cancer identity.

Discriminant Analysis

Table 2. Discriminant Analysis of HCIC and LCIC.

<table>
<thead>
<tr>
<th></th>
<th>Cluster</th>
<th>M</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Identity</td>
<td>HCIC</td>
<td>29.90</td>
<td>3.473</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>LCIC</td>
<td>17.20</td>
<td>5.392</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>23.50</td>
<td>7.818</td>
<td>119</td>
</tr>
<tr>
<td>PTG</td>
<td>HCIC</td>
<td>72.90</td>
<td>20.059</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>LCIC</td>
<td>52.82</td>
<td>28.274</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>62.77</td>
<td>26.442</td>
<td>119</td>
</tr>
<tr>
<td>Illness Intrusiveness</td>
<td>HCIC</td>
<td>56.58</td>
<td>18.250</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>LCIC</td>
<td>36.77</td>
<td>16.690</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>46.59</td>
<td>20.048</td>
<td>119</td>
</tr>
<tr>
<td>Adjustment</td>
<td>HCIC</td>
<td>46.54</td>
<td>6.084</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>LCIC</td>
<td>40.08</td>
<td>5.700</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>43.29</td>
<td>6.705</td>
<td>119</td>
</tr>
<tr>
<td>Sense of Coherence</td>
<td>HCIC</td>
<td>4.64</td>
<td>1.720</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>LCIC</td>
<td>5.60</td>
<td>.887</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>5.13</td>
<td>1.441</td>
<td>119</td>
</tr>
</tbody>
</table>

Once the group membership for the two clusters was determined by cluster analysis, a discriminant analysis was performed to confirm the distinction between the two clusters with regard to cancer identity (Field, 2005). As shown on Table 2, cancer identity in HCIC had a mean of 29.90 (SD=3.473) while in LCIC the mean was 17.20
Illness intrusiveness (HCIC $M=56.58$, $SD=18.250$; LCIC $M=36.77$, $SD=16.690$) was also higher in the HCIC. HCIC had a PTG range of 51 to 105 ($M=72.9$, $SD=20.059$) while the LCIC had a PTG range of 0 to 97 ($M=52.8$, $SD=28.274$).

Psychological Adjustment was evaluated on its five component factors which showed minor distinctions between the groups: Fighting Spirit (HCIC $M=15.02$, $SD=2.047$; LCIC $M=13.52$, $SD=2.311$); Fatalism (HCIC $M=10.24$, $SD=1.546$; LCIC $M=9.28$, $SD=1.738$); Avoidance (HCIC $M=4.41$, $SD=1.652$; LCIC $M=4.08$, $SD=1.430$); Helplessness/Hopelessness (HCIC $M=6.66$, $SD=2.771$; LCIC $M=5.62$, $SD=1.878$); and Anxious Preoccupation (HCIC $M=9.92$, $SD=3.059$; LCIC $M=7.82$, $SD=2.182$).

Then, a two-group stepwise discriminant function analysis was conducted to assess the relative importance of the independent variables in classifying the dependent variable and to determine the variables which contribute most significantly to the distinctiveness of each cluster, HCIC and LCIC (Field, 2005). Each of the independent variables was broken into its component factors. Six steps were performed to achieve the final model which contained four elements as significant predictors of group membership: the PTG factor New Possibilities (Wilks’ $\lambda = .781$, $F(1, 119) = 32.834$, $p = .000$), Psychological Adjustment factor Anxious Preoccupation (Wilks’ $\lambda = .863$, $F(1, 119) = 18.612$, $p = .000$), Illness Intrusiveness factor Intimate Relationships (Wilks’ $\lambda = .794$, $F(1, 119) = 30.348$, $p = .000$), and Illness Perception factor Perceived Life Impact of Cancer (Wilks’ $\lambda = .783$, $F(1, 119) = 32.412$, $p = .000$). The effect size of each was evaluated by deriving the standardized canonical discriminant function coefficient: Anxious Preoccupation was .338, New Possibilities was .630, Intimate Relationships was
.431, and Perceived Life Impact of Cancer was .363. A chi-square analysis of the classification of the groups revealed that the groups classified by the discriminant function were significantly different than chance ($\chi^2(1) = 65.805, df = 4, p < .000$). The Eigenvalue was .772 with a canonical correlation of .660.

**Cluster Membership by Socio-demographic Variables**

Several variables proved to non-significant with regard to differences between the clusters: age (both current age and age at diagnosis), sex, socioeconomic status, ethnicity, and cancer- and treatment-related variables. The two variables which proved significant were cancer-related residual impairments and partnered status. That the two clusters were indistinguishable on almost all sociodemographic variables demonstrates that the variable of cancer identity is distinct, not an artifact, since almost every variable that could account for this found no difference.

**Age**

No substantial differences were noted between the clusters with regard to age at diagnosis ($\chi^2(45, N = 119) = 54.30, p = .16$). The range of ages at diagnosis in HCIC is from 21 to 62 years old (n=59; $M=44; SD=11.236$) and in LCIC is 18 to 75 (n=60; $M=46; SD=14.064$), therefore LCIC has a broader range.

No substantial differences were found in current age between the clusters ($\chi^2(42, N = 119) = 46.24, p = .30$). The range of current ages in HCIC is 23 to 82 years old ($M=51; SD=11.071$) and 18 to 76 ($M=52; SD=13.008$) in LCIC.
Sex

Table 3. Sex of Survey Participants by Cluster.

<table>
<thead>
<tr>
<th>Cluster</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCIC = 59</td>
<td>10 (16.9%)</td>
<td>49 (83.1%)</td>
</tr>
<tr>
<td>LCIC = 60</td>
<td>9 (15.0%)</td>
<td>51 (85.0%)</td>
</tr>
<tr>
<td>Total = 119</td>
<td>19 (16%)</td>
<td>100 (84%)</td>
</tr>
</tbody>
</table>

No substantial difference was found between the two clusters in regard to the sex of the participants, \( \chi^2(4, N = 119) = 2.48, p = .65 \). As shown in Table 3, HCIC contains 10 men (16.9%) and 49 women (83.1%), while LCIC contains 9 men (15.0%) and 51 women (85.0%).

SES

Table 4. Socio-economic Status by Cluster.

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>Low to Middle</th>
<th>Middle</th>
<th>Middle to Upper</th>
<th>Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCIC n= 59</td>
<td>1 (1.7%)</td>
<td>4 (6.8%)</td>
<td>28 (47.4%)</td>
<td>23 (39%)</td>
<td>3 (5.1%)</td>
</tr>
<tr>
<td>LCIC n= 60</td>
<td>0</td>
<td>6 (10%)</td>
<td>26 (43.3%)</td>
<td>22 (36.7%)</td>
<td>6 (10%)</td>
</tr>
<tr>
<td>Total = 119</td>
<td>1 (0.8%)</td>
<td>10 (8.4%)</td>
<td>54 (45.5%)</td>
<td>45 (37.8%)</td>
<td>9 (7.5%)</td>
</tr>
</tbody>
</table>

No substantial differences were noted in SES between the clusters \( \chi^2(4, N = 119) = 2.48, p = .65 \). As shown in Table 5, 1 participant (1.7%) from HCIC identified as SES of Low, 4 (6.8%) participants as Low to Middle, 28 (47.4%) as Middle, and 23 (39.0%) Middle to Upper, and as 3 (5.1%) Upper. In LCIC, 6 (10.0%) participants as Low to Middle, 26 (43.3%) as Middle, and 22 (36.7%) Middle to Upper, and 6 (10%) as Upper.
Ethnicity

Table 5. Ethnicity by Cluster.

<table>
<thead>
<tr>
<th></th>
<th>Caucasian</th>
<th>Hispanic</th>
<th>African-American</th>
<th>Multiracial</th>
<th>Asian</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCIC n=59</td>
<td>54 (91.5%)</td>
<td>2 (3.4%)</td>
<td>2 (3.4%)</td>
<td>1 (1.7%)</td>
<td>0</td>
</tr>
<tr>
<td>LCIC n=60</td>
<td>54 (90%)</td>
<td>2 (3.3%)</td>
<td>0</td>
<td>3 (5%)</td>
<td>1 (1.7%)</td>
</tr>
<tr>
<td>Total = 119</td>
<td>108 (90.7%)</td>
<td>4 (3.4%)</td>
<td>2 (1.7%)</td>
<td>4 (3.4%)</td>
<td>1 (0.8%)</td>
</tr>
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</table>

If non-Caucasian ethnicities are included together, no substantial difference is found between the clusters \(X^2(5, N = 119) = 3.99, \ p=.55\). As shown in Table 6, of the 59 participants in HCIC, 54 (91.5%) persons identify as Caucasian, 2 (3.4%) identify as Hispanic, 2 (3.4%) as African-American, and 1 (1.7%) as multiracial. In LCIC, 54 (90.0%) persons identify as Caucasian, 2 (3.3%) identify as Hispanic, 3 (5.0%) as multiracial, and 1 (1.7%) as Asian.

Cancer- and Treatment-related Variables

Table 6. Cancer- and Treatment-Related Variables by Cluster.

<table>
<thead>
<tr>
<th></th>
<th>Cancer-free/ on treatment</th>
<th>Cancer-free/ not on treatment</th>
<th>Cancer-free total</th>
<th>Not cancer-free/ on treatment</th>
<th>Not cancer-free/ not on treatment</th>
<th>Non cancer-free total</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCIC = 59</td>
<td>9</td>
<td>38</td>
<td>47 (79.7%)</td>
<td>9</td>
<td>3</td>
<td>12 (20.3%)</td>
</tr>
<tr>
<td>LCIC = 60</td>
<td>10</td>
<td>34</td>
<td>44 (73.3%)</td>
<td>13</td>
<td>3</td>
<td>16 (26.7%)</td>
</tr>
<tr>
<td>Total = 119</td>
<td>19</td>
<td>72</td>
<td>91</td>
<td>22</td>
<td>6</td>
<td>28</td>
</tr>
</tbody>
</table>

Non-significant differences were found on cancer-free and on-treatment variables. As shown in Table 4, in HCIC, 47 (79.7%) people reported being cancer-free while in LCIC, 44 (73.3%) report as cancer-free, \( \chi^2(1, N = 119) = .666, \ p=.42 \). Eighteen (30.5%)
HCIC survey participants reported being on treatment and 9 (50%) of those reported as cancer-free. In LCIC, 23 (38.3%) participants are currently on treatment and of those 10 (43.5%) reported as cancer-free. The differences in groups with regard to being on treatment were also found to be statistically non-significant, $\chi^2(1, N = 119) = 1.21, p=.27$.

*Cancer-related Residual Impairments*

Each participant who identified as cancer-free was asked if they have any residual impairments and statistically significant differences were found between the two groups, ($\chi^2(1, N = 119) = 6.17, p=.01$). Of the 44 (73.3%) participants in HCIC who report being cancer-free, 20 (45.5%) reported residual impairments such as pain, scars, loss of sensation and erectile dysfunction. The percentages are different in LCIC. While a slightly lower percentage is cancer-free, the percentage of those with residual impairment is substantially higher. Of the 47 (68.1%) persons who report being cancer-free, 35 (74.5%) report residual impairments such as pain, swelling, lymphedema, and hormonal changes.

*Married or Partnered*

Likewise, the difference between clusters with regard to partnered status was found to be statistically significant, ($\chi^2 (1, N = 119) = 3.84, p=.05$). In HCIC, 43 (72.9%) participants who identified as partnered since the time of diagnosis while 16 (27.1%) identified as either non-partnered or not partnered with the same person since the time of diagnosis. A substantially lower percentage in LCIC identified as partnered with the same spouse/partner since the time of diagnosis: 34 (56.7%) participants while 26 (44.3%)
identified as non-partnered with the same individual since the time of diagnosis. Several members of LCIC reported being divorced related to their cancer or being widowed.

Qualitative Methods

First, the qualitative data collection process is described and the mixed methods results presented on the five factors of psychological adjustment, the five factors of PTG, and the three factors of illness intrusiveness. This will demonstrate the degree to which the qualitative data corroborates the quantitative findings and provide the basis for interpreting the quantitative data. Then the qualitative data are presented along with a description of the prominent themes found in the narratives. Finally, two processes which were prominent in the narratives will be discussed.

Qualitative Data Collection and Analysis

The qualitative data were derived purposefully to give voice to the lived experience of the participants. It contributes richness and complexity to better explain the variance between the two clusters as well as the universal themes of the interviewees. The purpose of the study was to identify the role of identity in an experience of cancer with particular attention to psychological adjustment and posttraumatic growth.

The qualitative component involved personal interviews with current/former cancer patients and their spouses with the goal of learning more about the role of cancer identity for adults with cancer. A semi-structured interview guide contained open-ended questions centered on changes in self-perception, roles, priorities, and relationships since the time of diagnosis and throughout treatment. The format was designed to facilitate
narrative telling and to not interfere with the participant’s response (Creswell & Clark, 2007). Consent was obtained and extensive notes taken. All except one of the interviews was audiotaped with the permission of the participants. One couple declined to be audiotaped.

Interviewees were recruited from the sample of individuals who completed the online quantitative instrument. Each participant who indicated being with the same partner since diagnosis was given an opportunity to provide contact information for follow-up about a possible future interview. Of the 77 participants who reported being partnered with the same person since diagnosis, 45 (58.4%) provided contact information. Each one was sent an email to invite them to learn more about a follow-up interview. Twenty-seven responded to seek more information and 17 were eventually interviewed with their spouses/partners, 10 from HCIC and 7 from LCIC. All 17 interviewees were Caucasian. An additional 65 participants provided comments and/or narrative information in the optional section of the survey.

Data were transcribed immediately after collection and a field note written (Charmaz, 2007; Creswell & Clark, 2007; Miles & Huberman, 1994). Data analysis was ongoing throughout the entire research process and analytic memos were utilized to guide the analysis. Then the data were coded for emergent themes. Codes were created that related to the data collected and new codes were added as needed. I listened to each interview several times to fully capture the narrative of each person and couple. Narratives were read and re-read carefully to see how interviewees made sense of these experiences in their lives. Field notes, journaling, and analytic memos contributed to the recognition of important patterns with regard to roles and identities that interviewees and
their partners identified. Themes common to all participants and common to a particular group membership were sought, but differences and non-confirmatory findings were also identified.

This qualitative study appears to have face validity as the underlying theory and assumptions are consistent with the existing literature and with my clinical experience as a therapist working in the area of oncology for the past ten years. Interviewing both patients and partners provided triangulation of data sources. The use of both quantitative and qualitative data also provided triangulation for validity.

Where necessary, it is noted whether findings apply primarily to one individual or are representative of the group. Also, similarities as well as differences were noted in presentation of the findings as these are important to distinguish the context of meaning. While the term “patient” is generally avoided as a loaded word with excessive social connotations and socially constructed meanings, the term has been used here for clarity and convenience. The preferred terms are person with cancer, person living with cancer, cancer survivor, or adult with cancer. Cancer survivor, a more socially positive term, is not a term embraced by all adults with cancer and therefore, its use is not meant to imply any meaning about survivorship and is used only in the most literal sense to describe one who has survived or is surviving cancer.

First, the qualitative data which correspond to the quantitative variables – identity, psychological adjustment, PTG, and illness intrusiveness – are discussed with an emphasis on comparing the data for corroboration. Second, the qualitative themes of uncertainty, suffering, and woundedness are discussed. The relevance of each theme to the clusters is presented and discussed, as well as outlier or non-confirmatory themes that
may be more prevalent in one cluster. And finally, two processes emerged: 1. an Assimilation process called Performing Normalcy, and 2. an Accommodation process called Constructing Survivorship.

**Mixed Methods Findings**

First, the qualitative data derived from personal interviews with seventeen couples was examined for corroboration of the quantitative findings with regard to the importance of the significant variables: illness intrusiveness, PTG, psychological adjustment, and cancer identity. The qualitative data are consistent with the statistical findings of the quantitative data with regard to substantial correlations between cancer identity and illness intrusiveness (three factors: Intimate Relationships, Relationships and Personal Growth, and Instrumental Life Domains), PTG (five factors: Personal Strength, Appreciation of Life, New Possibilities, Relating to Others, Spiritual Change), and psychological adjustment (five factors: Fighting Spirit, Fatalism, Avoidance, Helplessness/Hopelessness, and Anxious Preoccupation). The qualitative data corroborates the quantitative findings and the comparison of both types of data together contributes to the triangulation of data.

