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The Impact of Prostate Cancer on Survivors' Sense of Meaning in Life

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Walden University
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Abstract

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Carol L. Brady

MAC, Colorado Christian University, 2009

BA, Bellevue University, 2002

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Research has shown that meaning in life is a universal human need, regardless of cultural identity or education. This research study investigated how the encounter with prostate cancer impacted men's sense of well-being and what they considered meaningful in life. An interpretative phenomenological research design was used because of its descriptive nature and its focus on the individual’s perspective. The sample included 6 men between the ages of 18 and 65 who had been out of treatment for 1 year. Participants completed essays about their perceptions and experiences over 3 periods of time: before diagnosis, during treatment, and as survivors. The analysis concentrated on exploring participants’ perceptions; identifying themes, commonalities and discrepancies in the data; and drawing comparisons between participants’ definitions for meaning in life with the meaning making model of Park and Folkman. Study results addressed issues including a lack of information about side effects and the depth of the mental and emotional toll taken not only on the patients but also on people around them. Social change implications include the importance of (a) educating men with prostate cancer about the mental and physical health challenges they may face as they undergo treatment; (b) encouraging them to reach out for support (including professional services) should they encounter psychological difficulties over the course of dealing with their illness; and, (c) providing them with opportunities to speak about the mental, emotional, physical, and relational challenges they have faced and may still be facing in their lives as a consequence of the disease and its associated treatments.

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Dedication

This dissertation is dedicated to my mother, Jewel Lessley Brady and my father Walter LaVerne Brady, for teaching me I could do anything I set my mind to and modeling their Christian faith to me. I would also like to express my most sincere gratitude to my husband, Dale Simmons, for being patient and extremely understanding during this process. My friends Dr. Ray Crawford, Glenda Seeley, Jane Eaman, and Lynn Russell for their encouragement and support as well as all my friends at Walden which are too many to name. Last but not least, my thanks to Dr. John Astin, Dr. Donna Heretick, and Dr. Kelly Davis for all their hard work and support throughout this process.

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Chapter 1: Introduction to the Study

This study was an empirical phenomenological investigation into meaning making in the lives of prostate cancer survivors. Many studies have considered meaning making in female survivors of breast cancer, but the literature examining male survivors of prostate cancer is limited. This qualitative study explored the experiences of prostate cancer survivor’s sense of meaning, and how their encounter with this illness impacted them. The chapters consist of an overview of the study in Chapter 1, a literature review in Chapter 2, the study methodology in Chapter 3, the results of the study in Chapter 4, and the interpretations of the findings in Chapter 5.

Background on Meaning in Life Research

Though there has been substantial research on meaning in life in general, and a small number of studies have explored meaning making in cancer patients and survivors, the literature has focused almost exclusively on either women or other types of cancer such as breast and lung cancer. Research on meaning in life in prostate cancer survivors is limited, and most studies have been quantitative rather than qualitative in nature. Additionally, no qualitative studies could be located that addressed meaning in life with regard to prostate cancer survivors over the duration of their experience. Many other studies exploring meaning in life have studied individuals who were asked to write essays on or rate in a questionnaire what they consider the most important contents of meaning in life issues. This study was intended to fill a gap in the research by examining the perceptions of participants over three periods of time: before diagnosis, during treatment, and as prostate cancer survivors.

Problem Statement

The problem statement for this study was the following: How does the encounter with prostate cancer impact a person's sense of well-being and what they consider valuable, important, and meaningful in life? According to Park (2010), there are four unresolved issues in the literature: (a) a failure of researchers to examine meaning making overall; (b) the limitations of language to adequately describe the phenomenon; (c) clarity regarding whether individuals can accurately describe the meaning-making process and what it entails, due to the view that individuals are not aware that they are actually processing the meaning of their experiences; and (d) the time frame for examining this process is usually at one point in time, rather than a more sophisticated model that examines meaning making as a dynamic ongoing process to be studied over time, or at least in a retrospective sense.

Researchers have concluded that meaning making is a complex construct and that attempts to conceptualize and measure it are too broad and in need of refinement (Davis, Wortman, Lehman, & Silver, 2000; Pargament, 2002; Park, 2010). Therefore, this research is needed to better understand patients’ needs and to create interventions to help them through stressful life events. This study aims to help fill a gap in the literature through refining our understanding of what individuals with prostate cancer consider meaningful and purposeful in their lives and how their encounter with the disease has impacted their sense of meaning and purpose.

Research conducted in the past 5 years has primarily focused on the physical problems associated with prostate cancer. Even quality of life and life satisfaction studies have concentrated little on feelings or meaning making; instead, these studies examined an individual's experiences with prostate cancer and the coping mechanisms associated with different side effects, but did not mention aspects of meaning in life (Christie, Meyerowitz, Giedzinska-Simons, Gross, & Agus, 2009; Eton, Lepore, & Helgeson, 2005). Furthermore, Eton and Lepore's (2002) meta-analysis of health-related quality of life studies found that the bulk of the literature published from 1996 to 2001 concentrated only on prostate cancer specific and general health-related quality-of-life issues. They provided no studies that centered on meaning in life issues.

Therefore, in this study, I addressed a gap in the current literature by explicitly examining meaning making in the population of prostate cancer survivors. I also addressed the issue of inconsistencies in how individuals define meaning in life, as well as provided a more extensive examination and comparison of meaning making in life over time from a retrospective perspective.

Purpose of the Study

Previous research using quantitative designs has attempted to create a more uniform approach to assessing an individual's view of meaning and process of meaning making. Although this is a worthwhile endeavor, a review of the literature by Park (2010) showed that the data gathered to date have not been able to adequately capture the complexity of the phenomenon.

Assessing prostate cancer survivors' meaning in life can inform stakeholders about potential areas where additional services or interventions may be needed. Although there are assessments that consider an individual's sense of meaning in life, they are quantitative in nature and therefore limited in their capacity to delve deeply into the subjective experiences of these individuals.

Park (2010) found, in examining the literature, that over time, researchers have tried to translate the statistical information from their studies but that the “conceptual richness” underlying the statistics is often lost. Some researchers have used different questions containing the words “made meaning” or “made sense” of the stressful experience, whereas others have examined meaning making in the context of posttraumatic growth, changes in overall global meaning, or situational meaning. Because of these differences, the definitions researchers have used appear to have created an incomplete picture of meaning making with regard to the theoretical models and constructs they are trying to elucidate (Park, 2010). Qualitative methods that delve more deeply into the actual process and reasons underlying individuals’ meaning making can play an important role in bringing out more of this conceptual richness that has been lacking in previous studies.

Understanding how prostate cancer survivors may construct meaning from their experiences can, in theory, aid clinicians and others in developing more effective interventions to help individuals cope with their initial diagnosis, especially when the issues of survival and death tend to overshadow their lives. Helping men through the initial diagnosis is even more critical due to the increased rate of suicide. Fang et al. (2010) found that men are at a 90% greater risk of suicide during the diagnosis phase of the disease.

Many studies have investigated meaning in life in myriad situations such as chronic illness and bereavement in conjunction with different types of chronic illnesses and types of cancer. This study was unique in that it specifically considered men who were prostate cancer survivors by delving deeply into their descriptions of meaning, as well as exploring and comparing the differences and similarities across participants' responses. Although this was not an all-inclusive, comprehensive treatment of the concept of meaning in life, it will add to the literature of prostate cancer survivors' experiences and how they made or did not make meaning while adjusting to a life that became the "new normal" (Katz, 2011).

Research Questions

The purpose of this study was to examine how prostate cancer survivors construct meaning from their experiences, and how this meaning influences their life satisfaction. The research questions for this study are as follows:

1. What is the demographic make-up of prostate cancer survivors with respect to marital status, education, religion/spirituality, type of cancer treatment, experiences with recent crisis, cancer stage at diagnosis, treatment option chosen, side effects, depression, anxiety, and mental health treatments if any?
2. How do prostate survivors define meaning in life?
3. Prior to (a) diagnosis, (b) during treatment, and (c) now as a prostate cancer survivor, do participants report changes over time in terms of how they view themselves, their place in the world, their relationships, their work life, and/or their spirituality?