The comparison of data was able to explain some of the quantitative findings. For example, while two groups were identified with regard to the variable cancer identity, the high identity group could not be characterized by any universal narrative or theme. This was confounding until the analysis of data revealed two distinct subgroups within HCIC: positive and negative. The characteristics of each cancer identity cluster are presented in Table 7. The positive HCIC subgroup is characterized by Fighting Spirit, Anxious
### Table 7. Characteristics of Cancer Identity Clusters

<table>
<thead>
<tr>
<th>Positive HCIC</th>
<th>Negative HCIC</th>
<th>LCIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>High to very high cancer identity</td>
<td>High to very high PTG</td>
<td>Very low to moderate cancer identity</td>
</tr>
<tr>
<td>Moderate to high illness intrusiveness</td>
<td>Moderate to high fighting spirit</td>
<td>Very low to moderate PTG</td>
</tr>
<tr>
<td>Fatalism – acceptance</td>
<td>More likely to be partnered</td>
<td>Low to high psychological adjustment</td>
</tr>
<tr>
<td>“Cancer survivor’ means that I conquered something that tried to stop me. I won. Being a competitive swimmer for many years, I look at the cancer as a competitor, my Olympics. The word ‘survivor’ is my gold medal!”</td>
<td>“There's no way to prepare yourself for a cancer diagnosis. I wanted nothing more than to distance myself from the experience. I don’t talk about it very often. It's how I imagine many war veterans feel.”</td>
<td>“I have cancer. I am getting better – but I am me and there are way too many other things that are important about me and who I am that have nothing to do with cancer to have being a ‘cancer survivor’ be any part of my identity. Having cancer, to me, is a disease, a health problem, not an identity.”</td>
</tr>
<tr>
<td>Illness Intrusiveness-Intimacy</td>
<td>Helplessness/Hopelessness</td>
<td>Less likely to be partnered</td>
</tr>
<tr>
<td>Moderate to very high anxiety</td>
<td></td>
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Preoccupation, and PTG. It appeared that the positive subgroup of the HCIC contained those who had created the highest positive meaning from their cancer experience. This subgroup did not necessarily experience less illness intrusiveness, but reported higher positive consequences in terms of PTG. The individuals who indicated lower PTG (below the \( M \)) represented the negative subgroup. These individuals were more likely to endorse items of Illness Intrusiveness-Intimacy, negative Fatalism, Helplessness/Hopelessness, Anxious Preoccupation, and anger. There was also a paradoxical finding in that the scores on the survey identity items were above the mean but these individuals were more likely to expressly repudiate that the experience of cancer has become a central element of their identity. These participants were less likely to have been partnered with the same person since the time of diagnosis and more likely to have residual impairments.

*Psychological Adjustment*

The narratives of participants in the HCIC were more likely to contain themes related to *Fighting Spirit* while themes of *Helplessness/Hopelessness* were more common in LCIC or negative HCIC, and *Avoidance* was almost non-existent in the entire sample. *Fatalism* and *Anxiety* were prominent in both clusters. With regard to the Adjustment variables, as noted previously, factorial analyses by Watson and Homewood (2008) led them to conclude that Fighting Spirit represents positive adjustment while the factors of Fatalism, Avoidance, Helplessness/Hopelessness, and Anxious Preoccupation combined represent negative adjustment. In this study, the factors of Avoidance \((r = .075, p = .418)\) and Helplessness/Hopelessness \((r = .046, p = .623)\) were not found to be statistically robust relative to cancer identity, while Fatalism \((r = .452, p = .000)\) and Anxious Preoccupation
A statistically significant moderate or strong correlation to Fighting Spirit.

_Fighting spirit_ is characterized by optimism and a determination to fight cancer. It was moderately correlated with cancer identity \((r=.436, p=.000)\), PTG \((r=.371, p=.000)\), and illness intrusiveness \((r=.260, p=.004)\). Forty-three-year-old 3 year survivor of ovarian cancer stated:

And now, I recently faced a 2\textsuperscript{nd} kidney transplant and I was so thrilled that I was able to get through it all with the same strong fighting spirit and determination as I had back when I was 18! I am a strong believer on how physical fitness impacts on how we do in recovery, no matter if it is cancer or some other life-threatening illness. You will see me out cycling, always training for a cause as I am in October. I will be participating once again in the Lance Armstrong Foundation ride, Live STRONG Challenge in Austin, TX. I find that in order to be able to determine how you are recovering, you need a goal to work towards. Biking has always been my passion, and I have used it in very productive ways!

A 21-year-old man who is surviving acute leukemia stated, “I didn’t fight for my life to spend the rest of it down, depressed, or ashamed.” A 62-year-old Hodgkin’s Lymphoma survivor said, “For me cancer is all about the fight. Don't ever give up. Believe that you can fight it and give yourself permission to be as strong through the experience as you can be.” At least one participant noted a paradoxical outcome of Fighting Spirit: Alicia, 34-year-old, 7-year survivor of ovarian cancer stated:

I have become more assertive since being diagnosed. Because I was only 27, I felt as though I was being ‘blown off’ by my original oncologist. I took it upon
myself to find a second opinion. I truly found my voice, while fighting for my life. I also have become more cynical, less trusting simply because of the fact that the people I trusted hid my diagnosis from me.

While Fighting Spirit was prevalent in the positive HCIC, anger and betrayal was more represented in the LCIC and negative HCIC and will be discussed later. Fighting Spirit is most evident in the themes of Seeking and Performing Normalcy, and Constructing Survivorship.

Anxious preoccupation is characterized by rumination and preoccupation accompanied by anxiety and fear. It demonstrated a strong correlation with cancer identity \( (r=0.447, p=0.000) \), a moderate correlation with illness intrusiveness \( (r=0.292, p=0.001) \), and a statistically insignificant relationship with PTG \( (r=0.106, p=0.250) \). Zola, a 64-year-old 8-year breast cancer survivor, explained “I’m constantly concerned about recurrence and anxious about life expectancy.” Matt, at 37 a 10-year survivor of mouth cancer said, “It was probably the utter most hell I have ever been through. My faith was questioned and I learned that I was going to die.” This factor is clearly seen in the narratives in the qualitative sections on Uncertainty, Lingering Vulnerability, and Mortality Salience. Managing anxiety was prominent in many stories.

Fatalism is characterized by accepting what comes and living day to day. It was found to be moderately correlated with cancer identity \( (r=0.406, p=0.000) \), with illness intrusiveness \( (r=0.278, p=0.002) \), and a strong correlation with PTG \( (r=0.613, p=0.000) \). While Watson and Homewood (2008) suggested that Fatalism might be a component of negative adjustment, in this population Fatalism appeared to be positively represented by acceptance and negatively represented by resignation, which explains why some
individuals scored high on both fatalism and helplessness/hopelessness while others did not. Donna, 46-year-old woman who just completed treatment for Non-Hodgkin’s lymphoma, stated, “Overall, I take it a day or a week at a time, and find it hard to think about a ‘5 year plan.’” Cynthia demonstrated acceptance and a need to create meaningfulness when she stated, “everything happens for a reason.” A 50-year-old man, an eight-year survivor of colorectal cancer, wrote, “Each day is a chance!!!! You can either complain or moan or try to get into the solution.” A 57-year-old ten-year breast cancer survivor stated, “My husband, now deceased, was diagnosed at the same time (that I was re-diagnosed). During the six months we were both under treatment, we came to grips with what was important in life and became ready to go.”

Feeling as if one is in God’s hands is another aspect of fatalism. For example, 48-year-old breast cancer survivor Dianne who is just finishing treatment said, “God doesn’t give us more than we can handle and He knows who to pick on.” Karen, 62 and a 7-year survivor of multiple myeloma, stated, “I remember thinking, ‘well, God got this one right. I don’t have children or anyone to count on me so He got this one right.”

_Helplessness/Hopelessness_ is having a feeling of no control and no hope. It demonstrated a weak but significant correlation with cancer identity ($r=.195, p=.017$), an insignificant relationship with illness intrusiveness ($r=.158, p=.086$), and an insignificant negative relationship with PTG ($r=-.111, p=.228$). Henry (HCIC), a 62-year-old 2-year survivor of colorectal cancer, described an extreme case of illness intrusiveness and hopelessness:

I cannot control my bowels at certain times, which makes it very difficult for work and/or public situations, which I now avoid. I have leakage at night.
sometimes and have to change bedding in the middle of the night. Mentally, I feel broken. I have no zest for this life anymore. I am just waiting to die, even on antidepressants. I feel sad much of the time.

Avoidance is characterized by avoiding discussion or reminders of cancer and was not significantly correlated with cancer identity ($r = .153, p = .049$) with illness intrusiveness ($r = .046, p = .618$) nor with PTG ($r = .140, p = .128$). This was confirmed by the absence of robust qualitative data with regard to avoidance. However, John, a 31-year-old survivor of testicular cancer stated:

I kind of checked out of life for six weeks and tried to wall myself off from this scary experience. There's no way to prepare yourself for something like a cancer diagnosis. I wanted nothing more than to distance myself from the experience. I don't talk about it very often to this day. It's how I imagine many war veterans feel. We've experienced something so surreal and difficult to relay to others, that we find it best to keep it to ourselves.

It may be that cancer patients/survivors who engage in avoidance are unlikely to participate in research.

Posttraumatic Growth (PTG)

Likewise, PTG also corresponded to the statements made by the participants in the qualitative interviews. As shown in each of the five sections below, the qualitative data serve to corroborate the quantitative data and to provide greater understanding of the five PTG factors: Personal Strength, New Possibilities, Appreciation for Life, Spiritual
Change, and Relating to Others. Relating to Others will be handled later in conjunction with Illness Intrusiveness – Relationships and Intimate Relationships.

More participants in the HCIC endorsed items of PTG and the ratings also tended to be higher. These individuals fell into the positive subgroup of the HCIC, those who had created positive meaning from their cancer experience. This subgroup did not necessarily experience less illness intrusiveness, but reported higher positive consequences in terms of PTG.

Awareness of strength: “Stronger than I ever thought.”

Paradoxically, in addition to the common theme of Lingering Vulnerability is that of Awareness of Strength. This corresponds to the PTG factor of Personal Strength and has a moderate correlation to cancer identity \( r = .440, p = .000 \) and Fighting Spirit \( (r = .285, p = .002) \), and strongly correlated with Fatalism \( (r = .528, p = .000) \). The sense of positive Fatalism (Acceptance) manifests as accepting circumstances as they are and is critical to claiming one’s own strength.

It was one of the most common and profound themes, a realization of being stronger than believed. Strength referred to managing fear and negative emotions, ruminations, and meaninglessness, and sometimes sheer survival. That generally came through in two ways, either becoming stronger than before – having increased in strength – or discovering strength one was unaware of. Selma, for example, stated, “From before, things might derail me, but then I realize if it’s not life or death, you can get through it. This is a bad speed bump but I’m back and better. I came back, only stronger.” She also said, “Now I think that . . . I know that if there’s something to do, I’ll get through it. Do
what you have to do until I can’t get through it anymore. I can get through almost anything. I can bounce back. I always feel like I do.” Barbara, a three time cancer survivor (breast, lung and skin), celebrating her 8th year of remission from lung cancer, had this to say, “I can't help but think I'm not cancer-free, I do know that when a problem arises again, I will again soldier through.” Melissa, 45-year-old patient with leukemia for the past 13 years stated, “I'm not saying that it wasn't painful - it was. More so than I could have imagined or would have believed that I would survive, but I'm still standing.”

Some compared their present strength to that prior to cancer. A 59-year-old woman (in LCIC) recently diagnosed with invasive breast cancer stated, “I have had a very difficult life, and I knew before cancer that I am very strong and can handle a lot on my own.” Ellen reported, “I used to wonder if I was strong; I don’t wonder anymore.” Further, she speculated that lack of strength was the cause of her cancer: “I do think . . . I was susceptible because I didn’t handle stresses too well. I wasn’t emotionally strong. I took on too much. I don’t think that caused it just made me susceptible.” Ellen also noted increased strength in her spouse: “We both feel much stronger now.” Harvey’s wife, Sadie, stated, “I had no idea that I could cope with this.”

*Shifting priorities: “I know now what’s important.”*

Some interviewees talked about shifts in their priorities, goals, and dreams. These responses correspond to the PTG category of *New Possibilities* {which was strongly correlated to cancer identity (r=.540, p=.000) and Fatalism (r=.546, p=.000), and a moderate correlation with Fighting Spirit (r=.285, p=.002)}, or finding new opportunities or paths not previously considered or explored. This factor, statistically found to be one
of the most significant predictors of cluster membership, was more common in HCIC, particularly in the positive subgroup.

Selma noticed that she has more compassion for others going through similar circumstances: “It’s definitely made a difference with my job – a lot of the kids (students) are going through cancer themselves. I know better what they go through.” However, she also “realize(d) that I have control over that (her future) and it’s time for me to start working on that. I used to have the part of me that was a musician, and I used to paint. I’ve been letting my job define me. I need to go back to working on my creativity.” In contrast, Emilio’s “sense of urgency to complete goals evaporated. I didn’t care anymore about finishing my PhD.” He recognized that there were things in his life that mattered more. Nicole, 51-year-old breast cancer survivor, stated:

I would never say like some people that cancer was the best thing that ever happened to me. But it did make me more aware of myself and what I want and what my priorities are . . . I like to read and listen to music go hiking and kayaking all of which I do much more of now. In fact, before cancer I didn't own a kayak and I do now. I also went back to college and will complete a Bachelor’s degree this year. I may not have done that otherwise.

Many patients/survivors expressed feeling that they have been given a second chance and need to make that count. Karen, a 62-year-old survivor of multiple myeloma stated, “I feel that I've survived for a reason but I don't know quite how to deal with that ‘obligation.’ Perhaps I survived to help other cancer patients which I've tried to do but on a small scale. I feel that I should do more.” A 48-year-old breast cancer survivor who recently completed treatment stated, “It was very important to me to ‘keep going’ during
my treatment. I wanted to be an inspiration to someone else who might be diagnosed.”

“Cancer has given me a new purpose in life.” “I need to do something to deserve this.” A forty-three-year-old 3-year survivor of ovarian cancer stated:

When I returned to working at the outpatient cancer clinic after my 5-month medical leave, I realized how much my cancer experience really enhanced my practice skills in dealing with cancer patients and their families. I was able to present to them a unique level of empathy that no one could and the patients really respond to that! I realized that by being able to face cancer, go through treatment and then return to work, I provided these folks the hope that they needed to be able to get through their cancer journey.

A 48-year-old woman who just completed treatment for breast cancer, stated, “It was very important to me to keep going during my treatment. I wanted to be an inspiration to someone else who might be diagnosed.” Melissa, 45-year-old patient/survivor living with leukemia, stated:

I started doing marathons to raise money for the Leukemia Society and loved it. I felt like I was doing something for me and for others with this disease. I lost so many people in my family to leukemia that it felt good to be fighting back. I felt powerful and like I had a purpose. Life made sense when I was doing that. It felt noble and good. I felt like I was making a difference . . . I am achieving my goals and my dreams.

Feeling lucky or grateful.

Seven participants in the High Cancer Identity Cluster and three in the Low
Cancer Identity Cluster reported feeling lucky or fortunate at how things turned out. This corresponds to the PTG factor of *Appreciation of Life* which is strongly correlated with cancer identity ($r=.544$, $p=.000$), moderately correlated with Fighting Spirit ($r=.384$, $p=.000$) and strongly correlated with Fatalism ($r=.592$, $p=.000$). A 24-year-old melanoma survivor had this to say: “I am cancer free, but my chances of once again having melanoma are extremely high. After 11 years, I still have to have my lymph nodes checked once a year. It's annoying more than anything. I know I was extremely lucky because they caught my cancer just before it invaded my body.” Despite everything, breast cancer survivor Selma said, “Things always went well” for her; that she had the right kind of tumor markers so “I’m one of the lucky people;” and that “Things seem to really always go my way.” Another breast cancer survivor, 57, stated, “I am fortunate . . . my cancer was detected very early.” John, a 31-year-old survivor of testicular cancer stated, “I feel like I got off with a warning . . . like testicular cancer was just a good shake from someone up above, saying ‘Wake up son. Go! Live!’ Six weeks of chemo. A 96% cure rate. That's why I call it the lucky cancer.”

Others talked about a new appreciation for life or finding benefit in the cancer experience. Sadie, wife of Harvey, a 58 year old leukemia patient, noticed: “He started to appreciate things more. He had more patience, which was a big thing for him.” Ellen reported that cancer was “a gift” and had given her a new perspective on life. “Lance Armstrong was right. It’s taken a while to understand that.” A 58-year-old woman who has been living with Chronic Myelogenous Leukemia for three years stated:

Cancer is the best/worst thing that ever happened to me. I see myself as a medical miracle who is benefitting from the first and most effective targeted therapy
(Gleevec) and also from cochlear implants because the cancer left me totally deaf.

I sometimes feel like the luckiest person alive. Cancer has given me a whole new appreciation of life.

Feeling fortunate or grateful is not mutually exclusive with having a great impact from cancer. Shauna, 36-year-old 9-year survivor of cervical cancer, stated, “I wouldn't wish what I've had to go through on my worst enemy . . . I know that this will eventually lessen the years of my life, but I am thankful that I am cancer free - even if it makes my life a challenge.”

“My faith sustained me.”