4. What are the most meaningful or important changes (if any) participants have seen on their journey with prostate cancer before, during, and as a survivor?
5. What are the commonalities and themes (if any) between survivors with respect to meaning in life changes during their journey with prostate cancer?

The aim of the study was to shed further light on the definitions and key components that comprise meaning in life for prostate cancer survivors. It was hoped that the information gleaned from this interpretative phenomenological investigation helps to clarify the processes that prostate cancer survivors employ as they attempt to make meaning during and in the wake of their illness experiences. It was also hoped that the study adds to the literature examining prostate cancer survivors' experiences, how they adjusted to life, how they used meaning-making to cope with living as a prostate cancer survivor, and how they perceived their lives with respect to having a sense of meaning for their experiences.

Nature of the Study

Phenomenological research, by its nature, examines participants' perceptions, experiences, and meanings of particular situations or events and therefore was considered to be well suited to examine the research questions here. A phenomenological study exhibits the following characteristics: (a) the researcher formulates questions that are able to be understood by the participants; (b) the researcher gathers data by engaging in dialogue with participants who are considered to be "co-researchers"; and (c) the researcher analyzes the data by exploring the "configuration of meaning," which involves both "the structure of meaning and how it is created" (Moustakas, 1994, pp. 15–16). As previously described, the concepts for this study were meaning in life; the phenomenon being investigated was the process of how individuals made or did not make meaning, and how it influenced or did not influence life satisfaction in the lives of prostate cancer survivors.

I contacted prostate cancer survivors from support group websites such as the You Are Not Alone Cancer Support Site, MD Anderson Cancer Support Group, Prostate Cancer Message Board, Prostate Cancer Message Board on AOL, the Active Prostate Cancer Message Board, prostatepointers.org, and acscsn.org, as well as from prostate cancer support groups such as the Urology Center of Colorado’s prostate cancer support group and the Man-to-Man, A Prostate Cancer Support Group. Flyers and notices were also posted on social media sites such as Facebook.

The data were collected by asking individuals to compare the period of their initial diagnoses with their current experiences as survivors. I was interested in the experiences, feelings, beliefs, and meanings and how or if they have changed. Participants were given an eligibility questionnaire to determine their eligibility for the study.

The data analytic method that was used in this study was one that Giorgi (1979) suggested using to analyze qualitative data: (a) The researcher should read the entire response to gain an overall sense of it; (b) the researcher should read the responses again but much more slowly to gain the meanings derived from participants’ responses and parse them into fundamental pieces called “meaning units”; (c) the researcher should then eliminate redundant units and analyze these units to relate them to each other and to the whole meaning; (d) each separate unit is then examined for its own revelation and deciphered into language relevant to the inquiry; (e) the researcher should then divide and recombine the information into a description that brings information to the research problem.

Definition of Terms

The following are the terms that were used in this study and their definition:

Adjustment to illness: A mental process that starts when symptoms are presented and goes on throughout the course of the illness; it is also the response to the changes during that illness (Sharpe & Curran, 2006).

Appraised meaning: The assignment of meaning to a particular experience or event (Janoff-Bulman, 1992; Lazarus & Folkman, 1984; Taylor, 1983; Wortman & Silver, 1987, 2001).

Chronic illness/disease: This includes diseases or illnesses that impair or deviate from the norm, causing a permanent or residual disability from an incurable alteration in pathology, requiring special training, care, or rehabilitation for the patient, as well as long periods of supervision, observation, or care (Sidell, 1997).

Global meaning: The system that individuals use to orient themselves; it includes their beliefs, their goals, and their subjective feelings (Dittman-Kohli & Westerhof, 1999; Pargament, 1997; Reker & Wong, 1988).

Meaning in life: According to Steger, Frazier, and Oishi (2006) and Ryff (2000), in recent years, meaning in life has been regarded as being a positive state of well-being indicating an individual’s ability to have goals, be engaged with others, and be able to maintain strength in the face of challenges.

Meaning making: The process an individual uses in the search for personal meaning in life, which may differ among individuals and over time (Frankl, 1992,).

New normal: A reconfiguration of the old normal with regard to the time before a diagnosis of prostate cancer; it also includes information, hope, and a new chance to again engage in life (Katz, 2011).

Quality of life: Fellbaum (1998) defined quality of life generally as an individual’s personal contentment or lack of contentment about their “culture/intellectual” circumstances, distinct from materialism.

Religion: For this study is defined as “a tradition of spiritual beliefs and practices shared by a group of people” (Alcorn et al., 2010, p. 582).

Situational meaning: Meaning in the context of a particular experience; one’s situational meaning starts at the beginning of a stressful event and is a process throughout the duration of the event and beyond to make meaning from the event (Park, 2010).

Spirituality: Spirituality is defined as “a basic human experience where individuals seek understanding, meaning, and strength” (Sheehan, 2005, p. 109).

Survivor: For this study, a survivor is an individual who has persevered “from the time of diagnosis, through the balance of his or her life” (Twombly, 2004, p. 1414).

Well-being: Present research on well-being is divided into two general perspectives: (a) Hedonic well-being focuses on happiness, defining well-being as the attainment of pleasure and the avoidance of pain, and (b) eudaimonic well-being focuses on the concepts of meaning and self-realization, which are considered in terms of how well an individual is considered to be fully functioning (Ryan & Deci, 2001).

Assumptions

In designing this study, I assumed participants would be forthcoming with their experiences, would answer the questions as truthfully, and would describe as accurately and honestly as possible their experiences over time with prostate cancer. I also assumed that people construct their own version of reality from their experiences. Even though participants had similar experiences, each individual filtered those experiences through the lens of their own personal reality. Additionally, I assumed that using a phenomenological research method was an appropriate means of seeking to answer the research question of this study.

Limitations

There were several limitations to this study. The first was size. The generalizability of this study was limited due to the relatively small sample size of from a minimum of three to 10 participants, which might not be representative of prostate cancer survivors in the general population. Additionally, the age group of participants did not consider meaning and purpose in men (over 65). Furthermore, the responses of these men might be quite different in scope and in context. Memory was another limitation to this study. Participants were asked to think about or remember their lives before the diagnosis and as survivors. Because this study was not be undertaken in real time to catalog the experiences of the men during the previous two phases of their experiences with prostate cancer, their past memories might be somewhat unreliable. Moreover, the findings of this study might not generalize to men diagnosed with prostate cancer who are currently depressed due because they are struggling to find a sense of meaning regarding diagnosis, treatment, and the after effects of survivorship.

Scope and Delimitations

The specific aspects of meaning in life were chosen to discern if they were integral factors in the lives of men experiencing prostate cancer. This research design was chosen due to the lack of understanding regarding the underlying issues surrounding meaning making that remained unanswered in quantitative studies into meaning in life in response to stressful life situations such as cancer.

For this study, because prostate cancer is a male-only disease, men were the only gender. The study participants were English speakers, computer literate, had private access to a computer, and were able to e-mail their responses to me. The participants were not over the age of 65 or under 18, and they were required to be out of treatment for at least 1 year.

The generalizability of this study is limited due to the relatively small sample size, which may not be representative of prostate cancer survivors in the general population. While the study results might not be completely transferable to other men facing a diagnosis of and treatment for prostate cancer, understanding how this particular group of men made meaning as prostate cancer survivors provided insight into the different ways men cope with the disease.

Cziko (1992) affirmed that generalizability is valuable because it allows for a window of temporary understanding, which helps society understand under limited conditions how a particular group perceives themselves and the world around them before, during, and after their disease experience. Understanding a small group of individuals and their perceptions was the goal of this study. This study also aimed to assess the state of prostate cancer survivors at a particular point in time.

Significance of this Study

Given the limited number of qualitative research studies in this area, it was anticipated that the study would provide additional and valuable information regarding how sense of meaning was constructed by men who have experienced a life-threatening stressful event. This subject was important to investigate, in part owing to the paucity of research examining the population of men experiencing prostate cancer and the impact of this experience on meaning-making and its relationship to quality of life. Furthermore, research to date has not examined differences of meaning-making over the three different phases: that is, before diagnosis, during treatment, and as a survivor of prostate cancer. It is hoped that the results from this study will be useful to clinicians as far as exploring the subject of meaning in life and its relationship to coping and quality of life in cancer patients and survivors. Moreover, this study will provide the groundwork for future research and the creation of interventions to help lower the distress level of men experiencing stressful life situations such as cancer.