Some participants noted faith and spirituality as important in their cancer experience. This corresponds to the PTG factor of Spiritual Change which has a moderate correlation with cancer identity \((r=.282, p=.002)\) and Fighting Spirit \((r=.272, p=.003)\), and a strong correlation with Fatalism \((r=.482, p=.000)\). This is quite evident in the statement of a 65-year-old woman who is a three year colorectal cancer survivor:

I thank my God everyday for the faith in my heart. I know whether I live here or in heaven it is due to the sufferings and death of my Savior, Jesus Christ. I am much more apt to talk about this faith now than before cancer, because so many people ask me how I can be so happy facing an incurable cancer. I answer that it is not me, but the Holy Spirit.

Cynthia (HCIC), 60-year-old survivor of renal and thyroid cancer, credits her faith with helping her to manage terror. She stated:
When I was first diagnosed, I was catapulted into abject fear. I knew that fear and faith could coexist, but not equally, so I made the decision to stand on the side of faith and trust that everything happens for a reason for my good. So I look for the God - or good - in all situations.” A 62-year-old Hodgkin’s Lymphoma survivor had this advice for others with cancer, “Keep your faith in both God and your family.

*Illness Intrusiveness: Impact of Cancer on My Life*

Another common point of discussion is the ways in which cancer changes how individuals feel and look, as well as its effect on life activities and valued roles. Interviewees readily identified examples of the intrusion on their life, work, relationships, and personal development that impacts their quality of life. One of the most salient features is the emotional response to this intrusion and the amount of adaptation that is required.

Illness intrusiveness demonstrated a strong correlation with cancer identity ($r=.551, p=.000$). The three factors of the Illness Intrusiveness Rating Scale (IIRS) are relationships and personal development ($r=.454, p=.000$), intimacy ($r=.487, p=.000$), and instrumental life domains ($r=.383, p=.000$).

Several individuals discussed severe impact of cancer on their quality of life. For example, Karen, multiple myeloma survivor, reported:

I am 6 inches shorter and have back problems/pain due to the 9 compression fractures caused by the cancer. I am limited in my mobility and ability to sit or
stand for long periods of time. I have only lost 40 of the 75 lbs that I gained from
my treatment.

Shauna, 36-year-old survivor of cervical cancer, stated:

I wouldn't wish what I've had to go through on my worst enemy. Just being able
to empty my bladder without self catheterization is a huge accomplishment for
me. I know that this will eventually lessen the years of my life.

A 75-year-old 18-year survivor of an “unknown primary” cancer stated, “I watched
myself deteriorate and couldn't believe this was me or my life. I had always been the
person who saw the glass half full.”

Harvey, 58, stated that, “When I first got diagnosed (with leukemia), I really felt
bad. I could hardly get out of bed. Now I have to come to terms with the fact that I will
be on medication for the rest of my life.” Ellen identified a shift in her most recent
recurrence and noted that her:

cancer (experience) has three stages: each one separate and distinct. This one is
much more serious. It’s metastasized. It’s chronic now. It’s much, much, much
more serious. It’s the first time cancer made me feel bad. I never looked bad
before either. It’s really only the last diagnosis that it’s been this way . . . Before,
everything was good so it was easy to act as if nothing had changed.

Now, she notes that it’s:

hard because my voice has been so affected (by radiation). People ask me all the
time if I have laryngitis or a bad cold . . . Losing my hair was not as bad as losing
eyelashes and eyebrows. Then I looked freakish and people noticed. I didn’t want
to go out.
Valued roles: work and family.

Participants were able to discuss the effects on valued roles, such as the cost to their professional identity because of cancer. Harvey noted that, “That pharmacy has been my life. I didn’t want her to know how hard that was for me.” The importance of this was deliberately hidden from his spouse. His wife, Sadie, stated, “Quitting work for him was not as big a deal as I thought.” Ellen reported that her career came to a sudden and abrupt halt when her illness interfered with deadlines, “My work – I’ve done 25 books. They weren’t willing to hire me again after they found out I had cancer. I’ve worked for them for 20 years. After that I didn’t tell employers.” Selma recounted that “yesterday, my boss came to me and said he is giving my job to someone else. . . then I realized, my job doesn’t define me. I’m a lot stronger now. I’m not going to get derailed over it.” Selma also discussed maintenance of valued roles with regard to work: “I tried to put in a little work every day, even on chemo days. It was important to me . . . There was one time that I was on the phone with a [client]. I put him on hold, puked, carried it to the dumpster and then got back on the phone. Dr. [R] told me I’d have to take a year off. I told her she could take a year off.” Maintaining dignity was highly prized by Selma:

I didn’t want to paste eyelashes on. I have to do this in a dignified manner . . . My hair was gone; I’d get dressed for work and try to make myself look nice . . . I’d be dressed for work, I’d get a hot flash (from the hormones) and be all wet and have to go back inside and try again.

Mike, a 51-year-old man who has been on treatment three years for Chronic Myelogeneous Leukemia stated:
It was a devastating blow to be told I had cancer, I continued to work at a very physical job. That turned out to be a mistake, it really took its toll on me. I get very down and side effects from medications make some days very difficult to deal with.

Another area of discussion for the interviewees was that of family. Ellen, for example, stated, “I can’t be there for my family like I used to.”

Responses of others.

Every patient/survivor talked about the impact of cancer on their social and intimate relationships. The ‘responses of others’ powerfully shaped the experience for patients/survivors. One of the most significant common elements of the narratives was that of the responses/reactions of others, social support or social constraint, as well as a prevailing sense of either connectedness or isolation. An outpouring of love and support reinforces relationships and helped some people embrace a new understanding of how much they matter to others. Others were silenced or made invisible by the judgment, indifference, or ambivalence they perceived. While some noted finding out how much others really cared about them, some lost close friends who drifted away or avoided them. These responses correspond to the PTG factor Relating to Others and the Illness Intrusiveness factors of Relationships and Intimate Relationships. Relating to Others is moderately correlated with cancer identity (r=.427, p=.000) and Fighting Spirit (r=.332, p=.000), Illness Intrusiveness-Relationships (r=.378, p=.000) and strongly correlated with Fatalism (r=.566, p=.000). Illness Intrusiveness-Relationships is strongly correlated
with cancer identity ($r=.533, p=.000$), moderately correlated with Fatalism ($r=.301, p=.001$), Fighting Spirit ($r=.248, p=.006$), and Anxious Preoccupation ($r=.258, p=.005$).

One of the more interesting significant findings was the importance of supportive intimate relationships. Illness Intrusiveness-Intimate Relationships is strongly related to cancer identity ($r=.487, p=.000$), moderately correlated with Anxious Preoccupation ($r=.290, p=.001$), and Trauma ($r=.359, p=.000$), and is not significantly correlated with Fighting Spirit ($r=.133, p=.150$), Fatalism ($r=.116, p=.150$), or the PTG factor of Relating to Others, but has a weak significant correlation with Helplessness/Hopelessness ($r=.197, p=.032$). In other words the intrusion of cancer on intimate relationships is associated with trauma, anxiety and rumination, and helplessness, but not with fighting for life or acceptance of circumstances.

This factor was found to be a significant predictor of cluster membership. This is of particular interest since the discrepancy between the HCIC and LCIC with regard to being partnered was statistically significant. Fewer participants in the Low Cancer Identity Cluster reported being partnered as they went through treatment for cancer. More persons from LCIC and negative HCIC reported being widowed or divorced.

_Social support and connectedness._

A common theme is around those people who were supportive or “there for them” and those who were not. Selma reported, “Everybody (at work) was so sweet. They all pitched in and gave me $300 for copays.” Ellen even attributed her survival in part to the support of loved ones:
I’ve survived because I’ve had a lot of love. A lot of people care about me. I’m surprised by how many people cared and prayed for me. I know other people were praying for me. Just the thought that people were actually thinking of me. . . it meant so much.

Donata agreed, “Just knowing how many people were pulling for me got me through.”

Linda, cervical cancer survivor stated, “Having cancer made me realize how many people cared about me and that was worth everything. I learned to trust people and to let them in. That was big.” Finally, Ellen stated, “Cancer is the price that had to be paid for me accepting people caring about me. This is a gift.”

Even this type of support and attention can have a cost for some, however; Selma noted that “The bad part (of cancer) is too many phone calls from friends.” Some participants report having to be strong for others. A 59-year-old newly diagnosed breast cancer patient stated, “When you are a cancer patient, you are a caregiver. I have found myself consoling my mom and others.” Cassandra stated, “I didn’t even tell my dad because I knew he would make it all about him and I just couldn’t deal with it. He’s such a drama queen.”

Lack of social support and social constraint (lack of fit between support received and support desired) are themes more commonly reported in the LCIC and in the negative HCIC. A 46-year-old woman who is currently on treatment for breast cancer stated, “I feel that a diagnosis of cancer can be very isolating. Friends, family, coworkers, etc., just don’t know what to say to you about it. That makes it harder to talk about, even when you need to talk about it.” Mike, a 51-year-old still on treatment for Chronic Myelogenous Leukemia said:
I try to get through and stay positive but it catches up with me here and there. I keep much of my dismay to myself, because everyone has an answer . . . like, ‘everyone dies, get over it’ or their own problems to deal with. I’ve found who my friends are and that there a lot of cold people out there. There are times I would just like a compassionate ear, but they are hard to find.

Constance, 62, had a unique perspective:

Because I was carried through the entire cancer/treatment experience by wonderful family and friends, I did not deal with the emotional consequences of cancer. One year after my treatment concluded, I went into a deep depression where I was so low that I didn't get out of bed and would not have minded if I died. Drugs and counseling with a psychologist, plus patience of my family and friends, pulled me through.

Some people responded with fear or revulsion. Ellen stated that, “Other people see you differently once you have cancer.” Selma noted “I was the cancer zombie. A lot of people still don’t recognize me. I went to the dentist, a man I used to date, and when he saw me, all bald and weird, he was scared.” Her explanation of this is that other people want to learn from her mistakes and protect themselves: “There’s a big difference about how people react to you when you have cancer. People react to you like Night of the Living Dead. People look at you like ‘what did you do to get cancer?’ Like, ‘what can I do to protect myself?’” This reaction gave patients a sense of being different or “other.” Karen reported that because of her loss of six inches of height and weight gain of 75 pounds, friends didn’t even recognize her. “They would pass me in the store without a second look.” She felt invisible.
Many people noted that others have expectations about how cancer survivors should be and act. Selma stated: “They expect you to run on Race for the Cure. People are amazed that I don’t have pink ribbons on my car.” Ellen reported, “Other people see you that way and respond to that. They see you as a warrior.” Sally, 60 years old and on treatment for breast cancer stated:

The emotions continue long after treatment has ended. It is important for people to understand that. There are many good days but there are times when it is difficult. The assumption of others that you are now fine and you should be back to ‘normal’ can be difficult. I am overall a very optimistic person who enjoys life but it is difficult to have ‘bad days’ sometimes because people do not understand.

Once they felt and looked “normal,” patients/survivors had to make a decision about how, when, and to whom to disclose about their cancer to others. Leukemia patient Harvey stated, “I don’t really tell people. I don’t think it’s any of their business. But almost everyone knows anyway.” Ellen reflected, “It’s a conscious decision. I don’t tell just anyone, but in a social context, I don’t hide it either. But I know now that there is a risk in telling . . . but I don’t want to always be identified by cancer.”

And finally, some patients/survivors found a comradeship with other survivors that they did not have with those who are not cancer survivors. Ellen reported that “Other people with cancer understand better.” In fact, she stated that she went to some of her friends with cancer “I told everybody when I got good news. I did it as much for them because they need to hear that.” Her husband Emilio echoed that by saying “Everyone’s successes are your successes; everyone’s losses your losses.” Linda stated, “I feel like I belong to a sorority of survivors, that only those others can really understand.”
Intimate relationships and sexuality.

The couples frequently described a united front with their partner/spouse. Emilio, Ellen’s husband, stated, “We’re like two little kids lost in the woods together . . . we’re simply together in this.” Ellen agreed, “We’ve had to rely on ourselves, on each other. If it comes back, when it comes back . . . whatever. We’ll face it.” she also added “We haven’t had a big support system, just each other and our son.” Harvey stated, “I could not have done this without Sadie. I wouldn’t have wanted to.” Selma reported that at the time of her diagnosis, she went to Nick and said, “I’m going to need you here. Let’s pull together.” She added, “It’s something we got through together.” Marge, 59-year-old bone cancer survivor, stated, “Larry (my husband) kept me grounded. He kept me from losing myself when doctors were cutting me up and life was tearing me apart. He kept me me.”

Many couples noted that the experience has strengthened their marriage to an unbreakable bond. Selma stated, “When I needed him, he was there for me. We were able to work through it together. It strengthened our bond . . . I can fall back on him. He didn’t even care that I was bald. He was wonderful. He’s a great guy.” Sadie also reported, “We had our problems in the past, but after he got sick, they just went away.” There is also a sense of protecting one another as much as possible. Ellen reported keeping things from Emilio: “I didn’t tell him. I didn’t want him to take it on.” Melissa stated, “I have a new partner now who loves the new me and was thrilled when I moved more toward a more authentic self.”
But there was also concern and fear with regard to intimate relationships and sexuality. Selma reported, “I feel less of a wife now.” A 46-year-old woman who is currently undergoing treatment for breast cancer said:

The surgeries that I've had gave me a scar across my breast, plus a lopsided appearance to my breast. The man I had been dating for a year decided he couldn't handle my diagnosis and stopped dating me prior to my surgery. Now I'm 46 and single and concerned with the appearance of my breast should I start dating and become intimate with someone again. I haven't had the radiation yet, but I understand that will produce even more changes in that area, so I'm concerned about that as well.

Several women noted that their marriages ended as a result of cancer of disfigurement. A 35-year-old breast cancer survivor stated, “My husband left and blamed me because I did not have breasts.” Another survivor stated, “My husband divorced me because I was disfigured” but added, “I realize now how shallow a person he was and it was the best thing that ever happened to me.”

Men with prostate or testicular cancer noted the impact on intimacy and sexual performance. A 54-year-old prostate cancer survivor reported:

Having the prostate removed you lose part of your ability to have an erection without the aid of a pump, pill, or in some cases a shot. It does take a little more planning when you are planning to be intimate with your spouse or whomever.

He also noted:

There are other precautions that have to be taken because of the side effects. Pads have to be worn to hide the small amount of leakage that does occur. I find myself
not wanting to be as intimate with my girlfriend as before and that is not fair to her. Although she is great and is understanding and when we are intimate it is still very satisfying to both of us. It’s just the preparation and planning that has been frustrating.

John, a 31-year-old testicular cancer survivor reported his changes as an identity issue:

Obviously the removal of a testicle has a profound impact on your sense of self. The impact was much more psychological than physical, however. The fact that everything functions the same physically was a major relief and contributed significantly to my ability to rebound from the experience. I opted for a testicular implant to help cope with the thought of losing a testicle. It provides a sense of normalcy for me.

Women survivors of cervical, ovarian, vulvar, and breast cancer discussed the impact on sexuality and sexual intimacy. Cassandra, 32-year-old cervical cancer survivor reported, “Due to the type of cancer I had, I now look at sex differently.” Selma and Nick agreed that their sex life has suffered as a result of Selma’s induced menopause for breast cancer: “Sex is not what it used to be. It used to be fun. Because of the medication I went through menopause. Now it’s all about planning and lubrication” (Selma). “It’s no longer spontaneous so a lot of times we don’t even bother” (Nick).

_Cancer Identity_

With some participants, there was a disconnect between the quantitative and qualitative data with regard to cancer identity. Participants in the High Cancer Identity Cluster (HCIC) scored higher on CES than participants in the Low Cancer Identity
Cluster, and had scores about the mean. However, there are individuals in each cluster whose narrative or interview data were inconsistent with their score on the CES. The non-confirmatory cases are those who reject a cancer identity but endorsed CES items on the survey such as: “I feel that cancer has become part of my identity,” “Cancer permanently changed my life,” and “Cancer was a turning point in my life.” For example, Constance, in the High Cancer Identity Cluster (CES z score = 0.95990), stated, “Cancer happened to me, it’s not who I am. I don’t want to give it any more energy or attention than it has already taken.” In contrast, Niki, a 51-year-old breast cancer survivor in the Low Cancer Identity Cluster (CES z score = -0.06342) stated, “I don't live as a victim. I live as a survivor and do all the things I can to help keep the cancer from returning.”

The Low Identity Cluster seemed to have three types of members: those for whom cancer was almost a non-event (an interruption), those for whom cancer is in the past and life has moved on, and those who are newly diagnosed or so close to the end of treatment that they have not yet begun to process this event. The very nature of this cluster, however, is difficult to characterize since its defining feature is the absence of a strong identity. Unique sub-themes of the Low Cancer Identity Cluster were anger/betrayal; refusal to allow cancer to take center stage; and history of prior trauma.