Implications for Positive Social Change

Through the findings from this study, I hope to promote positive social change by increasing the knowledge and understanding of clinicians in assessing patients’ abilities to cope effectively with prostate cancer. This includes increased understanding of the relationships between global and situational ways of making meaning and adding to the literature on the meaning making model developed by Park and Folkman (1997). I hope that this study is a springboard for additional research with this population concerning the issues of meaning with regard to stressful life situations.

Summary

Although much investigation has been done on meaning in life in different settings and with different populations, this study was unique in its design and focused on a single gender and a single type of cancer. Because many men will face the eventuality of prostate cancer if they live into advanced years, and because the numbers of aging post-WWII individuals is burgeoning, this study hopes to open a dialogue for clinicians to talk with men concerning more than just the physical side effects of having and surviving prostate cancer. It is also important to pay attention to how men are or are not making meaning from their experiences, and also whether a loss of meaning could be an indicator that they are at risk for more serious emotional distress.

In Chapter 1, I presented an overview of prostate cancer and the potential information that could be gleaned from a qualitative inquiry such as this. Chapter 2 goes into greater depth concerning the different models and theories about meaning in life, as well as adjustment to illness in general and adjustment specifically related to cancer. Additional information is provided on spiritual challenges for survivors, as well as the inventories and assessments presently available for quantitatively measuring meaning in life. Chapter 2 covers a detailed review of the significant theoretical and conceptual aspects of meaning in life, and the assessments for measuring meaning in life quantitatively. Chapter 3 presents an overview of the research design, interpretative phenomenology, that will be used for this qualitative study. Chapter 4 presents the results gathered from the data. Chapter 5 discusses the study implications including positive social change and suggestions for future research.

Chapter 2: Literature Review

Introduction

The problem statement for this study was the following: How does the encounter with prostate cancer impact a person's sense of well-being and what they considered valuable, important, and meaningful in life? The purpose of this study was to examine how prostate cancer survivors construct meaning from their experiences, and how this meaning influenced their life satisfaction.

The constructs, theoretical models, measurement scales, and tests for the study of meaning in life are discussed in this chapter, as well as relevant research that was conducted beginning in the 1950s. The review of literature for this study includes the themes that have emerged from these areas of research and revolves around the following issues: (a) theoretical constructs of meaning in life, (b) theoretical models, (c) understanding individuals' adjustment to illness, (d) measuring meaning and subjective well-being, and (e) spiritual challenges.

Search Strategy for Literature Search

Google Scholar, Google Books, the Google search engine, PsycArticles, PsycInfo, PsycBooks, Walden Library's Thoreau, which includes other databases such as ProQuest and dissertation databases, as well as Medline and Medscape databases and other medically related internet sites such as WebMD and the Mayo Clinic site were used in finding articles for this literature review as well as statistic and general information on prostate cancer. The general search criteria employed such terms as *meaning*, *meaning in* *life*, *adjustment to illness, life satisfaction, quality of life, meaning in life measurements, meaning in life inventories,* and *meaning in life studies*.

The search criteria were expanded to include prostate cancer survivors' experiences, meaning in life, prostate cancer, adjustment to illness, and adjustment to cancer. A further expansion of the search terms included meaning in life theories, meaning in life models. Articles written in the last 7 years were the main focus. However, articles as well as books that contributed to the history of the subject matter and considered to be foundational writings were included as far back as 1997.

Theoretical Constructs

Meaning in Life

The issues surrounding meaning in life are important, and when addressed, help an individual create a more fulfilled life. Over time, philosophy, psychology, and psychiatry have contemplated, studied, and researched the construct of meaning in life. Many researchers have given much speculation to clarify what factors are included in the construct and what specifically affects and influences each individual's sense of meaning in life (Cohen & Cairns, 2012). It has been suggested that all human beings have an innate sense that there is "something more" to life than just the trappings of material success (Firestone, Firestone, & Catlett, 2003).

Frankl (1997), a prisoner of the Nazis during World War II and later the father of logotherapy, gave considerable thought to the concept of meaning in life, attempting to understand how only some prisoners appeared able to find meaning in their experiences in the camps. Frankl concluded that meaning in life is an individual experience, differing from person to person, day to day, and sometimes even hour to hour. Frankl's experiences in the concentration camps led to the belief that meaning in life is found outside the person in the world rather than inside the mind. When people became other centered rather than self-focused, they created meaning for their lives (Frankl, 1997). Frankl also suggested that human beings are meaning-seeking creatures and cannot pursue a goal such as happiness by itself but instead must pursue the things in life that ultimately bring happiness.

According to Cassell (2004), to be able to understand illness and suffering, it is impossible to eliminate the consideration of meaning. The relative importance of experiences is always personal and individual. Experiences may be shared by other people, but the significance of any experience is constituted by the personal meaning of it (Cassell, 2004). Park and Folkman (1997) asserted that individuals who perceive undesirable circumstances such as a health crisis as a challenge rather than a threat show more positive growth and believe they are better for having experienced the challenge. This positive growth may lead to an increased sense of life's meaningfulness, lessening the individual's stress and leading to more effective coping responses (McMillan, 1999).

Conceptual Aspects

Meaning in Life

Four theoretical aspects have also been posited by researchers to be included in an overall concept of meaning in life: a sense of coherence, emotional intelligence, hardiness, and self-actualization.

Sense of coherence. Antonovsky (1990, para 23) defined the construct of sense of coherence as the following:

> 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.

Eriksson and Lindström (2005) found that after more than 20 years, even after the theory's revision, their synthesis of the literature found the theory and the scale measuring it to be fundamentally sound and psychometrically valid and reliable. However, the structure of the concept is still in need of more research, particularly in developing qualitative methods to study the sense of coherence.

Emotional intelligence. Emotional intelligence, according to Goleman (1998), refers to the extent an individual is able to recognize his or her own feelings and the feelings of those around them. Goleman included the ability individuals have to motivate themselves and manage their emotions and relationships. A model for emotional intelligence was proposed by Salovey and Mayer in the 1990s, consisting of four factors: perceiving, reasoning, understanding, and managing emotions. Perceiving emotions is the first step to being aware of them; this may include body language or facial expressions, which are considered nonverbal indicators (Salovey & Grewal, 2005).

The second step is to reason with emotions, which involves cognitive activities like thinking and problem solving; using thinking helps prioritize the occurrences that try to get one's attention and allows them to make decisions concerning the issues they care about or respond to (Salovey & Grewal, 2005). Step 3 involves understanding one's emotions; emotions tend to involve a broad assortment of meanings that may need interpretation (Salovey & Grewal, 2005). Step 4 is managing those emotions; effective management of emotions is a fundamental component of emotional intelligence (Salovey & Grewal, 2005).

Hardiness. Hardiness is also considered a personality trait by some researchers. Kobasa (1979) developed the term in relationship to meaning to characterize individuals who, under high stress, would be less likely to become ill as a result of that stress. Maddi (2004) proposed that there are three components to hardiness that enable individuals to resist illness: commitment, control, and challenge. If people are strong in commitment, they desire to stay involved with their lives, people, and events that they find interesting and especially meaningful. People who are strong in control want to have an influence on their lives and their surroundings. These people are also interested in challenges that enable them to learn from new experiences (Maddi, 2004). These elements informed Maddi's (2011) model of meaning making through decisions, discussed later in this chapter.

However, when measuring Kobasa's composite score, Hull, van Treuren, and Virnelli (1987) found that the three factors needed to be studied separately. They discovered that commitment is the factor that seems to be most closely aligned with health outcomes (Hull et al., 1987). Kobasa (1979) sought to assess if cognitive hardiness would have a direct effect on high life stress and the current psychological functioning of a group of male and female college students (*n* = 187). Kobasa's (1979) research showed that cognitive hardiness produced a mitigating effect on somatic and psychological anxiety.

Self-actualization. The term *self-actualization* was originally presented in the literature in the 1930s as Goldstein's (1939/1995) organismic theory, which stated that individuals by nature move toward their potential. People who have high scores on self-actualization and meaning in life seem to be able to withstand the challenges in life better than those individuals with low scores; a positive attitude seems to be at the core of these two constructs (Cohen & Cairns, 2012). The most recent study in this area of research by Cohen and Cairns (2012) indicated that it is not self-efficacy that has a moderating influence on happiness when searching for meaning in life but self-actualization.

Theoretical Models

Below I present three of the more prominent models for meaning in life (the meaning-making model, dual-systems model, and meaning making through a decision-making model) found in the literature.

Meaning in Life

Meaning-making model. A model or framework was proposed by Park and Folkman (1997) to explain how individuals make meaning in response to especially stressful events. Their model centers on comprehending the differences between global and situational meaning.

Global meaning. Global meaning in their model refers to the beliefs individuals hold about life and the universe in general but also includes one's personal life goals (Park & Folkman, 1997).

Situational meaning. Park and Folkman's (1997) definition of situational meaning includes goals, beliefs, and assumptions that an individual holds that are basic and fundamental when trying to comprehend life experiences. They asserted that situational meaning encompasses how individuals relate to the events surrounding people and the circumstances in which they encounter those people and events; to them life is made up of "situation-specific" events (Park & Folkman, 1997).

The following aspects comprise situational meaning:

Appraised meaning. This is the earliest meaning of an event that includes an appraisal of whether the experience is able to be controlled by the individual or whether there is a fear or threat that contains implications for the individual's future (Aldwin, 2009; Sweeney, 2008).

*Discrepancies**.*** The discrepancies between two types of meaning (appraised and global) arise after the appraisal of an experience or event. People determine the amount of fit between these two types of meaning. The range of discrepancy is determined by the individual's ability to control or comprehend the situation or event. If the individual senses a lack of continuity or closeness between these two types of meaning, it is theorized that this distance creates the distress that drives the individual to the process of meaning making. Therefore, the further apart the two meanings are, the greater the level of distress and more incentive there is for the individual to reconcile the appraised and global meanings (Park, 2010).

Automatic *vs. deliberate processes.* The meaning-making process has been thought of as both self-regulating or requiring efforts to cope and a process that is also conducted behind the scenes of awareness (Park, 2010). Purpose may change and previous life goals may shift through a process that extends beyond intentions; for example when goals become blocked, the opportunities may come to the fore and the reappraisal of the previously untenable situation becomes much more acceptable because of this reframed meaning (Park, 2010).

How people reconcile global meaning and these situation-specific events helps to either dispose them or not to feeling stress in a particular event. If this reconciliation is not achieved by efforts at coping with it, then the process of making meaning out of it either is changed or a reevaluation of the circumstances is needed to help create that reconciliation.

Dual-systems model. Wong (2011) described the aspects of individuals in this model with the following attributes:

1. People are individuals; there are individual differences in all of us. Each individual’s personal mindset is related to how they interpret the world. These individual differences create the attributes (favorable or unfavorable) that affect people’s abilities to cope with the stresses of life (Wong, 2011). For example, an individual from a collectivist orientation would be more concerned with their family’s well-being than themselves.

2. Along with personality are other factors such as culture; culture shapes the way one perceives the world around them (Wong, 2011). For example, an individual from a collectivist orientation would be more concerned with their family's well-being than themselves.
3. Positive and negative situations occur in life; in this theory, some negative instances people encounter are actually helpful in creating overall well-being (Wong, 2011).
4. Additionally, situations, both negative and positive, are experienced by everyone.

Favorable consequences/outcomes come from an individual's ability to adapt that in turn lead to occasions of personal growth, fulfillment, and satisfaction. These occasions then lead to positive emotions that reinforce the previous behaviors. Unfavorable consequences/outcomes may result from the inability to adapt, which in turn leads to blocked goals and feelings of distress. These unfavorable situations may lead to contradictory emotions such as "anger and anxiety" (Wong, 2011).

The purpose, understanding, responsibility, and enjoyment system is based on a set of principles, which include the following:

Purpose. To have one of the most critical pieces for flourishing, an individual must have purpose that they have determined is right for them (Wong & Wong, 2011). An individual may do good deeds in order to produce happiness, but unless the individual has created and is living the life that is right for them, those efforts probably will not produce the desired long-term results (Wong & Wong, 2011).

Understanding. Understanding and purpose are closely related and are vital components of meaning in life (Wong & Wong, 2011). With the knowledge and clear sense of self—who one is, who one is meant to be and how one sees their place in the world—a meaningful life is possible (Wong & Wong, 2011). Understanding is integral to creating purpose. Without understanding the realities of living in the world and being able to not only understand but access its opportunities and meet its challenges, setting life goals is extremely difficult (Wong & Wong, 2011). This concept is also related to the concept of coherence; if one cannot understand life with its changing landscape and how it ultimately works, then life becomes a fearful reality (Wong & Wong, 2011).

*Responsibility****.*** The concept of responsibility in this model is concerned with “doing what is right” (Wong & Wong, 2011). To make right decisions, one must have the self-determination, commitment to other’s well-being, and accountability for those decisions (Wong & Wong, 2011). People who own their decisions and are committed to virtues such as honesty and integrity make the right decisions (Wong & Wong, 2011).

Enjoyment and evaluation. The premise behind this aspect is that enjoyment drives feeling good from doing good, especially when one is committed to a higher purpose and understanding of that purpose (Wong & Wong, 2011). Enjoyment, however, must be accompanied by evaluation, because when there is a negative experience, regulation of the self requires actions that may require a revision of direction or “midcourse correction” (Wong & Wong, 2011, p. 602). Evaluation serves to help individuals continue to move forward, enabling them to keep from being immovable; feelings of dissatisfaction, then, help create positive changes (Wong & Wong, 2011).

The hypothesis of the dual-systems model is that individuals are able to make meaning out of positive as well as negative situations and outcomes. In this system, individuals make decisions through a process of logical and rational processes in an effort to manage situations; in essence, creating a dynamic invigorating life results from being able to balance fortuitous situations with ones that are challenging (Wong, 2011). By using approaches such as mindful awareness, openness, compassion, empathy, acceptance, and nonjudgmental awareness, individuals are able to make lives that are full of meaning and adaptable to any negative occurrences that are encountered (Wong, 2011).

Even setbacks and failures can enable individuals to incorporate lessons learned from those experiences to rise higher what do you mean by this and be more caring, compassionate people (Wong, 2011). However, this system recognizes that there is a negative line that, when crossed, becomes a breaking point: i.e., when negative situations are no longer beneficial such as when an individual becomes overwhelmed by a situation (Wong, 2011). Enacting this dual system in one’s life is to have a meaning mindset that entails creating and living a life of balance; this balance comes from sources such as attainment of goals, relationships with others, spirituality, and a sense of justice (Wong, 2011).

Making meaning through a decision-making model. This theory, advocated by Maddi (2011), is based in existential core assumptions related to the way human beings see the directions of their lives and the attributes that are inherent in themselves through the type of personality they exhibit. These assumptions recognize the basic core needs of people such as food, clothing, and shelter and a need for community (Maddi, 2011). These attributes enable human beings to take in information, understand and filter it, and to make decisions regarding it (Maddi, 2011). Human decision making and directionality takes two forms: looking at the past for insight and imagining the future (Maddi, 2011).

Looking to the past may bring security, but may limit future options by endorsing the "we've always done it that way" thinking (Maddi, 2011). Imagining the future involves thinking that considers new experiences as different from previous ones, requiring a different course of action or direction (Maddi, 2011).

Future decisions may initially seem to be fraught with bouts of apprehension, but over time, the more decisions are made and the process for making them becomes entrenched in the individual's decision-making capabilities, hardiness takes over (Maddi, 2011). The concept of hardiness involves three complementary beliefs: commitment, control, and challenge (Maddi, 2011). The commitment aspect of hardiness addresses feelings of acceptance and encouragement from parent to child; the control aspect describes a child's mastery and ability to master tasks through effort; the third belief is in challenges, which must be frequent but not chaotic, so tasks are interesting rather than threatening (Maddi, 2011). Hardiness is considered a learned behavior that has been acquired in childhood or adolescence (Maddi, 2011).

Research studies on hardiness have shown that it can be a positive aspect that helps to change stressful situations into growth opportunities rather than potential disasters, and helps keep people healthy by modifying stress (Maddi, 2011). Through positive decision making and hardiness, individuals who decide to choose the future rather than the past say to themselves that anything is possible, opening up an unlimited number of opportunities (Maddi, 2011).