Participants in HCIC were more likely to report that awareness of one’s mortality prompted a re-evaluation of goals, priorities, and relationships, as well as creating greater appreciation of life and a need for symbolic immortality. Some survivors described a need to create meaning by making something positive from their distressing circumstances as well as a need to ‘make it count.’ The sub-themes found which were
more prominent to High Cancer Identity Cluster were ‘making it count’, ‘why not me?’, feeling lucky, and enhancing self-efficacy. Anger and repudiation of a cancer identity were also findings within LCIC and negative HCIC.

Two HCIC subgroups: positive and negative.

High Cancer Identity Cluster does not necessitate a positive cancer identity. In fact, it appears that individuals in the HCIC constitute both positive and negative representations. The positive subgroup is characterized by those for whom a cancer identity is a positive means to give expression of their cancer experience. They tended to score high on both illness intrusiveness and PTG, demonstrating a need or ability to find the positive in negative circumstances. They were able to integrate cancer into identity while maintaining or creating a positive sense of self. Cancer became a defining feature which said something profound and positive about them, and integrating a positive cancer identity was ultimately a way to manage terror and make something meaningful from something terrifying. Positive cancer identity appears related to enhanced self-efficacy. For those whose efforts proved futile, anger and helplessness ensued, resulting in either despair or renewed efforts to regain control in alternate ways to create something positive or meaningful. Table 7 shows characteristics of the cancer identity clusters.

The negative subgroup is characterized by those with high illness intrusiveness who have yet to create some perspective in cancer and are still living it but who did not strongly endorse items of hopelessness. They scored high on illness intrusiveness and lower on items related to PTG. These individuals are distinguished from the LCIC
primarily by higher scores on the identity scale, and on the psychological adjustment scores which demonstrate increased strategies to manage stress.

*Cancer survivor.*

‘Cancer survivor’ proved to be a divisive term with some interviewees choosing the term but other rejecting or criticizing it. While many connected with a cancer identity, others did not. The reasons for rejecting it ranged from “too passive,” or “implies special qualities,” to a refusal to be “so closely tied to cancer.” Those participants who stated that cancer does not define them either rejected a cancer identity due to a refusal to allow cancer to have power in their lives or the overall impact of cancer was low, particularly if they never believed they would die, if they maintained close, supportive relationships and if they were able to maintain valued life roles. Individuals with low-intrusiveness reported minimal effect on their identity, as did many who were newly diagnosed.

When asked to define or describe ‘survivor identity’ during the interview, some interviewees focused on a literal perspective of the term. Theresa (LCIC) stated, “Survivor means someone who has survived the treatments and is cancer free at that time.” Heather (LCIC) stated, “Cancer survivor for me means I survived the treatment.” Others seem to view it as a triumph of will and personal power. Cynthia (HCIC) stated:

I don't really like the term ‘survivor at all’. To me, the word *survive* is much too passive . . . and there is *nothing* passive about a cancer diagnosis and the subsequent journey. I prefer the word *conqueror* because that's really what cancer patients have to do. They have to conquer every fear, every thought, every new
challenge, every minute of the day . . . or else it would be impossible to look forward to the next minute.

Alicia, 34-year-old ovarian cancer survivor, agreed:

The term ‘cancer survivor’ means that I have conquered something that tried to stop me. I won. Being a competitive swimmer for many years, I look at the cancer as a competitor, my Olympics if you will. The word ‘survivor’ is my gold medal!

John (HCIC) rejects the term for the very reason that it attributes his survival to him:

I don't like thinking of myself as a ‘cancer survivor.’ I think it falsely implies some special qualities that enabled me to beat cancer. I accept the title and how it allows me to reach those living with cancer now. And I am grateful to have the opportunity to counsel friends and strangers through their battles by sharing my own story. But the label is unimportant to me beyond its ability to open doors and opportunities for sharing my story and enriching someone else's life.

Kate (LCIC), on the other hand, rejects the term because it ties her identity to cancer:

I personally hate the term. I have cancer. I hope to one day not have cancer and the same risk level of recurrence as everyone else – but my identity is not as a cancer survivor. I have a disease. I got treatment. I am getting better – but I am me and there are way too many other things that are important about me and who I am that have nothing to do with cancer to have being a ‘cancer survivor’ be any part of my identity. Having cancer, to me, is a disease, a health problem, not an identity. I survived cancer – but I am not interested in it becoming my identity.
Likewise, Constance (HCIC) stated, “I don’t like the term ‘cancer survivor.’ It separates me from you and we’ve all survived something.” Susan, survivor of a stem cell transplant and bone marrow transplant for Acute Myelogenous Leukemia, had a different reason for not claiming the term: “I don’t like the term ‘cancer survivor’ because it implies vulnerability. I will never call myself cured even though I’ve been off treatment for twelve years.”

Twenty-four year-old testicular cancer survivor, Alan, suggested age might play a role in his cancer identity:

I cannot possibly overestimate the impact that cancer had on my personality and identity. I know it sounds silly, and perhaps it is a function of the age at which I underwent treatment, but this has been, by far, the most significant event in my life.

Others noted that cancer identity has changed over time or that shifts between background and foreground. A 54-year-old 4-year ovarian cancer survivor stated:

I do not identify myself as a person who HAS cancer. I do identify with being a survivor of cancer and certainly see the still daily effects of my diagnosis and treatment. At some point, if the cancer does not return, you move through different stages of experience and identity.

Linda, 43-year-old cervical cancer survivor, stated:

Being a cancer survivor is just part of my identity. Sometimes it’s more important than others, like when I have a doctor’s appointment or when I’m with other people who’ve had cancer. Then I think about it a lot. Or something reminds me. But I don’t think about it all the time.
Anger/betrayal.

A sense of anger or betrayal was more frequently reported in LCIC or in negative HCIC, and occasionally found in positive HCIC. Individuals in this category seemed to be angry at either the diagnosis, the care from the healthcare community, the frustration about managing the bills and insurance, or feeling betrayed by their bodies. Some people are angry at the doctors or the system that let them down. Bryn, 52-year-old 13-year survivor of breast cancer, had a very moving story about her experience with cancer, other concurrent stressors, and the indifference of the healthcare providers:

When I was first diagnosed, I felt like I lost control of my life. The radiation therapy department told me exactly what time I had to be at the hospital for treatments. The time wasn't convenient but that didn't matter to them. I would have to leave work early or go in late (depending what day of the week it was) to work. One time I was crying during a CT scan because the liver scan was abnormal and the tech person told me that I needed to get help because I was getting too emotional. I was 39. I had breast cancer (yes, I breast fed both my children and I have never smoked anything in my life) but I didn't have a right to show emotion. My next round of cancer came in 1995 (at age 41). Same type, same breast--so much for the radiation treatments. That year was terrible for our family. My mother died of lymphoma in her brain at age 64 (March). The day after my mastectomy and TRAM procedure (September), my father-in-law died in his sleep. I spent the next week in the hospital and missed his funeral. I was grieving by myself (for the loss of my breast, the loss of my mother and now the loss of my father-in-law). This was a very tough emotional time for me and my
entire family. My son was in grief counseling at his elementary school and the
counselor told me that he had so much sorrow in his life that he didn't have much
room to learn.

A 50-year-old woman who survived breast cancer reported, “I went to the doctor because
I knew I was sick and three separate doctors told me it was all in my head. A nurse
practitioner is the one who ultimately caught the cancer.”

John, a 31-year-old survivor of testicular cancer, identified multiple sources of his
anger: “I got angry that no one knew what chemo felt like and that cancer just made no
sense. I got angry at myself for being angry when my cancer had a 96% cure rate!”

Constance, a 64-year-old cancer survivor, expressed her anger at cancer, “I was furious
that cancer interfered with my life, my plans, our trip. Cancer was an interruption not a
derailment of my life. Now I’m done with cancer.” Cynthia, a 60-year-old survivor of
both renal and thyroid cancers, stated, “Being a control person simply made me angry
most of the time, so my perceptions, responses, choices and thoughts reflected that
anger.”

Billing and healthcare systems were also targets. A 58-year-old 12-year survivor
of Non-Hodgkin’s Lymphoma who reports multiple residual impairments has this to say:

You need to consider the social context of cancer and social determinants of
health . . . access to care and medication barriers and experiences, insurance
issues . . . the financial devastation that many of us face due to a cancer diagnosis.

You need to look at how we now fare in broken healthcare system as survivors, an
impact of policies of the Bush Administration on our lives.
A 25-year-old man who just completed 3½ years of chemotherapy for Acute Leukemia stated:

I learned way more about the healthcare crisis in our country and how nasty hospitals and billing agencies can be. That was honestly the worst part about cancer. That’s sad when I was battling a life-threatening disease and dealing with insurance agencies and medical billing was the biggest challenge.

*Cancer as a non-event.*

Some interviewees in LCIC or in negative HCIC made a point to define cancer as a non-event or at least as non-trauma. Cassandra, 34-year-old survivor of cervical cancer, said, “I realize that my cancer diagnosis was not serious when compared to the many people that are battling this horrible disease.” In other words, she compared her situation to others and found it not significant or worthy by comparison. She underscored this by saying, “I thought my cancer was too insignificant for you to call me for an interview.” Others, like Dan, 72-year-old prostate cancer survivor said, “I had cancer, but so what? Snip, snip, it was gone.” Selma’s response was, “I had cancer. I’m not forever tied to it.”

*History of prior trauma.*

Several participants in the LCIC reported a history of prior trauma. For these participants cancer was a non-event, created resiliency, or contributing to feeling overwhelmed. Madelyn, a 60-year-old breast cancer survivor had this to say:

Cancer was not the turning point in my life. I learned all the things you are measuring by having a child die at age 2 after living in a hospital NICU most of
her life. Later I found that my husband was having an affair and ultimately, 9 yrs and a few affairs later, divorced. Those two events really got my attention and made me appreciate life and the support of others. Cancer was rather ho-hum after those experiences.

Other survivors report that their prior trauma has created resilience. Theresa, a 60-year-old breast cancer survivor stated, “Cancer was not the most traumatic experience of my life. I had clinical depression a few years before and that was by far my worst experience. In a sense, it prepared me for the cancer.” Another participant, 56-year-old breast cancer survivor, reported a more complex reaction:

I think my experience in being diagnosed with cancer is somewhat - if not much - different than most because I have already experienced significant losses and change and trauma in dealing with 20 orthopedic surgeries over the past forty years for a childhood condition. On the one hand I have more coping skills than most; on the other, I have had so much trauma that the cancer just sort of tipped the scales so far off that I've not really recovered fully. I am doing much better physically and emotionally, yet I cannot say that the cancer made me a better person, or that I feel more grateful – just more depleted.

Qualitative Themes

While the narratives correlate to quantitative data and expand our understanding of those variables, the qualitative data derived from the narratives also yielded interesting universal themes of suffering, woundedness, and uncertainty. Suffering is evidenced by the perceived impact of cancer on their lives and physical integrity, their ability to
maintain relationships and valued roles, coping strategies, and their ability to make meaning of events evidenced in part through identity changes. Woundedness in this study represents damage to core identity. It denotes injury and an enduring impact. The narratives also suggest that an ongoing sense of uncertainty created by mortality salience and lingering vulnerability enhance suffering.

_Suffering and Woundedness_

Given that Anxious Preoccupation, Illness Intrusiveness-Intimate Relationships, and Perceived Life Impact of Cancer were three of the four the primary quantitative variables that predicted group membership in the cancer identity clusters, it is no surprise that suffering (and its emotional fallout) is a central concept of the narrative themes. Evident in the data are the prominence of suffering, attempts to manage or minimize suffering, and efforts to make meaning of suffering.

The degree to which suffering from cancer invades an individual’s life, future, and intimate relationships causing uncertainty and anxious preoccupation shapes the residual woundedness of the individual. Uncertainty as foreground leads to woundedness. However it is not just the level or duration of impact or intrusion that is important, but the emotional responses and cognitive appraisals which shape an individual’s understanding. The awareness of one’s mortality proved less significant than the intense fear or helplessness one experienced. Just as striking was that some patients did not consider themselves cancer survivors until they had experienced suffering as a result of cancer.
Uncertainty

One of the most powerful, prominent themes was that of uncertainty due to fears of dying, of relapsing, or of losing control which evoked a lingering sense of vulnerability. For many, uncertainty has become a defining feature of their cancer experience and survival, and is an integral part of the suffering/woundedness they’ve experienced as a result of cancer. Patients/survivors spoke of being changed by their experience in constantly looking over their shoulder, wondering when they will get bad news or when cancer will come back into their lives. The knowledge of one’s mortality is so profound that it cannot become unknown even once the immediate danger has passed. In that sense cancer never ends for many. One interviewee described it as a “loss of innocence.” Between the mortality salience and one’s intense visceral and emotional responses, an enduring sense of vulnerability is created. Many patients/survivors expressed that life will never be the same again.

Mortality Salience

For most participants, their diagnosis of cancer was the first time they really considered their own death and mortality. Mortality salience is the awareness of one’s own mortality, that life is finite and thus more precious or important in its fragility, and is a profound way in which cancer intrudes on the lives of patients/survivors. This was measured quantitatively by the question, “Do/Did you perceive being diagnosed with and treated for cancer as a threat of death or serious injury or a threat to your physical integrity?” and is moderately correlated with cancer identity ($r=.454$, $p=.000$), illness intrusiveness ($r=.381$, $p=.000$), and Anxious Preoccupation ($r=.420$, $p=.000$), while
mildly correlated with Fighting Spirit ($r=.255, p=.005$) and PTG ($r=.216, p=.018$).

These findings are corroborated by the qualitative findings.

The impact of awareness of death as a suddenly real possibility is reflected in the narratives of the majority of participants throughout both clusters. Realizing that life is a fragile, unpredictable, and not unlimited resource suddenly at risk tends to create an appreciation for its presence yet adds to the pervasive sense of vulnerability. This awareness or acknowledgement does not appear to be a static concept, but shifts according to current beliefs and understanding of the situation. (As noted below, the perceptions of the partners were different with regard to their spouse/patient.) Karen stated that “Cancer wasn’t the most traumatic event of my life; learning that I was going to die was. I had to come to terms with my own mortality. That was harder than facing cancer.” As 56-year-old throat cancer survivor Ted stated, “When a person is diagnosed with cancer, you don’t hear ‘You have cancer,’ you hear, ‘You are going to die.’” Sarah, a 56-year-old renal cancer survivor, stated, “When I was first diagnosed, I was told I would most likely die during surgery. Being somewhat of a lifelong control person, I was catapulted into abject fear.” Matt, at 37 a 10-year survivor of mouth cancer said, “I learned that I was going to die. A lot of people don’t realize that one day they are going to die. That is most of what I got out of this whole situation.” However, Candace, a 46-year-old woman who just finished treatment for vulvar cancer, stated, “Having cancer made me get over a deep fear I had my entire adult life of death.” Thirty-one-year-old John reported cancer as a wake-up call, “Cancer awakened me like nothing else ever has or possibly could.”
On the other hand, there are participants who have no expectation of dying from their cancer. This was more representative of the LCIC. Kate, 48-year-old newly treated breast cancer survivor, “My cancer is not life threatening - so I am not thinking in terms of having limited time. I realize that many people diagnosed with cancer - even "curable cancer" are confronted by their mortality. I have a much greater chance of getting hit by a bus or dying of cardiac disease then dying of cancer - so I have not experienced all of this in a life threatening or life limiting way. I have always tried to live in the moment and take full advantage of where I am and what I am doing. I plan for the future - I am only 52 and I have an 11-year-old son - I will hopefully have a full life ahead of me.” Selma reported that, “Death was not going to be part of the equation. (When I thought of that, I thought) I’m going to be fine.” Harvey stated, “But then I realized that I had to focus on myself or I would die.”

A related element is living in the moment – a natural extension of an uncertain future. Emilio described living in the moment and not in the future: “Everything is good now, just live.” He also said, “This is so life altering . . . people should appreciate the freedom to not have to worry.” Selma said simply, “I’m going to be alive for the rest of my life,” acknowledging the uncertainty of life and a commitment to living fully during whatever time is left. Donata’s statement about that was, “I don’t think about the future. I live for now. I don’t plan more than a month ahead. It causes problems for my husband who wants to plan a vacation but I just can’t. Maybe one day, but I can’t think that far ahead.”

Fear of death is a fear of an unfulfilled life or of unfulfilled commitments and promises and can create an existential crisis or re-evaluation of priorities, and was more
prevalent in the positive subgroup of HCIC. The awareness of one’s mortality either seems to stay with one or cause a shift to making the most of life. Melissa, a 45-year-old woman being treated the past thirteen years for leukemia, stated:

Cancer changed my life and rocked my world. My marriage ended in part because my husband at the time could not understand how much it affected me knowing that I would die. When I thought I would lose my life I realized how off-track my life had been, how much that life was not what I wanted. I became a different person. I started on a journey to the me I should have been and will be. Cancer brought this amazing understanding that I am mortal and this life is transient. That thought brought a clarity to my life that I had not had before. I could no longer pretend that things were ok or that tomorrow would always be there. I was trapped in a life that didn’t fit and I didn’t even realize it. I guess I thought that I could always change it someday. Well, suddenly I learned that some day was now or never. I was stripped bare and now I am free to be me. It changed me in ways I don't even have words for. I feel like a different person on a cellular level. It's chemical, physical, emotional, intellectual, and social. All because I realized that life does end and I want this one to count. Life is too short to have regrets, especially when you are given the chance to change things.