Meaning-maintenance model. Heine, Proulx, and Vohs (2006) proposed the meaning-management model, advocating that all people have an intrinsic need to make meaning from events and that meaning is constructed from how they perceive the world. When their perceptions are threatened, individuals must then compensate for that threat by *fluid compensation* (Heine et al., 2006). Fluid compensation is attained when people look to other domains to help them cope with psychological threats and help keep other areas of meaning in place: the self, the external world, and the self and its relationship to the external world (Thompson & Janigian, 1988). This idea is not new, as it builds on the previous theories of Heidegger (1953/1996) and Kierkegaard (1843/1997). As Kierkegaard stated, “I have, I believe, the courage to doubt everything; I have, I believe, the courage to fight against everything; but I do not have the courage to acknowledge anything, the courage to possess, to own, anything.”

Heine et al. (2006) argued that responses such as Kierkegaard’s (1943/1997) serve as a response to the threats and disruptions to an individual’s meaning framework; however, rather than making the threat vanish or diminish, it helps focus the individual’s attention away from the perceived threat and to a different domain’s framework to reduce the individual’s suffering. For instance, rather than suffering distress from a derogatory comment (seeing it as a perceived threat) about one’s ability at a certain sport, the individual reminds themselves that they are very good at another sport, to combat the perceived injury to their self-esteem.

The motivation and self-determination model. This model, suggested by Weinstein, Ryan, and Deci (2011), explains the motivation and process for meaning making, which includes three aspects: (a) the process of meaning making involves motivations for comprehending, accommodating, and symbolizing insight; (b) their environment strengthens or decreases the ability for individuals to incorporate new meanings, which includes beliefs, values, practices, and social mores or contextual factors; (c) the frame of reference that people support as being important to them; and (d) the meaning itself is likened to a basic need, psychological health, or well-being.

Self-determination theory. Self-determination theory (SDT) maintains that all meaning is not equal, even though it may make sense, create wellness, and is even strongly preferred by individuals (Weinstein et al., 2011). According to this theory, people have an innate inclination toward self-organization of knowledge, as espoused by Piaget (1971); and there is a natural tendency toward psychological integration. This integration is deeply rooted in individuals due to their tendency to assimilate social mores, beliefs, and cultural practices (Weinstein et al., 2011). SDT contends that these inherent tendencies and motivations function as growth supports and help individuals achieve basic psychological needs for competence, autonomy, and relatedness (Weinstein et al., 2011). With these basic needs met, individuals are then able to propel themselves into a greater sense of internalization and autonomy, which produces growth (Weinstein et al., 2011).

SDT has its roots in motivation and personality theory, assessing an individual’s basic tendencies toward growth and satisfying psychological needs (Deci & Ryan, 2002).

This theory looks at incentives and desires underlying why people make the choices they do without outside influences (Deci & Ryan, 2002). SDT addresses the degree that self-determination and motivation influence behaviors (Deci & Ryan, 2002).

According to Deci and Ryan (2002), there is a dialectic behavioral component intrinsic in SDT; an active interplay between human nature and social contexts that either encourage or discourage growth. This interplay will either integrate or disintegrate the processes individuals use to construct behavior that represents the darker or lighter sides of the human experience (Deci & Ryan, 2002). Basic SDT is a theory of personal experience that identifies three innate needs that are necessary for the optimal function and growth of the individual: competence, relatedness, and autonomy (Deci & Ryan, 2000). These basic needs are universal across the human experience and transcend time, gender, and culture (van den Broek, Vansteenkiste, & De Witte, 2008).

Weinstein et al. (2011) studied the relationships between the search for meaning, the satisfaction of psychological needs, and well-being. They found that pursuing meaning did not predict any particular outcomes, although pursuing meaning did tend to help in satisfying needs, psychological health, and well-being (Weinstein et al., 2011). Weinstein et al. (2011) also found that the aspects of autonomy, relatedness, and competence are associated with life satisfaction. Meaning arises from an individual’s tendency toward growth through motivation to explore, understand, and relate their experiences with others. It also involves having the sense that what one does is important (Weinstein et al., 2011).

There are presently five theories that are included as streams of inquiry in SDT: cognitive-evaluation theory (CET), organismic-integration theory (OIT), causality-orientations theory (COT), basic-psychological-needs theory (BPNT) and goal-contents theory (GCT).

Cognitive-evaluation theory (CET). CET theory examines intrinsic motivation in behaviors that are undertaken for their own sake, such as children’s play. It also considers issues of competency and autonomy and how those variables relate to intrinsic motivations, which are seen in the behaviors of people in the arts, sports, and other areas of endeavor (Ryan & Deci, 2000).

Organismic-integration theory (OIT). OIT looks at extrinsic motivations with the intent of examining the outcomes of behavior. Subtypes of these motivations indicate forms of agency including the incorporation of the identified, internalized, and integrated behaviors of others; in this case, the more internalized the motivation, the more autonomy the person possesses when performing these behaviors. OIT is concerned with the social context that hinders or amplifies what encourages individuals to resist, accept, or incorporate goals, values, or belief systems (Ryan & Deci, 2000).

Causality-orientations theory (COT). COT characterizes the differences in individual’s orientations to their environment and how they tend to manage various behaviors. COT examines three different types of orientations: (a) self-determination orientation where individuals act out of self-interest and value the outcome; (b) a responsibility orientation that centers on benefits, achievements, and validation; and

(c) emotionless and dispassionate orientation, which is depicted by anxiety in an individual’s abilities and competencies (Deci & Ryan, 1985).

Basic-psychological-needs theory (BPNT). This theory focuses on examining an individual’s psychological needs and their relationship to mental health and well-being. The primary principles of BPNT are that (a) mental health needs define cultural and developmental building blocks for well-being and optimal functionality; (b) goals, ambitions, and impulses are constantly being evaluated as to whether they are being satisfied or hindered, and that determination will help or hinder wellness; and (c) these basic needs for autonomy, relatedness, and competence are variations of the fulfillment of these needs, due to inside and outside influences on each individual.

Goal-content theory (GCT). GCT is the last of the sub theories of SDT and originates from the differences between intrinsic and extrinsic goals and the influence they have on an individual’s motivations and ultimate wellness (Deci. & Ryan, 2012). The initial idea is that “all goals are not created equal” (Ryan, Sheldon, Kasser & Deci, 1996) and, thus, they have differing relational values to physical, mental, and social aspects of health. GCT queries the source that provides motivation for goals and how the pursuit is regulated by the individual; in essence, what forces drive goal-directed behaviors and why? The “what” concerns goal content and the “why” looks at the need for goal fulfillment (Ryan et al., 1996). Goal-directed behaviors are motivated by the expectations of successful fulfillment (Ryan et al., 1996).

SDT researchers have been spurred from these five theories into additional lines of inquiry: personality growth, effective functioning, wellness, which also includes aspects of mindfulness, awareness, and a new area called *vitality* that is a measure of overall wellness (Ryan et al., 1996).

Adjustment to Illness

Individuals may display different adjustment strategies to illnesses. Sharpe and Curran (2006) suggested that rather than being ascribed as a psychological function, adjustment to illness is a process by which individuals respond to a set of changes brought on by symptoms, diagnosis, treatment, and survivorship. The processes individuals use to cope with and find positive attributes in their illness experiences are very important to the understanding of clinicians and practitioners (Sharpe & Curran, 2006).

Karademas, Karamvakalis, and Zarogiannos (2009) examined whether stress may also be associated with the different ways patients understand and then respond to illnesses and the possible relationships between life stress, and illness-related perceptions and coping. Their results indicated that patients’ coping mechanisms with regard to illness are related to how they see their overall life. Stress experiences of daily life were not directly related to individuals’ coping strategies with the illness but were related to their perceptions instead: higher levels of stress were linked to perceptions that the illness had a greater impact on their lives (Karademas et al., 2009). This negative perception seemed to create more worries concerning an individual’s health status and the use of more strategies to lessen distress, such as medicines to ease pain (Karademas et al., 2009). Especially for chronic illness, patients’ perceptions may be the most important aspect driving adjustment.

Adjustment and Well-Being to Prostate Cancer

In a meta-analysis of 60 studies completed between 1994 and July of 2006, Bloch et al. (2007) found that an individual’s adjustment to prostate cancer was quite complicated, especially due to the impact of the diagnosis, treatment decisions, and the overarching issue of mortality. Although the majority of men survive prostate cancer, men still need to be informed of these statistics to make informed decisions concerning treatment, and especially what quality of life issues they need to address (Bloch et al., 2007). Researchers found that adjustment is directly related to the diagnosed stage of the cancer, the time since the first diagnosis, and the treatment choice (Bloch et al., 2007). These findings mirror the literature review conducted by Eton and Lepore (2002) on quality of life issues.

Bloch et al. (2007) found that, considering the accomplishments that interventions have produced in helping breast-cancer patients, the lack of research on prostate cancer survivors is striking. Their meta-analysis found the articles covered numerous topics (Bloch et al., 2007), which they divided into five categories: cross-sectional studies, longitudinal studies, studies concerning patient coping, treatments of choice and their resulting psychological effects, and psychological interventions and their impacts on patients (Bloch et al., 2007).

Their analysis revealed gaps in the literature. Cross-sectional studies mirrored those by Eton and Lepore (2002), finding that localized prostate-cancer patients showed better adjustment to the disease than did advanced patients. Longitudinal studies did not indicate that adjustment worsens over time but early signs of distress such as depression and anxiety point generally to a less positive future course for the disease. They also found that coping includes awareness of interpersonal and emotional issues linked to a better outlook for adjustment. In contrast, a patient's sense of helplessness correlates to instances of less depression and fewer self-esteem issues.

The review also found that men do not seem to experience the same rate of adjustment impairment as women with breast cancer seem to experience; however this may indicate an underlying belief in men that admitting to adjustment difficulties is a sign of weakness (Bloch et al., 2007). Self-analytic questionnaires may not pinpoint responses exhibiting avoidance; future research should try to penetrate this possibility with more qualitative rather than quantitative data (Eton & Lepore, 2002).

Bloch et al. (2007) mirrored Eton and Lepore's (2002) data on treatment choice outcomes and their effects on adjustment, similar to those on quality of life. They found that levels of distress started lower with beginning treatment and that certain treatments had side effects of a particular nature. They concluded that, in future practice, clinicians could point out these side effects during the process of patient consent, thus making more information available for the patient to make more informed choices regarding treatment. The researchers found adequate interventions that had proven valuable in determining and identifying which patients were at high risk of suicide, but the value of psychotherapy was unclear, due to the lack of studies and limited methodology.

Implications of this review can inform clinicians: there are many advantages to detecting distress, not only in patients but in couples, to enable comprehensive risk assessments. Also, individuals and couples need programs and interventions to help alleviate psychological distress. To provide alleviation, scholars and clinicians need to understand how individuals make meaning of these life experiences.

Measurement of Meaning in Life

Park (2010) identified a problem with researchers' ability to clearly define meaning in life noting that it is one of the most substantial limitations in meaning research today. While some measures of meaning in life have employed definitions that primarily assess what meaning making is, others have used more broadly defined conceptualizations that include an examination of the processing of emotions (Park, 2010). Items in measures of meaning-making have asked questions about how often individuals search to make sense of their illness and/or why they believe a given illness has happened to them (Park, 2010). However, inconsistencies in how meaning in life is operationalized and the varying ways that terminology employed in these measures is interpreted has raised questions about the validity of these measures. (Park, 2010).

Current measures of meaning in life have evolved from many of the theories presented earlier in this chapter. However, these methods do not provide evidence as to underlying constructs that may be present. Due to the qualitative phenomenological nature of the study, a more comprehensive picture of the terms and definitions involving the constructs within the Meaning Making Model may emerge from the data collection. Due to the lack of more concrete definitions of meaning, researchers have used different approaches in measuring meaning in life by conducting quantitative studies which still may not truly encompass a generalized definition (Jim, Purnell, Richardson, Golden-Kreutz, & Andersen, 2006). Numerous scales, tests, indices, and questionnaires have been developed to measure meaning in life and this section of the chapter discusses eight scales and tests presently in use.

Life Regard Index (LRI)

The LRI, developed by Battista and Almond in 1973, measures meaning in life but without using personal values. It assesses an individual's engagement with specific goals that include aspects of fulfillment (Battista & Almond, 1973). The LRI is a measurement derived from the individual's self-report, composed of two subscales: Framework and Fulfillment. The LRI-Framework looks at the foundation or framework to determine the extent to which an individual is able to conceptualize their life from a meaningful viewpoint and have been able to develop a basic a life philosophy from this meaningfulness (Debats & Drost, 1995). The LRI-Fulfillment subscale seeks to measure how much individuals perceive themselves as having accomplished their framework or life goals (Debats & Drost, 1995). Debats and Drost (1995) determined that the scales measure the construct of meaning in life and are psychometrically sound for this purpose.

Meaning in Life Scale (MiLS)

The MiLS was developed by Warner and Williams in 1987. This 15-item scale is administered by an expanded online data collection questionnaire. Designed as a self-report of an individual's determination of the worth of the life they have left (Warner & Williams, 1987), it goes beyond aspects covered by life-satisfaction measurements already in existence (Warner & Williams, 1987). Warner and Williams (1987) defined meaning in life as focusing on an individual's sense of purpose, their beliefs, and faith statements. The MiLS was originally developed using four groups: patients with chronic disease, terminally ill patients, their relatives, and the health professionals attending them (Warner & Williams, 1987).

In their construction of MiLS, Jim et al. (2006) concluded that there were five distinct facets that should be considered: “Harmony and Peace, Life Perspective, Purpose and Goals, Confusion and Lessened Meaning, and Benefits of Spirituality” (p. 2). They found the scale to be reliable for test–retest reliability and construct validity and was a sound assessment to determine meaning in life with cancer patients (Jim et al., 2006).

Meaningful Life Measure (MLM)

Morgan and Farsides (2009) created the MLM, which encompasses five subscales addressing separate constructs in personal meaning: purposeful life, valued life, accomplished life, principled life, and exciting life. In addition to producing a composite value for meaning, the MLM’s separate components could measure these constructs separately (Morgan & Farsides, 2009). The authors found, in a three-study research project, that the MLM’s convergent validity indicated these five scales have a constructive use when applied to this five-factor approach to measuring meaning in life (Morgan & Farsides, 2009).

The multidimensionality of this measure, which contains a large number of constructs, may lead to problematic analyses of confounding variables. In this sense, these measures would not contribute to the study of meaning but might hinder it (Morgan & Farsides, 2009). Needing to add additional measurements due to this problem may require too much time or too complex circumstances (Chamberlain & Zika, 1988). The primary needs still remain for a measurement of meaning that can be all-inclusive, affordable, and acceptable from a psychometric standpoint (Morgan & Farsides, 2009).

Personal Meaning Profile (PMP)

The PMP assessment was developed to measure what people perceive as an "ideally meaningful life" (MacDonald, Wong, & Gingras, 2011). Personal meaning, defined by Reker and Wong (1988), is considered to be the recognition that there is an order to life, a purpose, and continuity to an individual's existence while in the pursuit of goals the individual considers worthwhile and their subsequent fulfillment (Reker & Wong, 1988). The PMP contains 57 items derived from studying individual laypeople rather than researcher or psychologists' models, in understanding what was considered to be meaningful to them; then results were compared to formal models already in existence (MacDonald et al., 2011).

MacDonald et al. (2011) asked participants to categorize how many of the 102 items fell into a particular category and whether the items were characteristic of an ideal life or of themselves by rating them on a Likert-type scale with a range from 1 (extremely uncharacteristic) to 9 (extremely characteristic; MacDonald et al., 2011). A score of 5 indicated they were unsure for both and scores less than 6 indicated the item was not characteristic of an ideally meaningful life (MacDonald et al., 2011). Participants also completed the Perceived Personal Meaning Scale developed by Wong (1998), an 8-item scale used as a criterion measure (MacDonald et al., 2011).