Fifty-one-year-old breast cancer survivor, Nicole, stated:

I have learned that life can be cut short without notice. I know we all know that. But the reality is for me it was on the back burner and I was not actively thinking about having my time cut short. One of the things I came to believe during the time of my treatment was how much of an honor it is to be able to grow old.
always thought of growing old as a negative thing. I now think of it as a privilege, that I want to be able to participate in and make the most of. I also learned not wait to do things especially if they are important. Because you never know when the chance to do things will come to a sudden and abrupt end.

Lingering Sense of Vulnerability

One of the most profound implications of the illness intrusiveness and mortality salience is living with uncertainty manifested as a lingering sense of vulnerability. This seems to have two constituents: uncertainty related to knowing that cancer never ends and that life will never be the same again. A 54-year-old Hodgkin’s Lymphoma survivor states, “I was diagnosed at 22, right before my graduation from nursing school and my wedding. The scariest time for me was after the treatment was over waiting to see if the cancer would come back. While I was having treatment I felt proactive and more in control over my disease. Once it was over, I felt quite alone facing the uncertainty of my future.” A 59-year-old survivor of melanoma and renal carcinoma said, “I suspect that eventually I will die of some sort of cancer. My mother died of brain cancer at 84, my father during surgery for osteo-cancer (bone cancer in the knee and thigh) at 86. But I think it will be cancer that gets me too. I just don't want the pain!”

Nicole, 51-year-old breast cancer survivor, stated, “I am very aware of my having a cancer diagnosis daily. It runs in my family and is of concern to all of us . . . When unexpected health symptoms occur I always run straight to the doctor to get checked out. Probably much faster than I would have previously.” Another 46-year-old woman has just finished treatment for lymphoma stated, “I have an underlying fear that my
lymphoma will come back – there’s a 20% chance – and that I will not survive. This underlying fear leaves an ongoing anxiety level and insecurity I didn't have before.”

Cynthia (HCIC), 60-year-old survivor of renal and thyroid cancer, stated, “Once you hear the word cancer, a headache is never just a headache, a pain is never just a pain.”

The view that life will never again be the same was evidenced clearly in the remarks of a 52-year-old man who is a 12-year survivor of colon cancer stated, “Although I have had no cancer for almost twelve years, I never consider myself to be cancer free. My life has been far too altered by the experience.” Nick, Selma’s husband, stated, “Cancer, chemotherapy, radiation turned our lives upside down. Put our lives on hold for a year and a half. There were highs and lows but they were minutes apart.” “I feel about 10 years older than before. I’ve aged 10 years in a year and a half. I gained 10 years worth of experiences. And I don’t have the same strength and stamina as I did before.”

Many people talked about never being over cancer, that cancer is always with them in some way, in part by affecting their relationships. They report that others do not understand that. Ellen stated that “Other people look at it and say, ‘Now that you’re over cancer.’ People don’t understand it . . . that it will never be over.” Her husband agreed, “Once you’re a cancer patient . . . always a cancer patient.” Selma too shared her thoughts, “People think that you get over cancer, that you get past it, but you never do.” Ellen also said, “That’s the one thing no one talks about. There’s a natural fear . . . the fear of recurrence. I get the CURE magazine . . . for years all I would read about cancer is when you first get it. Now is that because they don’t want to talk about it? There just isn’t . . . they don’t talk about it enough. When it happens, it’s like ‘oh boy I wasn’t really
ready for that.’” Harvey stated, “It’s something we’ll have to live with for the rest of our lives.” Melinda, 47, a seven-year survivor of metastatic breast cancer stated, “I am forever changed, not reduced, by what happened.” Joyce even mentioned the shame of not being over cancer: “People expect you to be over it but you’re not over it and you feel ashamed that you’re not over it when you should be over it.”

The statements of some participants exhibited both a paradoxical combination of lingering sense of vulnerability and a co-existing awareness of greater strength. Ellen stated, “I feel stronger but I can still get hurt. I still worry every day, every doctor appointment.” “A vulnerability,” Emilio agreed. “I know that I can survive whatever comes along but I really don’t want that to be tested again.” Kevin, a 54-year-old with Chronic Myelogenous Leukemia, stated, “I think it’s because I’ve been tested that I know how strong I am.”

Performing Normalcy and Constructing Survivorship

Two processes appear regularly in the narratives of the interviewees: Performing Normalcy and Constructing Survivorship. Performing Normalcy is represented by striving for normalcy and a return to status quo. Constructing Survivorship, on the other hand, represents the construction of meaning when the return to status quo is impossible because of ongoing illness intrusion.

Performing Normalcy

Participants attempted to re-create “normal” for themselves, a return to homeostasis. Normalcy was found in relationships and routine, including work. The
primary tasks were regulation of both distressing emotions and intrusive thoughts.

A ‘new normal’ is part of the vernacular for people coping with and surviving cancer. A 68-year-old woman who is still on treatment for breast cancer stated, “Things are better now and I am finding my way to a ‘new normal’ in my life.” Her ‘new normal’ includes living with cancer and the expectation that she will deal with cancer and cancer treatment for the rest of her life. A 48-year-old breast cancer survivor had this to say, “I'm still having difficulty with muscles in the arm on the side I had surgery. I push myself as I want to be back to ‘normal’ again. It has been 3 months since my surgery.”

Finding a ‘new normal’ also means accommodating to reality, but many people are eager to rid themselves of illness reminders as soon as possible. A 46-year-old woman who just finished treatment for Hodgkin’s Lymphoma stated:

The new normal isn’t completely normal yet. I want to not be sick for a while longer, not have the port in, not have symptoms, and be able to not wear my wig. Also still having a port in place to take blood is a constant reminder that I was the afflicted and still might be in the future. At first I resisted the idea of getting it in the first place, but realized my veins got very bad. It was a very painful experience to give blood. That was the worst part of getting the chemo. Then when I got the port placed I wanted it out as soon as I could to feel normal again. But at the urging of the doctor I left it in place and it’s still there. I might just leave it in for a few months more to be safe.

Normalcy was also preserved through maintaining a consistent sense of self. Selma’s narrative is a good example, strongly demonstrating the value she places on self-sufficiency and independence. She provided several examples: “During the whole thing I
was pretty self-sufficient.” “I pretty much did it by myself. I was pretty good. It was important to me to be independent.” “The day after my mastectomy, even though I was supposed to be in the hospital for two more days, I called my friend [B] to pick me up the day after my mastectomy and had her drive me home. I just wanted to get back to normal.” Her husband, Nick, confirmed this: “She’s always been independent. Selma isn’t going to let anyone tell her what to do.” “It was important to her to keep life as normal as possible and that was easy for me. I’m a creature of routine. The closer I can keep to that the better. That’s familiar and comfortable.” Nick’s sense was “My job the way I saw it was to be there for her and stay positive; to do the best I could to react to her. I still went to work most days. I took off if she had surgery. I took off an hour once to come to the doctor with her. But she wanted to be self-sufficient and it was my job to let her do that. That’s just the kind of person Selma is; she’s going to do it her way.”

Ellen’s husband, Emilio, talked about maintaining normalcy through denial: “it’s faulty thinking. I just want it to go away. It’s classic denial . . . I want to go back to normal . . . The first time, I said, ‘I just want my life back’ . . . ‘I have my life back!’ How many times did we say that? It lasts for a little while and then reality kicks in . . .”

**Constructing Survivorship**

Constructing survivorship represents the meaning that individuals attempt to create from their experience with cancer or a brush with death when the usual methods are not working. This was more evident in HCIC, both positive and negative. For some, even though a diagnosis with cancer is distressing, they are able to put it into the framework of their lives and get back to business as usual (as represented in Performing
Normalcy). When that becomes impossible, others have to re-write their definition of self in order to accommodate a new understanding of events. This explains why some individuals have a greater sense of identification with a cancer identity; it represents increased struggle. It also explains why LCIC were more likely to report cancer as a non-event or at least as non-trauma, and why the levels of illness intrusiveness and residual impairment were higher in HCIC. PTG is one of the ways that people make sense of suffering and increased struggles in their lives, and individuals in HCIC had higher scores on PTG than their counterparts in LCIC.

More participants in HCIC identified themselves as ‘cancer survivors’ and described that as an active process. Cynthia and others used the word ‘conquer’ to describe their actions that led to the development of a cancer survivor identity. This active effort represents efforts to accommodate to events which do not fit into the existing framework. Individuals discussed two ways specifically: survivorship earned through suffering and fighting spirit, and transformation in the form of accelerated self-development.

*Earned through suffering and fighting spirit.*

Narratives about cancer survivorship in the HCIC indicated that among patient participants who embrace that identity for themselves it had to be earned through suffering, survival, and fighting spirit. This appears to constitute a perceived enhancement of self-efficacy and was more commonly found in HCIC. Ellen stated, “Survivor – I didn’t understand that term. I didn’t see myself as a survivor but now I do. You feel like you’ve earned it.” Similarly, Selma said, “I got plugged into the poison
hose. I was meat on a slab. Some caregivers were wonderful but some treated you like meat on a slab. I had to go through that to survive.” Ellen’s husband, Emilio, also stated, “You’ll have to fight. That’s what it’s been like for Ellen. She’s been attacked emotionally, physically, spiritually, in every dimension. You learn to feel your own strength.” Ellen agreed: “There’s sense of fight that connects with that.” Harvey described that at the time of his diagnosis with leukemia, “I just couldn’t believe it. I thought they were wrong. I just kept saying, ‘I’m going to fight this. I’m going to lick this thing.’” Selma alluded to having responsibility for fighting for her life: “I really looked into the pathology. My cancer was survivable. It was a lot to get through, but I knew if I worked at it, I had a really good chance of having a good outcome.”

Accelerated pace/exaggerated sense of self.

There was a sense from some HCIC interviewees that their cancer experience created an acceleration of development or that they became more authentic. Melissa, 45-year-old woman on treatment for leukemia for thirteen years stated, “I am finally me. In the journey of cancer I found my way to me . . . I think I became more me. Everything just happened so fast. I think it would have happened anyway, but having cancer made everything happen so much faster. Out of sequence almost.” Selma stated, “You become an exaggeration of yourself.” Sadie reported that Harvey “was his old self, but an exaggeration. He had to be in control. Just like always, but even more so. For a while it drove me crazy, but I came to understand it. I could see he needed it.”
Partners

Partners seem to feel that their needs are less legitimate and they have no right to them or to make requests. Ellen’s husband, Emilio, captured it with this statement, “We did this together but with very different perspectives. I wasn’t going through it; she was.” He added: “It’s kind of a passive role for men. That’s hard. I don’t mean to make it a gender thing, but when I’d go the doctor, a lot of times the doctor wouldn’t even look at me. I know they want to bond with the patient but it’s an alienating feeling. But for men, to be in that passive role . . . it’s a reversal. We have to kind of sit back. . . it’s hard.” However, it is important to note that spouses/partners did not complain about this perceived dynamic.

Emilio expanded on the sense of helplessness that was unique to the partner narratives:

There’s a kind of helplessness, life is kind of taking you over. I found myself thinking too much, reaching a kind of chaos in my mind. So, I had to shut it off. I won’t watch cancer programs on TV and I’m embarrassed to admit that. I found myself reading death rates and I thought, ‘what am I doing? What am I reading this for?’

He also noted, “We really had to come to a place of ‘surrender’ to the doctor – we trust him now.” Sadie, Harvey’s wife, reported, “I can’t do anything for him; just sit by his side and be there. It’s a very helpless feeling.” Nick, Selma’s husband, however, stated that, “When it’s going on, you don’t have time to think about it. Don’t have time to be depressed about it.”
Spouses verbalized some things about their partners that the partners themselves did not identify. For example, with regard to mortality salience, patients tended to deny thoughts of death while partners reported about spouse/patients’ ruminations. Nick, for example, stated, “Looking back, what stands out is very near the end, the young black woman you met at the cancer center passed away and she said it was the first time she realized she could have died. That wasn’t really true. I remember times when she said, ‘If it’s my time, I’ll just go.’ It just didn’t really sink in for her how mortal she is.” It is possible that the different perspective may offer insights that patients themselves may not have access to. Another example is Sadie noticing changes in Harvey's personality and priorities before he did: “I didn’t know it at the time, but she noticed it before I did.”

Summary

This study was performed to determine the role of identity in posttraumatic growth and psychological adjustment for adults with cancer. A sample of 119 adult cancer patients/survivors completed an online survey and were statistically divided into two clusters based on the integration of cancer into identity: High Cancer Identity Cluster (HCIC; cancer identity scores above the mean) with strong cancer identity and Low Cancer Identity Cluster (LCIC; with scores below the mean) with a weak or absent cancer identity.

HCIC had more participants who had been partnered since the time of diagnosis, and significantly fewer individuals who reported having residual impairment from cancer following the end of treatment. The Low Cancer Identity Cluster had significantly more participants who expressed anger, reported a history of prior trauma, or perceived cancer
as a non-traumatic event. For this group, cancer is not integrated into identity. A positive and negative subgroup were determined to exist within HCIC. The positive HCIC subgroup is characterized by Fighting Spirit, Anxious Preoccupation, and PTG. The negative subgroup indicated lower PTG (below the $M$), were more likely to endorse items of Illness Intrusiveness-Intimacy, negative Fatalism, Helplessness/Hopelessness, Anxious Preoccupation, and anger.

A discriminant analysis revealed which variables contributed most significantly to the uniqueness of each cluster: Illness Intrusiveness-Intimate Relationships, Anxious Preoccupation, Perceived Life Impact of Cancer, and the PTG factor New Possibilities. The qualitative data from the interviewees confirmed the quantitative data with regard to the importance of these variables. The variable of ‘cancer identity’ was more complex. The impact of cancer on one’s physical integrity, life, work, relationships, and personal development was significantly related to the development of a cancer identity.

The interviews revealed universal narrative themes relating to suffering, woundedness, and uncertainty. Between the mortality salience and one’s intense visceral and emotional responses, an enduring sense of vulnerability is created. The knowledge of one’s mortality is so profound that it cannot become unknown. In that sense, for many, cancer never ends. *Performing Normalcy* and *Constructing Survivorship* emerged as two distinct processes. The first in which individuals experience a challenge and overcome it to return to normal, and the second in which a return to normal is not possible and they accommodate to the event in an effort to integrate it. Cancer identity is not a quality of life measure, but provided some patients a framework for understanding themselves and the role of cancer in their lives.
CHAPTER 5
DISCUSSION

This chapter summarizes the key findings of this study regarding identity for adult cancer patients/survivors, its implications for posttraumatic growth and psychological adjustment, and places them into the context of the extant literature. A new Cancer Identity Process Model will be offered and described, as well as recommendations for counselors and future research.

This mixed methods sequential research study was performed to explore the relationship of identity to posttraumatic growth and psychological adjustment for adults with cancer. Mixed methods research allowed for a depth and richness of data that better captured the complexity of a lived experience of cancer in ways that neither qualitative nor quantitative can provide on their own. The following research questions guided this study:

1. What is the role of identity in posttraumatic growth and psychological adjustment in adults with cancer?

2. What are the identity clusters (or profiles) that emerge when looking at measures of psychological adjustment to cancer, posttraumatic growth, illness perception, illness intrusiveness, integration of trauma, and sense of coherence of adults with cancer or who have survived cancer?
   a. What are the differences on these measures among the clusters?
b. What is the role of identity within these groupings?

c. What is the nature of the relationship of these variables to adjustment?

3. What are the emergent themes in the narratives of adults with cancer that relate to identity?

Cancer and Identity

Assessing identity is challenging and elusive, hampered not only by the inconsistencies between the external lived performance of identity and the internal perception, but also because of its mercurial nature, emerging or asserting in some situations more than others. Identity is also thorny in the sense that most people have the least understanding of their own identity. Nick points out that once one is changed, it is nearly impossible to review the prior time unbiased: “I’m sure it changes you as a person (this experience); it’s hard to go back and think like you did before, so it’s hard to see the changes.”