This approach from experiment to theory was intended to eliminate bias from researchers or others about previously developed theories (MacDonald et al., 2011). First, they chose participants' walks of life; then asked participants to "describe what constituted an ideally meaningful life or ideally good life, if money were not an issue" (MacDonald et al., 2011). After responses were collected and analyzed, they were catalogued into 102 items, gathered into five categories of psychological functioning: cognitive, motivational, affective, relational, and personal (MacDonald et al., 2011).

Measuring Illness and Suffering

An additional aspect of meaning and purpose is associated with suffering and illness. The following measures are used in assessing meaning in life when it is associated with negative events such as illness or tragedies.

Meaning in suffering test (MIST). When considering illness or negative circumstances, measures such as the MIST, seek to assess the meaning an individual assigns to experiences that involve unavoidable suffering (Starck, 1983). Part 1 of the two-part MIST involves three subscales: (a) the emotional aspects of suffering, (b) the individual's personal response to suffering, and (c) the meaning an individual attributes to suffering (Schulenberg, 2004). Part 1 consists of 20 items using a Likert-type response ranging in scale from 1 to 7 (Schulenberg, 2004). Part 2 consists of 17 statements that ask individuals to choose one or more choices from a group of possible responses; as an example, "how they respond when undergoing a suffering experience" (Schulenberg, 2004). The information gained from Part 1 is valuable as a research tool and Part 2 provides information that is useful for therapeutic purposes (Schulenberg, 2004).

Constructed meaning scale (CMS). The CMS is also useful to assess meaning when it is in the context of a life-threatening illness such as cancer (Janoff-Bulman, 1989). This short test has eight questions scored on a 4-point Likert-type scale ranging from 1–*Strongly agree* to 4–*Strongly disagree* (Fife, 2003). The CMS is based on the theoretical framework of symbolic interactionism by Blumer (1969), which posits that (a) people's actions toward objects are based on the meanings they ascribe to them, (b) the meanings are taken from or come out of social interactions individuals have with others and society, and (c) meanings are fluid and are constantly change through the interpretative information gained in dealing with the objects that the individual encounters daily. The CMS assessment is intended to assess how an individual's identity and social environment have been affected by illness or disease and to serve as a measure of the quality of adjustment an individual is likely to achieve (Fife, 2003).

Since its inception, the CMS has only been used with cancer patients, but is designed and could be used with individuals having chronic diseases. However, because it is "disease specific" in its construction, and different diseases would require different norms, the scale's questions would need retooling (Fife, 2003). According to Fife (2003), more research needs to be done to support its validity and reliability and to study whether it is sensitive to different interventions.

Spiritual Challenges of Cancer Survivors

Cancer survivors experience a range of physical effects from the cancer and its treatments. Along with physical effects are mental and spiritual effects; realities that impact everyday life such as losing income, potential income, and a change in roles that may be due to having to quit a job (Jedford, 2009). Adjusting to ongoing changes even after the end of treatments for months or years, including the specter of death, present problems over time that are sometimes extremely difficult to overcome without help (Jedford, 2009).

Park and Folkman (1997) found that individuals use religion and spirituality when making meaning because they provide a foundation and direction for understanding world events and situation-specific events especially when the events are antagonistic, stressful, and conflicting in nature. When suffering from a chronic illness or disease such as cancer, spirituality can be important in helping individuals find meaning from their suffering (Held-Warmkessel, 2006). In many instances, it helps to provide comfort and strength, especially when facing issues of mortality (Held-Warmkessel, 2006).

In a small phenomenological study by Albaugh (2003), spirituality provided not only strength, but many blessings in the face of the hardships produced by illness; all individuals who participated in the study had strong spiritual beliefs and felt their spirituality helped define the meaning given to their lives by their disease. Six studies from 1977 through 1993 found the following aspects: participants relied on religion and prayer for a cure for disease when they were in later stages of disease, and religion seeking was associated with greater psychological health and well-being and better adjustment to the medical problems produced by cancer than was a coping style that employed an external locus of control, avoidance, and a style based in denial and minimization (Livneh, 2000).

Sherman and Simonton (2001) found similar results in the studies they surveyed; for many participants, religion allowed them to adapt to the crisis of illness in their lives. However, although there were myriad measures used to study religion, they found that the ones that addressed individuals with cancer specifically were limited (Sherman & Simonton, 2001). In studying one measure specifically developed for patients facing bone-marrow transplants, the Santa Clara Strength of Religious Faith Questionnaire, they found that even for healthy individuals, the validity and reliability were quite good and scores were significantly associated with optimism (Sherman et al., 2001). There was additional evidence that the cancer group showed a greater increase in satisfaction with religion and meaning in life over the healthy group; results from the study (*n* = 153) overall showed that the questionnaire could be used reliably to measure the religious faith of cancer patients (Sherman et al., 2001).

Positive and Negative Styles of Religious Coping

Research suggests that there are both positive and negative types of coping involving religion and spirituality (Pargament, 1997). Positive coping involves behaviors such as a problem solving that is perceived as jointly shared between the individual and God, being able to help others, and pursuing religious and spiritual support from within the community. Negative coping behaviors include having a deference toward God and relinquishing all responsibility for outcomes to God, feelings of abandonment and separation from God through instances such as the feeling prayers are not being answered and blaming God (Pargament, 1997).

Studies have shown that individuals with positive behaviors such as seeking strength, a comforting presence and support evidence greater mental and physical well-being (Bush et al., 1999). Conversely, those individuals exhibiting more negative behaviors experienced negative outcomes that were associated with patients either seeing their illness as a punishment or retribution from God; they also felt that when they need God the most, he had deserted or discarded them with a total lack of regard (Bush, et al., 1999).

Chosen Methodology

In a recent review of meaning-in-life assessments, Brandstätter, Baumann, Borasio and Fegg (2012) found that only 12 of the 59 studies used open-ended questions and narrative essays. Only one study dealt with meaning in life with cancer patients and in that study, all of the participants were women with breast cancer. The methodology chosen for the present study is interpretative phenomenological research examines circumstances using an approach that concentrates attention on three areas: (a) exploring how an individual participant's experiences appear, (b) allowing participants to speak for themselves, and (c) interpreting their experiences from the individual's point of view as well as looking for themes and commonalities across participants (Smith et al., 2009) using multiple cross-case analysis (Miles, Huberman, & Saldaña, 2014).

The methodology chosen for the present study is also supported by Empirical Phenomenology which neither lends its origins from Husserl nor from Heidegger but goes forth from the perspective that scientific data "must be grounded in the meaning structures" of the individuals being studied (Aspers, 2009). According to Aspers (2009), Empirical Phenomenology is not just a story from an individual's perspective but that narrative plays "a central role" in the research. A phenomenological study helps describe the experiences individuals have with regard to a particular phenomenon or concept (Creswell, 1998, p. 51). According to Littlejohn and Foss (2008) "Phenomenology is the way in which human beings come to understand the world through direct experience. We are able to know something through consciously examining it and by testing feelings and perceptions regarding it (p. 37) .”

I am using a qualitative research model because of its descriptive nature, the research questions being asked, and because of the focus on the individual’s perspective of their experiences with prostate cancer. The goal of the study is to describe the experiences of the participants and by using open-ended research questions typical of qualitative studies (Creswell, 1998, p. 99) hopefully the data will explore the participants’ viewpoints in detail.

Summary

After examining 151 studies, both quantitative or qualitative, they did not provide a single definition for meaning in life; the theories presented here do not provide a comprehensive overview of exactly how individuals construct meaning. Even though people may have a common experience such as illness and although the experience itself may be universal, each individual will create meaning and define it differently. There is a gap in the research literature regarding the way previous studies have conceptualized and measured meaning making (Park, 2010). Some studies were designed to reveal adjustment issues, whereas others were designed to address or reflect distress; the differences in assessing the relationship between distress and adjustment is enormous (Park, 2010).

This study intended to go deeper by comparing and contrasting meaning making experiences of prostate cancer survivors during and after treatment and exploring the extent to which mean-making changed over time and if so, what factors may have influenced these changes. This is important because the data will help clinicians be aware of the processes individuals use in making meaning in their lives over time when confronted by a life-threatening disease. There is a definite need to gather data about a cancer survivors' subjective experience that is descriptive and not merely numeric in nature (White, 2004). This can be achieved through the use of qualitative method and narrative essays are a particularly effective approach for capturing the essence of participants' phenomenological experience. White (2004) suggests that additional studies will help determine how to create better assessments and interventions, providing therapists with better tools to promote well-being.