Erikson conceptualized identity as providing continuity to an individual’s sense of self over time, providing a internal coherence, meaningful relatedness to others, and “a sense of knowing where one is going” (1980, p. 127). Grotevant (1992) proposed that understanding identity requires, in part, consideration of whether aspects of identity are ‘chosen’ or ‘assigned.’ Many participants in HCIC reported feeling pressure from others to conform to a ‘cancer survivor’ role which included being inspiring to others. While some were angry about the assigned role, others tried their best to fulfill what they believed was expected of them. Individuals may resist the assignment of an identity as a survivor but may embrace aspects of the identity which are meaningful to them. For
example, several participants expressed satisfaction at volunteering to provide support to other patients while others resented having to assume an imposed heroic façade. Grotevant further suggested that identity commitment to an organizing principle may be short-lived or enduring. In this study, there were those who reported adopting a cancer identity while in treatment but that ended following the completion of treatment, as well as those for whom the identity has persisted. Participants in positive HCIC appear to embrace cancer identity as a chosen identity. Therefore, negative HCIC may be, in part, representative of those who feel that cancer identity has been undesirably assigned.

**Enhancement of Self and Self-efficacy**

Evident in the narratives of many interviewees was a theme of enhancement of self (“I was stronger than I ever knew.”). Taylor and Brown (1988, 1994) suggested that individuals tend to have enhanced positive views of self. In fact they report positive illusory views of self, control over events, and views of the future. This was supported by many of the participants in this study. Vignoles, Regalia, Manzi, Golledge, and Scabini (2006) found that individuals embraced identity elements which provided a greater self-esteem, continuity, distinctiveness, and meaning, with the greatest emphasis on a positively enhanced view of oneself.

**‘Cancer Survivor’**

The term ‘cancer survivor’ presented a multiplicity of meanings and elicited some strong responses, from a literal interpretation (“It means I survived cancer.”), to positive (“Cancer is my gold medal.”) and negative (“I hate the term. Cancer happened to me, it’s
not who I am.”). Positive HCI tend to be those who embrace a cancer identity while those in LCIC tended to reject a cancer identity. While some tend to refer to the literal survival of cancer, others looked at cancer for a revelation about their nature or character. Those in the LCIC tended toward the notion that this experience “says nothing about me” rather than the predominant view in the HCIC which was that this experience “says something important about me.” Those in positive HCIC tended to perceive this experience as representative of their nature, a microcosm of who they are: “I knew if I could handle this, I could handle anything.” Those in LCIC tended toward in interpretation that this experience was aberrant - an anomaly – and therefore not important in their understanding of themselves. Some who have the benefit of time have concluded that this experience is only one aspect of their identity.

**High Cancer Identity Cluster Subgroups**

Narratives reveal that HCIC is characterized by a high degree of uncertainty. A positive high cancer identity was characterized by high illness intrusiveness (intrusive symptoms, particularly those that interfere with relationships, intimacy, and performance of valued roles), high anxious preoccupation often related to mortality salience, high PTG, high fighting spirit, positive fatalism (acceptance) and low hopelessness/helplessness. Lack of support, lack of self-efficacy, and anger without fighting spirit appeared to interfere with development of positive survivorship.

Negative high cancer identity was characterized by high or very high illness intrusiveness, high or very high anxious preoccupation, low or moderate PTG, low or moderate fighting spirit, negative fatalism (resignation), and moderate.
hopelessness/helplessness. These individuals verbally reject a cancer identity at the same time that they endorse items which indicate a substantial impact on their life narrative and trajectory. This is likely an attempt to enhance positive self-perception.

There is a distinction between accepting or embracing an identity in which cancer places a prominent role and being profoundly changed by an experience of cancer with increased fearfulness or debilitating depression. The subjective measure of individual perception of cancer identity is not necessarily correlated with objective measures. Some people denied a cancer identity at the same time they talk about how changed they are. Whitbourne, Sneed, and Skultety (2002) noted that people primarily utilizing identity assimilation resist acknowledging changes when those changes were discrepant with the identity they want to retain and they postulate that overuse of assimilation is related to defensiveness. Persistent discrepancy creates dissonance characterized by anxiety, negative affect, and intrusive rumination (Whitbourne, Sneed & Skultety, 2002). This explains the dichotomy of HCIC. As dissonance grows, negative affect prevails, and individuals struggle to create identity balance. This struggle represents the negative HCIC while positive HCIC is represented by identity balance which is characterized by high self-esteem and enhanced ability to cope with any new identity assaults.

*Cancer Identity Process Model*

Analysis of the data and research findings of this study led to the development of a new Cancer Identity Process Model which incorporates elements of Berzonsky’s assimilation/accommodation process model, Whitbourne’s emphasis on cognitive-affective schemata as the driving force in identity process, and Kudler’s description of
two processes for cancer patients/survivors: *Performing Normalcy* and *Constructing Survivorship*.

**Assimilation and Accommodation**

In regard to cancer as an organizing principle for identity, this appears to be driven by the extent to which the identity is congruent with former identities and values, as well as future or anticipated identities, i.e. the extent to which it is an extension of the past, the extent to which it is consistent with past and future anticipated identities, or the extent to which it could be predicted from past identities or behaviors. Some of the interviewees in this study discussed becoming more themselves and achieving a greater sense of authenticity. This may be a way of creating harmony, balance, or homeostasis. For example, Susan stated that, for her, being a cancer survivor means volunteering and giving back, but noted that she has always donated her time volunteering for causes she believes in. Therefore, being a cancer survivor means devoting her time to the cause of cancer since that has become relevant and meaningful, an extension of her existing behavioral pattern.

This is also evidence of the assimilation/accommodation identity feedback loop suggested by Berzonsky(1988). Berzonsky’s assimilation/accommodation process model suggested ‘identity structures’ provide cognitive schemata and scripted behavior changes to deal with distressing experiences. While relatively automatic assimilative processes are typically sufficient for routine challenges, when those efforts fail the resultant dissonance requires that cognitive processing adapt new schemata and behaviors (guided by the identity structures) which ensure consistency of self and ultimately, biographical
continuity. This constructivist perspective on identity, also proposed by Grotevant (1992), suggested that in assimilation new information is incorporated into the existing identity structure while in accommodation the existing identity structure is challenged and transformed by new information. Similarly, McAdams (1993), found that individuals try to absorb new events into their current life narrative.

Figure 2. Cancer Identity Process Model
For many of the participants in this study, cancer identity played a vital role in the feedback loop of assimilation and accommodation. Some individuals are able to create harmony or homeostasis from existing identity structures. For example, Marge was able to maintain valued roles which anchored her identity, while Anita was no longer able to care for her family in the way she was used to and had to create alternative strategies which initially undermined her view of herself as a competent caregiver but ultimately resulted in her enhanced views of her resilience.

Figure 2 shows the adapted feedback loop that relates to the participants in this study. HCIC tend to be represented in Accommodation, and LCIC in Assimilation. Consistent with the research on Accommodation, those in the HCIC demonstrated either positive or negative adjustment. Whitbourne, Sneed, and Skultety (2002) describe accommodative processes as inherently difficult in that it is a result of intense instability, when experiences are sufficiently discrepant enough to challenge existing identity structures. The process of literally changing oneself or identity in response to identity salient discrepancies is difficult and painful. Whitbourne, Sneed, and Skultety (2002) suggested that the unstable identity (dissonance) which precedes accommodative efforts leads to highly negative self-evaluation. The period of instability characterized by self-doubt and negative affect/adjustment clearly corresponds to the negative subgroup of HCIC. The period of Identity Balance following Accommodation is more stable and characterized by high self-esteem and positive affect, which corresponds to the positive subgroup of HCIC.

The LCIC is populated by those who utilized primarily assimilative processes or by those for whom cancer did not challenge their self-schema. Whitbourne, Sneed, and
Skultety (2002) characterized these individuals as defensive, rigid in their sense of identity, seeking self-enhancement, and utilizing denial. Because the challenging experience is less impactful with regard to the individuals’ identity structures, there is less impact on affect and less need for meaning-making to curb existential crises. They also found that people using identity assimilation characteristically exude optimism and pride in their accomplishments, but may experience social isolation, exhaustion from guarding against identity threats or discrepancies, and failure to engage in compensatory activities. This describes the participants in LCIC who did not report high levels of impact on their identity and were more likely to engage in assimilative efforts to defend and maintain existing identity structures.

Successful assimilation is followed by a period of Recovery in which homeostasis has been achieved and self-schema reinforced. Successful accommodation is followed by Identity Balance in which new identity structures provide harmony to the previous discordance.

Kudler’s (2005) description of adults with cancer includes two acts: Performing Normalcy – to fill the void left by an illness to restore balance for others – and Constructing Survivorship – to restore balance for self. In the Cancer Identity Process Model, Performing Normalcy represents Assimilation and Constructing Survivorship represents Accommodation. Both Performing Normalcy and Constructing Survivorship have the goal of restoring balance, as do Assimilation and Accommodation. Performing Normalcy is an effort to maintain or return to status quo as is Assimilation, while Constructing Survivorship and Accommodation both require deeper reflection and change.
Table 8 displays the findings from this study utilizing *Performing Normalcy* and *Constructing Survivorship* and Berzonsky’s assimilation/accommodation process model to provide a framework. However, Whitbourne’s emphasis on cognitive-affective schemata is featured rather than Berzonsky’s emphasis on information-processing and decision-making. As in Berzonsky’s feedback loop, assimilation processes occur when new experiences result in identity salient information is discrepant with one’s self-schema and processed successfully through existing identity structures. Accommodation occurs when dissonance activates identity structures but existing self-schema is unable to restore balance. Self-doubt and self-questioning precede a newly conceptualized identity.

Also represented in the model are cognitive, emotional, and existential challenges/responses of the interviewees. Cognitive reappraisal and emotional regulation are known to be central to adjustment and are integral in PTG (Calhoun & Tedeschi, 2006). Cognitive reappraisal is necessary to manage automatic and intrusive rumination and to begin the process of schema change. Brooding rumination is replaced with deliberate or reflective rumination in order to repair, restructure, and rebuild one’s understanding of the world and one’s place in it. For example, Joyce talked about not being able to sleep because of constant thoughts that she could die; spending time on the internet learning more about her cancer and various treatment options made her feel more in control and intrusive thoughts no longer kept her awake.

Psychological adjustment is represented in both cognitive and emotional categories, while PTG and psychological adjustment are both represented in the existential category. They are integrated into the table as their relationship to cancer identity is complex. In order to fully represent the lived experiences of the study...
Table 8. Cancer Identity Process Model Components

<table>
<thead>
<tr>
<th>Diagnosis (Presumes Cancer as Traumata or Seismic Event)</th>
<th>Cognitive (Comprehensibility)</th>
<th>Emotional (Manageability)</th>
<th>Existential (Meaningfulness)</th>
<th>Identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial (avoidance, rejection)</td>
<td>Numbing, Dissociation</td>
<td>Mortality Salience – perceived threat to life</td>
<td>Fragmentation</td>
<td></td>
</tr>
<tr>
<td>Automatic Rumination – intrusive distressing thoughts (obsession, preoccupation)</td>
<td>Overwhelmed – disruptive emotions (anxiety, depression, emotional extremes, panic attacks)</td>
<td>Shattered assumptions about self, the world, and one’s place in the world</td>
<td>Confusion</td>
<td></td>
</tr>
<tr>
<td>Denial (avoidance, rejection)</td>
<td>Numbing, Dissociation</td>
<td>Mortality Salience – perceived threat to life</td>
<td>Ego shock</td>
<td></td>
</tr>
<tr>
<td>Automatic Rumination – intrusive distressing thoughts (obsession, preoccupation)</td>
<td>Overwhelmed – disruptive emotions (anxiety, depression, emotional extremes, panic attacks)</td>
<td>Shattered assumptions about self, the world, and one’s place in the world</td>
<td>“What does this event say about me?”</td>
<td></td>
</tr>
</tbody>
</table>

Performing Normalcy (Assimilation)

I just want to get back to where and who I was (working to achieve status quo)

<table>
<thead>
<tr>
<th>Cognitive (Comprehensibility)</th>
<th>Emotional (Manageability)</th>
<th>Existential (Meaningfulness)</th>
<th>Identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Efforts to manage automatic rumination</td>
<td>Efforts to manage distressing emotions (self-efficacy)</td>
<td>Terror Management – o Seek reinforcing worldview and group identity</td>
<td>“Patient”</td>
</tr>
<tr>
<td>Cognitive appraisal o Uncertainty o Making sense</td>
<td>Sense of vulnerability</td>
<td>o Seek symbolic immortality</td>
<td>Disrupted feelings of fit</td>
</tr>
<tr>
<td>Making sense</td>
<td>Making meaning</td>
<td>o Making meaning</td>
<td>Discrepancy between actual and ideal self</td>
</tr>
</tbody>
</table>
| “I still have to remind myself that I’m still here. Cancer is always looming.” | Distressing emotions no longer overwhelm | “It was just something that happened.” | Threats to Identity:
| “I had cancer but it’s over; It’s behind me.” | “I won’t let cancer define or change me.” | “I won’t let cancer define or change me.” | o Body Cues |
| “I try not to think about it.” | “I still struggle with anxiety but now I know that I am strong enough to deal with it.” | “I am my old self again.” | o Changes in activities, valued roles, & relationships |
| Recovery |
| “I am my old self again.” | “Cancer doesn’t say anything important about me.” | “I survived because I am stronger than cancer.” | o Social pressures |
| “Cancer is only part of who I am.” | | “Survivor” Battle-scarred but still standing | |

Constructing Survivorship (Accommodation) & Identity Balance

I can’t go back to where and who I was so I will find something better (working to achieve higher purpose)

<table>
<thead>
<tr>
<th>Cognitive (Comprehensibility)</th>
<th>Emotional (Manageability)</th>
<th>Existential (Meaningfulness)</th>
<th>Identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continued and improved efforts to manage rumination</td>
<td>Continued and improved efforts to manage distressing emotions (self-efficacy)</td>
<td>Re-evaluate goals, relationships, and priorities</td>
<td>“Survivor” Battle-scarred but still standing</td>
</tr>
</tbody>
</table>
| Deliberate and reflective rumination | “I still struggle with anxiety but now I know that I am strong enough to deal with it.” | o PTG
| “I still have to remind myself that I’m still here. Cancer is always looming.” | “Seek symbolic immortality” | o Making meaning | “I survived because I am stronger than cancer.” |
| “I still have to remind myself that I’m still here. Cancer is always looming.” | “Renewed sense of purpose” | o Making meaning | In some ways I am better than my old self (enhanced self-efficacy) |
| | “Appreciation for life” | o Making meaning | Re-storying biography; (re-narrating life story) |
| | o Making meaning | o Making meaning | Establishing valued roles (Redefining, creating) |
| | | o Making meaning | “Cancer is only part of who I am.” |
participants, I made a purposeful effort not to oversimplify the data.

This model is not meant to represent mutually exclusive stages or even sequential phases, but rather possible aspects of the lived experience of cancer and processes which help individuals adapt to that experience. While Kudler suggests these processes co-exist, I conceptualize them as cyclical but potentially simultaneous – the paradox acknowledging the organic, dynamic nature of this experience. Since this represents a feedback loop, challenges such as increased physical symptoms, increased impact on valued roles or future self, disease progression or relapse, which are not ameliorated by an assimilation processes activate identity structures to guide an accommodation process.

_Diagnosis, Performing Normalcy, and Recovery_

In the immediate aftermath of diagnosis, the prevailing response for many is terror, confusion, rumination, and ego shock. Individuals then strive to regain homeostasis and some form of normalcy. To do so means having a sense of control. This attempt to recreate harmony and balance is a dynamic effort. To accomplish this one must attempt to regulate overwhelming feelings of fear or anger, as well as intrusive thoughts and negative rumination. Assimilation is prevalent as individuals utilize existing schemata to help reduce threats, minimize disrupted feelings of fit, seek those with reinforcing worldviews, and focus on what is manageable. In _Performing Normalcy_, patients/survivors most commonly attempt to create workable routines which resemble familiar patterns, utilize existing schemata to make sense of current circumstances and manage emotions. Existential terror is managed by making meaning in ways which reinforce existing identity structures. Some people will seek meaning in artistic
expression, spirituality, and close relationships. Close relationships appear to mitigate some of the extreme consequences for many survivors. Threats to identity include being assigned an identity as “patient” by the healthcare system, society, and sometimes loved ones and intimates. Other threats are created by the intrusion of illness, e.g. physical pain, interruption to valued roles such as work or parenting, and challenges to one’s image of future self.

For those individuals who complete treatment without severe disruption to life activities and views of self, a resolution process called *Recovery* may ensue in which life resumes. Assimilation is successful without the need to reorganize or transform identity. Cancer becomes an interruption, just something that happened but is over now and need not have an enduring impression. The effect on identity is low as one resumes life again, but may live with an enhanced sense of self-efficacy for having prevailed over adversity. These individuals tend to not have residual impairments – physical, emotional, or psychological – as a result of cancer. There is no significant change in the life trajectory and an individual reports that cancer has not changed his/her identity whether or not one describes cancer as a significant event. Also, a person may choose to bracket an experience of cancer as an aberrant event, one that has no lasting meaning as it lacks congruency within the overall structure of one’s life.

*Constructing Survivorship and Identity Balance*

The process of *Constructing Survivorship* corresponds to accommodation as individuals attempt to create a new sense of coherent identity when assimilative efforts have failed. Greater physical illness intrusiveness is associated with greater impact on
identity. For these individuals their experience with cancer has resulted in dissonance which existing identity structures cannot integrate. A subgroup are those who are in despondency or despair, with helplessness or hopelessness as the central experience of cancer. Some of these people are handicapped by self-blame.

For others, cancer becomes a chronic illness in which treatment continues indefinitely or residual impairments continue to impinge on life activities, valued roles, personal growth, presentation of self, intimacy, and relationships. Residual impairments come in the form of physical (pain, fatigue, immune-suppression, loss of mobility, neuropathy, amputation) with potential social or vocational consequences (altered appearance, disfigurement, scars), emotional (anxiety, fearfulness, depression, panic attacks), psychological (intrusive thoughts, rumination, obsessiveness), and existential (an overriding disruptive sense of uncertainty about the future, what does it all mean). For these people, the defining characteristic is uncertainty tempered with a sense of self-efficacy – that they feel vulnerable but can handle whatever comes. For many, but not all, this also means an ability to find some sense of benefit or meaningfulness. Emotional regulation and cognitive reappraisal continue as the individual copes with ongoing ‘anxious preoccupation.’ Affective and cognitive outcomes become integrated into a newly consolidated sense of identity, which contributed to a feeling of personal continuity over time.

During periods of quiescence following Constructing Survivorship, Identity Balance means the dynamic restoration of harmony when “the individual’s identity is flexible enough to change when warranted but not so unstructured that every new experience causes the person to question fundamental assumptions about the self.”
integrity and unity” (Whitbourne, 1996, p. 6). This represents integration of experiences into transformed identity structures. Whitbourne, Sneed, and Skultety (2002) reported that those in Identity Balance positive self-views and appropriately high self-esteem. Identity Balance is also relevant for those who have finished with cancer treatment and miss the immediacy of mortality awareness which prompts a keen appreciation for each moment. Linda stated, “As I get back to day to day living I yearn for that place again without the illness.”

**Other Major Findings: Suffering, Woundedness, and Uncertainty**

This study replicates findings of many other researchers, and also demonstrates the complexity of the phenomenon of living with cancer. The clusters were statistically derived, and revealed more depth than could have been anticipated. The complementarity of both quantitative and qualitative data greatly enhanced this study. Statistical evidence demonstrated the existence of relationships between the variables and the narratives provided richness and nuanced complexity which better represents the lived experiences of the study’s patients/survivors.

This section will briefly summarize the major findings. The quantitative data suggest a strong relationship between posttraumatic growth, psychological adjustment, illness intrusiveness, and the centrality of cancer to identity. The major finding of the quantitative research was that the variable factors of Adjustment-Anxious Preoccupation, PTG-New Possibilities, Illness Intrusiveness-Intimacy, and Illness Perception-Perceived Life Impact of Cancer were the most predictive of group membership for two clusters: HCIC and LCIC. HCIC contained two subgroups: positive and negative.
The overarching concepts which provide a framework for understanding the data are those of suffering, woundedness, and uncertainty: the prominence of suffering, attempts to manage or minimize suffering, and efforts to make meaning of suffering. The data suggest that suffering and the meaning created around it are primary (pivotal) factors in determining individual responses to cancer. Woundedness is related to damaged aspects of core identity.

**Suffering and Woundedness**

The intrusion of cancer to participants’ lives seems to be the defining feature of the narratives. A perceived high cancer impact may initiate personal growth as a result of crisis or may galvanize the individual to refute the threat.Thoits (1999) suggested that individuals managing the stress of a perceived threat may prophylactically de-emphasize the importance of that aspect of identity, i.e. if that identity is made less central then ongoing problems in that area will have less psychological impact, or may demonstrate increased, rather than decreased, commitment to a stressful domain.

Even rejection of an identity defined by cancer demonstrates the power of cancer on one’s life and the need for a response. It still tethers the identity to cancer. “Even the term ‘survivor’ is more related to identity as victim” (Mijares, 2005, p. 76). Charmaz (1994) stated that as illness intrudes, “discoveries of self . . . are typically framed in loss” (p. 238). It depends whether the new identity is framed as loss or gain. Gain may be a triumph of creation (the Midas touch), thereby enhancing perceptions of self. Some patients did not consider themselves cancer survivors until they had experienced suffering as a result of cancer. This is congruent with the research of McAdams (2006)
who reported that the American narrative is a story of redemption – gained through suffering, sacrifice and perseverance.

Within a trauma framework, it is not surprising that suffering and woundedness can create fertile ground for change. Ackerman and Maslin-Ostrowski (2004) suggested that wounding creates a state of dissonance to which one must adapt by re-organizing meaning. The destruction of former routines and assumptions leaves a vacuum and makes way for new ways of thinking and behaving. The importance of cognitive re-appraisal and emotional regulation were prevalent in this sample. This is consistent with Znoj (2006) who suggested that profound traumatic loss results in more complex representations of self and the world, as well as a need for an ability to tolerate distressing emotions and negative ruminations.

**Uncertainty**

Uncertainty represents the vulnerability which keeps cancer alive as a force in an individual’s life and influences their thoughts and choices about the future, and was not inevitably related to disease progression. This is consistent with the findings of other researchers who report that disease factors are not necessarily correlated with quality of life and that subjective factors, such as uncertainty, play a large role (Frain, Bervan, Chan, & Tschopp, 2008). Weiner and Dodd (2001) proposed that uncertainty shapes the trajectory for cancer patients. In other words, the impact of cancer is determined by the extent which the individual’s life trajectory is changed and the extent to which uncertainty shapes their projection of the future. The potential benefits of uncertainty were elucidated by Parry (2003) who concluded in her study of adult survivors of
childhood cancer, that “although uncertainty can be a source of distress, it can also be a catalyst for growth, a deepened appreciation for life, greater awareness of life purpose, development of confidence and resilience, and optimism” (p. 227). This explains the pervasiveness of uncertainty throughout the entire sample.

Uncertainty is mitigated by the perception of control. Those who recognized something was wrong prior to diagnosis were better able to move on after treatment ended. Those who noticed no symptoms remained anxious (“since I didn’t notice it before, I won’t notice if it comes back; therefore I must be extra vigilant”).

Uncertainty is even more relevant now that, for many, cancer has become a chronic, serious, potentially life-threatening illness rather than imminently life-threatening. It is currently more common to hear doctors speak of medical management of cancer rather than cure. Remission has been re-defined as ‘cancer-free’ or ‘no evidence of disease’ (NED). Cure is no longer part of the common medical vernacular with regard to cancer because of the frequency of recurrence and the lingering uncertainty. People are living longer, therefore, living with illness. Parallels can be drawn from those living with HIV/AIDS in that those living with HIV/AIDS before antiretroviral medications were presumed to be terminally ill, but afterward were presumed to be able to live a relatively normal life with the help of medication. The impact of disease and medication intrude on people’s lives but allow life to continue. The paradigm has experienced a radical shift.

**Intensity and Duration**

Trauma research has suggested that intensity and duration of trauma determines the impact of the traumatic event, and indeed, time since diagnosis or time since the end
of treatment appeared to be important factors. Newly diagnosed persons appear to have less perspective on the role of cancer in their life trajectory which hampers their ability to make meaning in a positive way. It may also represent that the majority of an individual’s resources are being fully taxed at that time. For those newly diagnosed, coping capacity is overwhelmed and meaning-making has not yet begun. This reflects the process aspect of this experience.

*Individual Reactions*

However it is not just the level or duration of impact or intrusion that is important, but the emotional reactions and cognitive appraisals which shape an individual’s responses. Theories of meaning-making suggest that the meaning individuals create around events accounts for the variation found not accounted for by differences in physical impairment or illness intrusion. The awareness of one’s mortality proved less significant than the intense fear or helplessness one experienced as a result of that awareness.

*Identity and Psychological Adjustment*

Psychological adjustment pertains to the emotional, cognitive, and behavioral responses to cancer. The five factors of Fighting Spirit, Fatalism, Avoidance, Anxious Preoccupation, Helplessness/Hopelessness provide benchmarks for understanding individual responses. Consistent with Charmaz’s research, illness intrusiveness played a large role in the individual adjustment. Znoj (2006) noted that individuals who learned
how to manage the effects of distressing events were the ones who demonstrated personal growth related to PTG.

The narratives of participants in the HCIC were more likely than LCIC to contain themes related to Fighting Spirit. Fatalism and Anxious Preoccupation were prominent in both clusters while themes of Helplessness/Hopelessness were present in negative HCIC and some individuals in LCIC; Avoidance was almost non-existent in this study but individuals who utilize avoidant styles may be unlikely to participate in research of this kind.

Anxious Preoccupation

Anxious preoccupation was prevalent in both HCIC and LCIC. Recent studies have demonstrated that chronic anxiety is associated with insular sensitivity in the brain, i.e. individual differences in insular sensitivity correlate with self-report of anxiety. While it had been believed that anxiety is counter-productive, Samanez-Larkin, Hollon, Carstensen, and Knutson (2008) found that moderate insular activation can actually be productive in assessing and avoiding threats while either low or excessive levels are not. This helps explain the prevalence of anxious preoccupation throughout the sample.

Anger, Fighting Spirit, And Helplessness/Hopelessness

Several participants expressed anger at their circumstances and at the healthcare system. Anger can be positive, purposeful, and productive, or negative and destructive. Anger may “restore a sense of control and self-esteem” but at the same time may reduce
social support (Rochman, Diamond, & Amir, 2008), which is consistent with the greater anger and lower partnered status found in the LCIC.

Anger had to do with betrayal and tended to be linked to either fighting spirit or to helplessness, which researchers suggest to be polar opposites. Fighting spirit in this study appeared to be comprised of optimism, determination, and perceived self-efficacy. Astin, Shapiro, Schwartz, and Shapiro (2001) posit that the factor Fighting Spirit is positive assertive, the polar opposite of helplessness/hopelessness which is negative yielding. Helplessness/hopelessness was found in both clusters and was most common in negative HCIC, associated with very high illness intrusiveness and depression.

Fatalism

While this factor was not significantly different between the two clusters statistically, there were narrative distinctions which correspond with the suggestion by Astin, Shapiro, Schwartz, and Shapiro (2001) that the factor Fatalism may in fact represent two distinct processes: Acceptance which they define as positive (yielding) and Resignation which is negative (yielding). This seems to represent the distinctions between the two clusters, with Acceptance/fatalism more prevalent in positive HCIC and Resignation/fatalism more prominent in LCIC and negative HCIC.

Identity and Posttraumatic Growth

Participants in HCIC endorsed both illness intrusiveness and posttraumatic growth (PTG) at higher rates than their counterparts in LCIC. This is consistent with other studies which found that increased traumatic impact can result in increased PTG.
The individuals with higher PTG scores fell into the positive subgroup of the HCIC, those who created positive meaning from their cancer experience. This subgroup did not necessarily experience less illness intrusiveness than the negative high cancer identity subgroup (indicating PTG below the mean), but reported higher positive consequences in terms of PTG. These participants were more likely to have been partnered with the same person since the time of diagnosis and less likely to have residual impairments following treatment.

Describing a curvilinear model, Tedeschi and Calhoun (2006) report that individuals with very high trauma or very low trauma were least likely to experience PTG. Similarly, in this study, individuals with the least illness intrusiveness were less likely to report cancer as a central element to identity, and those with the most illness intrusiveness reported either disorganized identity or negative high identity. Also, the history of earlier trauma which was reported more frequently in LCIC may have had a dampening effect in that prior earned resiliency could preempt impact necessary to activate change (e.g. identity or PTG).

PTG is also a way to reconcile existential questions and to cope with lingering vulnerability and uncertainty. Engaging in rewarding activities in other role domains should help counterbalance impacts on distressed role domains. Not surprisingly, PTG is also linked to emotional regulation, which includes ones’ ability to tolerate or manage distressing emotions (Znoj, 2006).

Many individuals in this study described their efforts to create ‘symbolic immortality’ (Fung & Carstensen, 2006) in which a person engages in activities which result in transcendence of mortality: procreation, artistic expression, investment in valued
relationships, or a sense of connectedness to a higher power or to nature. Cassandra reported that cancer made her realize her desire for children, several people described feeling closer to God and finding a strengthening of faith, and others, like Linda, reported feeling closer to people and better able to commit herself to relationships. Therefore, symbolic immortality is really about creating a sense of mastery over mortality through the creation of a lasting legacy and a sense of connectedness.

The majority of individuals discussed wanting to give back to others going through cancer, most through wanting to volunteer as peer support for newly diagnosed patients. McAdams and narrative therapists suggest that individuals make meaning and find coherence telling their stories, i.e. that we reclaim a coherency to our lives in telling our stories coherently. Through telling his/her story to encourage others, a person may rewrite his/her own narrative. This may help explain why so many survivors stay connected in a volunteer role in which telling their stories is meant to inspire others and give hope. It also allows them to remain connected to the world of cancer without the role of ‘patient,’ thereby gaining a sense of control and mastery on their own terms. Also, telling and re-telling the story facilitates cognitive processing and re-appraisal. This is consistent with the trauma literature in which working to achieve mastery in situations out of one’s control is a common finding.

Tedeschi and Calhoun (2004) characterized PTG as “focusing on the positive aspects of the struggle with trauma” (p. 2). They also noted their finding that PTG is not mutually exclusive with distressing thoughts and emotions, which is consistent with the finding of this study that participants in both HCIC and LCIC reported Anxious Preoccupation, as well as other distressing thoughts and emotions.
Implications for Clinical Practice

Individuals surviving a traumatic event often demonstrate a need to create meaning around events to make sense and regain coherence to their lives, thereby reestablishing the biographical continuity which had been lost. Narrative therapists suggest that we re-shape our stories to re-shape our understanding of them; and identity theories suggest that re-shaping our stories reconstruct our sense of self. Helping clients re-narrate their stories with a greater sense of mastery and coherence can help them find meaning and a renewed sense of self.

Taylor (1983) suggests a need for three vital themes: meaning, mastery, and self-enhancement. Counselors need to help clients find personal meaning and successfully manage illness to minimize negative impact on meaningful roles and activities. This may mean exchanging previously valued activities for new equally valued activities or accepting a different definition of participation or success. Assisting clients with finding their ‘new normal’ and embracing its possibilities is critical to their long-term success. Benefit-finding may or may not be important for clients as its role is not yet established. Establishing new routines is necessary in adapting to loss and to support one’s commitment to change.

For those individuals whose primary valued roles have been disrupted or shattered, encouraging them to engage in rewarding activities in other role domains should help counterbalance the distressing impacts of unresolved situations. Monica could no longer work at her job given that the physical toll of cancer interfered with her ability to maintain her usual arduous work schedule so she became a consultant and is happily working for herself. Another option is to help clients find alternative means of
satisfying those primary role domains. For example, Abe reported that he could no longer have sex with his girlfriend but noted that their intimacy has never been stronger and he does not miss the sex.

Helping clients manage emotional dysregulation and disruptive intrusive rumination through cognitive re-appraisal is also a necessary step in developing schema change. Meaningful social support, self-disclosure, and self-expression are important means to accomplish this.

Counselors can help clients understand that even positive changes come with a cost when trauma is the catalyst. While PTG is associated with strength, it is paradoxically also associated with vulnerability. Research finds only a weak or inconsistent relationship between PTG and adjustment (Stanton, Bower, & Low, 2006). In fact, PTG may be accompanied by decreased well-being and greater stress (Calhoun & Tedeschi, 2006). Despite the almost exclusive emphasis on the positive aspects of PTG, it is necessary to remember that it is born from suffering. Therefore, contradiction is inherent and inevitable (Neimeyer, 2006). Accepting one’s vulnerability is key to understanding one’s newfound strength.

Whittemore’s (2005) integration model involves increased attention to managing illness and self-exploration to find personal meaning in illness. In fact, a critical element of making durable lifestyle changes is exploring self and restructuring to support change. Personal strategies lead to changes in life patterns in which illness is no longer primary, illness intrusiveness is minimized, and attention to meaningful life events is recommenced. Trial and error allows idealized expectations to transform into reality;
creating workable routines and experiencing positive outcomes reinforces changes and increases the likelihood of lasting change.

Gergen’s suggestion of identities as multiple and disparate which often compete and sometimes contradict is a reminder that human beings are complex, and that complexity should be respected. Counselors should recognize that identity is evolving and dynamic, influenced by ongoing cognitive appraisal and assignment of meaning. It is important to remember, however, that each human voice is polyphonic and the self is populated by many identities which are not all mutually exclusive. As Linda stated, “Being a cancer survivor is not all that I am. It is part of who I am and I don’t even think about it all the time, mostly when I go to the doctor or have some suspicious symptom. I am many other things as well. It doesn’t define me.”

Consideration should be given to the idea that identity at any given point may only represent one point in time. To solidify or cement that aspect of identity may be detrimental to the individual as evolution or transformation continues. Also, there needs to be room for an individual to ‘regress’ to a former identity for a time if that is healthy. Also, counselors should pay attention to whether an identity is chosen or assigned as that may indicate the individual’s commitment to the identity and the meaning around it. Counselors should be prepared to help clients who choose to reject an assigned identity or to find positive aspects to claim, and thereby transform an undesirable assigned identity into a desired chosen one.

Overwhelming threats and challenges incapacitate the individual’s coping resources and capacities resulting in psychological distress and damage to concepts of self, but not everyone who experiences stressful events reacts with emotional disturbance.
(Thoits, 1999). Identity factors help explain why some people are distressed by stress experiences, whereas other people are not. Repeated disconfirmation of a valued identity or an identity that lacks support may lead to the abandonment of that identity. Individuals managing the stress of a perceived threat may also respond by prophylactically de-emphasizing the importance of that aspect of identity (Thoits, 1999). Therefore, if that identity is made less central then ongoing problems in that area will have less psychological impact. However, sometimes people demonstrated increased, rather than decreased, commitment to a stressful domain.

Erikson was careful to consider people in their context, and it is crucial for us to do the same. Not only must individuals be considered within the context of their lives and relationships, their hopes, dreams, aspired selves are vital to understanding the meaning that is created around (derived from) events.

Limitations

These results cannot be assumed to be generalizable to all patients with cancer as this study was performed with a relatively small sample of cancer patients/survivors. Obviously, there is a self-selection bias in this sample. Also, individuals who are willing to participate in a study may differ from those who choose not to. Also, this study represents only a moment in time for these participants. Longitudinal research would obtain a more complete representation of the role of identity in posttraumatic growth and psychological adjustment of adults with cancer. Finally, minority populations are under-represented in this study as in most other studies of cancer patients.
Recommendations for Future Research

This study began to explore the various elements of the process of identity renegotiation for adults with cancer but in no way fully answered the first research question about the process. Far more data are necessary to address that. As indicated, the interview itself may prove to have therapeutic value and should be explored in further studies. Finally, understanding more about this process may be helpful in understanding poorly understood aspects of the cancer experience, such as posttraumatic growth and psychological adjustment. This too deserves further study. Recommendations for future research include further recruiting from under-represented groups and sampling over a long period of time rather than cross-sampling. Finally, this research should be performed on other traumatized populations who contend with mortality salience, the possibility of identity wounding, and ongoing uncertainty.

Summary

This mixed methods study has shed new light on the identity processes related to the lived experience of cancer. A new Cancer Identity Process Model was offered in which assimilative and accommodative efforts are informed by identity structures. Performing Normalcy is an assimilative process in which stressful life events such as cancer activate automatic behaviors guided by existing identity structures with the goal of regaining status quo. As dissonance grows over the assignment of undesirable identities or the inability to re-establish valued former identities, negative affect and intrusive rumination prevails. Individuals then utilize accommodative strategies in a process of Constructing Survivorship to either regain valuable aspects of former identities or to create equally valued new ones.
Erikson conceptualized identity as providing continuity to an individual’s sense of self over time, providing a internal coherence, meaningful relatedness to others, and “a sense of knowing where one is going” (1980, p. 127). When life events challenge the continuity of one’s life story, shatter one’s sense of self and one’s view of the world, the story is re-written. The presumption of immortality is lost, the story’s ending is erased, leaving a void of uncertainty. Individuals attempt to re-write their role in the life story in ways which enhance their power, role, and self-efficacy. For many in this study, cancer was a rupture in the trajectory of their lives, and identity renegotiation was one way of regaining lost continuity, and coping with suffering, woundedness, and uncertainty.
CONSENT FORM GUIDE I

1) **Title of Research Study:** The Role of Identity in Posttraumatic Growth and Psychological Adjustment for Adults with Cancer.

2) **Investigator(s):** Principal Investigator Barbara Abernathy and faculty advisor Dr. Alexis Miranda. This survey is part of my dissertation research as a Ph.D. student at Florida Atlantic University in the area of Counselor Education and is designed to help me understand about the changes that may occur in adults since having been diagnosed with cancer.

3) **Purpose:** The purpose of this research study is to discover the role of identity, particularly with regard to posttraumatic growth (personal growth that results from crisis) and psychological adjustment (coping with psychological distress) for adults with cancer living in either Palm Beach, Martin, St. Lucie, or Broward counties in South Florida. Life experiences can impact the way we see ourselves and I am interested in how this may impact how people cope with an illness such as cancer. This research will help with development of counseling strategies for adults with cancer by increasing the understanding of changes that occur due to having cancer. Therefore, I want to know more about your experience with cancer and how it affected you, especially your views about yourself.

4) **Procedures:**
   Participation in this portion of the study is entirely voluntary and involves completing a single session of an online survey that is estimated to take about 20 – 40 minutes. Survey questions will focus on cancer diagnosis and treatment, illness effects, coping, and personal growth with regard to your experience with cancer.

   At the end of this survey, you will be asked if you are interested in participating in an interview that will seek more information about your experience with cancer. The interview is entirely optional and in no way affects this survey. If you are interested in learning more about the interview, you may provide contact information. This is completely your choice whether or not to provide that information. There is no penalty for not providing that information. A separate informed consent will be provided for those who participate in an interview.

5) **Risks:**
The risks of participating in this study are expected to be minimal. You may tire while answering the questions or you may experience some discomfort due to the personal nature of some of the questions.

6) Benefits:
Potential benefits you may get from participation in this research study include the satisfaction of knowing that you have contributed to a better understanding of the adjustment, growth, and changes in self-concept of adults with cancer. You may refuse to participate or withdraw from the survey at any time without penalty to yourself.

7) Data Collection & Storage:
All of the results will be kept confidential and secure and only the people working with the study will see your data, unless required by law. All responses are encrypted using SSL encryption technology. Data stored on the principal investigator’s computer are password protected.

8) Contact Information:
For related problems or questions regarding your rights as a subject, the Office of Sponsored Research at Florida Atlantic University can be contacted at (561) 297-0777. For other questions about the study, you should call me as the principal investigator, Barbara Abernathy or my faculty advisor, Dr. Alexis Miranda at (561) 297-3602. I can also be reached at babernat@fau.edu and Dr. Miranda can be reached at amiranda@fau.edu.

9) Consent Statement:
I have read the preceding information describing this study. All my questions have been answered to my satisfaction. I am 18 years of age or older and freely consent to participate. I understand that I am free to withdraw from the study at any time without penalty. A copy of this consent form is available from researcher upon request.
APPENDIX B

CONSENT FORM GUIDE II

1) **Title of Research Study:** The Role of Identity in Posttraumatic Growth and Psychological Adjustment for Adults with Cancer.

2) **Investigator(s):** Principal Investigator Barbara Abernathy and faculty advisor Dr. Alexis Miranda. This survey is part of my dissertation research as a Ph.D. student at Florida Atlantic University in the area of Counselor Education and is designed to help me understand about the changes that may occur in adults since having been diagnosed with cancer.

3) **Purpose:** The purpose of this research study is to discover the role of identity, particularly with regard to posttraumatic growths (personal growth that results from crisis) and psychological adjustment (coping with psychological distress) for adults with cancer living in either Palm Beach, Martin, St. Lucie, or Broward counties in South Florida. Life experiences can impact the way we see ourselves and I am interested in how this may impact how people cope with an illness such as cancer. This research will help with development of counseling strategies for adults with cancer by increasing the understanding of changes that occur due to having cancer. Therefore, I want to know more about your experience with cancer and how it affected you, especially your views about yourself.

4) **Procedures:**
Participation in this study is entirely voluntary and this portion of the study involves completing a single session of an online survey that is estimated to take about 20 – 40 minutes. The focus of the survey questions includes diagnosis and treatment, illness effects, coping, and personal growth with regard to your experience with cancer.

At the end of this survey, you will be asked if you are interested in participating in an interview that will seek more information about your experience with cancer. The interview is entirely optional and in no way affects this survey. If you are interested in learning more about the interview, you may provide contact information. This is completely your choice whether or not to provide that information. There is no penalty for not providing that information. A separate informed consent will be provided for those who participate in an interview.

5) **Risks:**


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The risks of participating in this study are expected to be minimal. You may tire while answering the questions or you may experience some discomfort due to the personal nature of some of the questions.

6) Benefits:
Potential benefits you may get from participation in this research study include the satisfaction of knowing that you have contributed to a better understanding of the adjustment, growth, and changes in self-concept of adults with cancer. You may refuse to participate or withdraw from the survey at any time without penalty to yourself.

7) Data Collection & Storage:
All of the results will be kept confidential and secure and only the people working with the study will see your data, unless required by law. All responses are encrypted using SSL encryption technology. Data stored on the principal investigator’s computer is password protected.

8) Contact Information:
For related problems or questions regarding your rights as a subject, the Office of Sponsored Research at Florida Atlantic University can be contacted at (561) 297-0777. For other questions about the study, you should call me as the principal investigator, Barbara Abernathy or my faculty advisor, Dr. Alexis Miranda at (561) 297-3602. I can also be reached at babernat@fau.edu and Dr. Miranda can be reached at amiranda@fau.edu.

9) Consent Statement:
I have read the preceding information describing this study. All my questions have been answered to my satisfaction. I am 18 years of age or older and freely consent to participate. I understand that I am free to withdraw from the study at any time without penalty. A copy of this consent form is available from researcher upon request.
CONSENT FORM GUIDE III

1) **Title of Research Study:** The Role of Identity in Posttraumatic Growth and Psychological Adjustment for Adults with Cancer.

2) **Investigator(s):** Principal Investigator Barbara Abernathy and faculty advisor Dr. Alexis Miranda. This survey is part of my dissertation research as a Ph.D. student at Florida Atlantic University in the area of Counselor Education and is designed to help me understand about the changes that may occur in adults since having been diagnosed with cancer.

3) **Purpose:** The purpose of this research study is to discover the role of identity, particularly with regard to posttraumatic growth (personal growth that results from crisis) and psychological adjustment (coping with psychological distress) for adults with cancer living in either Palm Beach, Martin, St. Lucie, or Broward counties in South Florida. Life experiences can impact the way we see ourselves and I am interested in how this may impact how people cope with an illness such as cancer. This research will help with development of counseling strategies for adults with cancer by increasing the understanding of changes that occur due to having cancer. Therefore, I want to know more about your experience with cancer and how it affected you, especially your views about yourself.

4) **Procedures:**
Participation in this study is entirely voluntary and this portion of the study involves an interview with the cancer patient/survivor and her/his spouse/partner/significant other. The interview is estimated to take 1 – 2 hours and will take place in your home or another place of mutual agreement within Palm Beach, Martin, St. Lucie, and Broward counties. Questions will focus on any changes in identity or self-concept since the cancer diagnosis.

5) **Risks:**
The risks of participating in this study are expected to be minimal. You may tire while answering the questions or you may experience some discomfort due to the personal nature of some of the questions. Researcher will followup with a phone call 7-10 days following the interview.
6) Benefits:
Potential benefits you may get from participation in this research study include the satisfaction of knowing that you have contributed to a better understanding of the adjustment, growth, and changes in self-concept of adults with cancer. You may refuse to participate or withdraw from the survey at any time without penalty to yourself.

7) Data Collection & Storage:
All of the results will be kept confidential and secure and only the people working with the study will see your data, unless required by law. All responses are encrypted using SSL encryption technology then downloaded to a spreadsheet on investigator’s computer. Data stored on the principal investigator’s computer require a unique user ID and is password protected. Storage of voice recording will be in a locked file drawer.

8) Contact Information:
For related problems or questions regarding your rights as a subject, the Office of Sponsored Research at Florida Atlantic University can be contacted at (561) 297-0777. For other questions about the study, you should call the me as the principal investigator, Barbara Abernathy or my faculty advisor, Dr. Alexis Miranda at (561) 297-3602. I can also be reached at babernat@fau.edu and Dr. Miranda can be reached at amiranda@fau.edu.

9) Consent Statement:
I have read the preceding information describing this study. All my questions have been answered to my satisfaction. I am 18 years of age or older and freely consent to participate. I understand that I am free to withdraw from the study at any time without penalty. A copy of this consent form has been provided to me.

Welcome to this survey. This survey is part of my dissertation research as a Ph.D. student at Florida Atlantic University in the area of Counseling and is designed to help me understand about the changes that have occurred in you and your life since having cancer. I want to know more about your experience with cancer and how it affected you, especially your views about others and yourself. For that reason, it is important that I know a little information about you. It is estimated that it will take 20 - 40 minutes to complete this survey. This information is considered confidential and will only be used for research purposes unless otherwise designated by law. Also, the data are encrypted for privacy.

At the end of this survey, you will be asked if you want to participate in an
interview. The interview is entirely optional and in no way affects this survey. If you decide to agree to participate in the interview, contact information will be requested. This is completely your choice whether or not to participate. The information you provide in this survey is extremely valuable to us in learning more about the experiences of adults with cancer and your information will help us immensely.

We understand that your time is valuable and want to thank you in advance for your commitment to helping us understand your experience so that we can learn how to better help others with cancer.

In order to participate in this survey, you must have been diagnosed with cancer at or after the age of 18 and must live in one of the following Florida counties: Palm Beach, Martin, St. Lucie, or Broward.

If you would like additional information, have any questions concerning the research study, or you would like to discuss any discomfort you feel as a result of completing this study, you may contact me, Barbara Abernathy, LMHC, by telephone or by email, abernathy_fau@yahoo.com. You may also contact my faculty advisor, Dr. Alexis Miranda, by telephone, (561) 297-2422 or by email, amiranda@fau.edu.

Thanks again for your help.

1. I understand that I am participating in a voluntary survey and that I may terminate my participation at any time without any penalty to myself.

Yes, I agree to participate in this voluntary survey but understand that I can revoke this permission at any time with no penalty to myself.

No, I do not choose to participate at this time but maintain the right to participate at a later time if I so choose.
APPENDIX D

Interview Guide

1. I’d like to know more about your life before cancer. (Prompt: Can you paint a picture for me of what your family life was like? Work life? Social relationships?) A typical day? What kinds of things were important to you then? (Prompt: Hopes, dreams, priorities, activities, clubs?)

2. Tell me about when you were diagnosed.

3. Is cancer the most stressful or traumatic event you’ve ever experienced?

4. How is your life different now, if at all, than before cancer? (Prompt: Tell me about your life now. Family? Work? Social relationships? Financial status? Hobbies? Lifestyle? Hopes, dreams, priorities, activities, clubs?) If not for cancer, how would your life be different? Or: How is your life different now than it would have been if you have never had cancer?

5. When you had cancer, how did you decide what to tell others about your cancer? How did you decide who to tell?

6. What was the response of others when you told them you had cancer? (Prompt: What was the response of those closest to you? Who was the most helpful? Can you tell me more about that? What was the least helpful? Can you tell me more about that?) What about people not close to you or those you didn’t know prior to having cancer?

7. How do you decide what and how to tell about your cancer now? What do you tell people now about your cancer experience?

8. What has your experience with cancer taught you about yourself? About your relationships with others?

9. Have you learned anything about yourself as a result of cancer? How has your view of yourself changed since you’ve had cancer? Or: How are you different than before you had cancer?
10. Have you learned anything about your spouse or your relationship since having cancer?

11. What does being a cancer “survivor” mean to you? Do you consider yourself a survivor? What does it mean to be a cancer survivor?

12. What gave you hope during cancer? What kept (or keeps) you going? What got (gets) you through it? What gave you hope?

13. What wisdom or personal growth have you experienced, if any, as a result of your cancer experience?

14. How has cancer influenced your thoughts about the future? What are your plans for the future?

15. What advice would you give someone just diagnosed with cancer?

16. What question do you wished I had asked during this interview? (Prompt: What have I not asked you that you want me to know about your experience with cancer?)

17. What was this interview like for you?

18. What advice can you give me to make this a better interview?

19. May I contact you again for any follow up questions I may have?

Interview Guide for the Spouse/Partner

1. I’d like to know more about your life before cancer. (Prompt: Can you paint a picture for me of what your family life was like? Work life? Social relationships?) A typical day?

2. How did your lives change when your spouse/partner was diagnosed with cancer? (Prompt: Paint me a picture of family during cancer.)

3. Paint me a picture of life after cancer.

4. What changes have you noticed in your spouse/partner since having cancer?

5. What changes have you noticed in yourself since your spouse/partner has had cancer?
6. What advice would you give someone whose partner was just diagnosed with cancer?

7. What have I not asked you that you want me to know?

8. What was this interview like for you?

9. May I contact you again for any follow up questions I may have?

A follow-up phone will take place 7 – 10 days after the interview:

I wanted to follow-up with you about our interview last week. I wondered if you or your partner had experienced any discomfort as a result of the interview. Did either of you find any value in the experience or have any insights? What was the most positive thing about the interview? What was your least favorite part? What suggestions do you have for me as I continue my research in this area?
REFERENCES


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