It was precisely because of the need for more descriptive data that this study used a qualitative approach to try to identify individualized patterns of meaning making and their influence, if any, on an individual's life. The research design for this study is discussed in detail in Chapter 3.

Chapter 3: Research Method

The problem statement for this study was the following: How does the encounter with prostate cancer impact a person's sense of well-being and what they consider valuable, important, and meaningful in life? In this chapter, I describe the research design and rationale for it, my role as observer, the selected methodology for participant selection, instrumentation, the procedure for securing participants, and the data-collection and data-analysis plans.

Research Design and Rationale

The purpose of this study was to examine how prostate cancer survivors construct meaning from their experiences, and how this meaning influences their life satisfaction. The research questions for this study are as follows:

1. What is the demographic make-up of prostate cancer survivors with respect to marital status, education, religion/spirituality, type of cancer treatment, experiences with recent crisis, cancer stage at diagnosis, treatment option chosen, side effects, depression, anxiety, and mental health treatments if any?
2. How do prostate survivors define meaning in life?
3. Prior to diagnosis, during treatment, and now as a prostate cancer survivor, do participants report changes over time in terms of how they view themselves, their place in the world, their relationships, their work life, and/or their spirituality?
4. What are the most meaningful or important changes (if any) participants have seen on their journey with prostate cancer before, during, and as a survivor?

5. What are the commonalities and themes (if any) between survivors with respect to meaning in life changes during their journey with prostate cancer?

The design for this study was a retrospective cross-sectional interpretative phenomenological study using interpretative phenomenology to explore prostate cancer survivors' experiences with regard to meaning in life. The use of open-ended questions about participants' experiences and the use of a case study approach helped illuminate the processes used by prostate cancer survivors to construct meaning in their lives. The study design aided in exploring three periods of time: before diagnosis, during treatment, and as a prostate cancer survivor. Participants were asked to complete a demographic questionnaire and respond to three sets of essay questions. Although these instruments did not provide an all-inclusive appraisal of the subject, it is hoped that they further the understanding of what prostate cancer survivors experience in terms of meaning making specifically. In this study, I examined how participants adjust to a life experience with prostate cancer. Additionally this study aimed to provide more clarity in defining the term *meaning in life*, particularly as it relates to stressful life experiences.

The rationale for deciding to use an interpretative phenomenological approach was to discern which of the theoretical models or constructs presented aligned with how individuals made or did not make meaning and how meaning influenced or did not influence the individuals' lives. The findings from this study affirmed some aspects of many of the theories, models, and constructs presented. According to Yin (2011), a methodology is important when research questions are descriptive and explanatory in nature, asking questions that begin with words such as how, what, and why.

Additionally, this design was appropriate for studying a phenomenon that has a “real world context” (Yin, 2011, p. 5).

Furthermore, choosing an interpretative phenomenological approach was based on the intention to understand the experiences of prostate-cancer survivors’ endeavors to search for meaning in their lives before, during, and after treatment, from their own perspectives. This rationale was consistent with the view that a qualitative study is an inquiry process to understand “a social or human problem based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting” (Creswell, 1994, p. 15). Qualitative designs are naturalistic in their approach in that they do not try to manipulate the research setting.

The phenomenon of meaning making includes basic themes that impact patients when recovering from extremely stressful experiences that involve meaning in life issues (Park, Edmondson, Fenster, & Blank, 2008). Many theories have emerged to help define and explain concepts, and many measures, assessments, and inventories have been created to examine the psychological phenomena surrounding adjustment to illness and trauma. The selection of the methodology was appropriate given that qualitative research is defined as a process of inquiry and understanding of “a social or human problem,” based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting (Creswell, 1994).

When creating research questions for a qualitative phenomenological study, researchers ask themselves, “What is the broadest question that I can ask in a study?” (Creswell, 2014, p. 139); researchers do this to elicit data on a particular phenomenon.

Because this dissertation focused on a single phenomenon—meaning making with regard to the experience of prostate cancer—the study was suitable for a interpretative phenomenological study, which aimed to describe the "essence of a phenomenon" (Creswell, 2014, p. 141).

Interpretative phenomenological research examines circumstances using an approach that concentrates attention on two areas: (a) allowing participants to speak for themselves, and (b) interpreting their experiences from the individual's point of view as well as looking for themes and commonalities across participants (Smith et al., 2009) using multiple cross-case analysis (Miles, Huberman, & Saldaña, 2014). Participants, while having the same disease, will often interpret their experiences differently, based on their unique point of view (van Manen, 1990).

Each of three sets of open-ended questions were designed to elicit responses concerning issues participants faced when they were first diagnosed with prostate cancer, during the course of their treatment, and now as a survivor. Each question was also intended to examine perspectives of participants concerning the impact cancer had on their views of themselves, their lives, and their relationships (see Appendix D). The questions were intended to generate data by following a collective case study style that informed and added to the body of literature in order to enhance understanding of the concepts surrounding meaning making (Hancock & Algozzine, 2011). These issues concerned meaning in life and were important in trying to discern the lived experience of participants about their psychological, physical, and relational experiences during and after being treated for prostate cancer.

Interpretative phenomenology assumes that the evidence gathered from the study will be important and relevant to the human experience in general and will speak to the experience of cancer specifically. In this kind of research design, researchers focus on the experiences of participants to understand the phenomena being studied (Smith et al., 2009). I chose this type of research design because it helped me meet my goal for the study. My goal was to orient the research in such a way so as to understand the experiences in question in an open and process-oriented manner (Smith et al., 2009). When using inductive processes, I regarded the participants as experts about their own experiences, rather than using a priori hypotheses, and I employed open-ended lines of inquiry to gather data from participants. Participants then spoke about the phenomenon using their own terminology rather than the my assumptions (Smith et al., 2009).

This study was designed to explore the process of how prostate cancer survivors derive meaning in life and whether the process changed over time and influenced their life, as survivors of the disease. The questions were designed to elicit responses that would identify participants' ideas of meaning in life (see Appendix D) and were also intended to consider how or if participants' original feelings regarding meaning in life may have changed. The wording of the questions was chosen to gain information for the study without biasing individuals' answers.

Role of the Researcher

Using an interpretative phenomenological design changed my role from that of an expert to one of an active learner and observer; I read the data and then reported each participant's story without passing judgment. As the sole researcher, I had no personal or professional relationships with any of the participants; I also had no supervisory or instructional relationships that involved power over the participants.

In interpretative phenomenology, the researcher adopts a hermeneutic approach, “trying to make sense of the participant who is trying to make sense” of their experience (Smith et al., 2009, p. 35). In this approach, participants’ meaning making was primary and my sense-making was secondary, trying to “walk in the participant’s shoes” standing beside the participant in order to arrive at a more objective viewpoint (Smith et al., 2009, p. 35).

Researcher neutrality was supported by a lack of preconceived expectations. I had not worked with nor had sufficient personal or professional contact with survivors of prostate cancer to form conclusions or biases about how these individuals would respond to the questions asked of them. I did not have any biases or preconceptions regarding meaning in life and how individuals would come to experience a greater sense of meaning. Because I was a full-time student, there were no issues involving work environment, conflict of interest, or power differential. I did not offer any incentives for participation in the study.

Methodology

Participant-Selection Logic

Because prostate cancer is a male-only disease, women were not included in the study. Additionally, because it is a disease of adult men, any male under 18 years of age was excluded from participating. Smith et al. (2009) suggested that the sample size for an interpretative phenomenological approach using case studies should be between three and

10 participants. Padgett (2008) agreed that qualitative phenomenological studies may either consist of one case or a group from six to no more than 10 participants.

The sampling strategy employed was purposive, due to the inclusion criteria of being a prostate cancer survivor; purposive samples are common in qualitative research (Creswell, 2009; Ritchie, Lewis, & Gillian, 2003).

Sample Saturation

The determination of sample size in qualitative research is most often based on the idea of saturation (Ritchie et al., 2003). Saturation is the point at which any additional data from participants no longer reveals new information to illuminate the research question (Ritchie et al., 2003).

Participants were males between the ages of 18 and 65. They were out of treatment for at least 1 year. They were English speaking, had private computer access, were computer literate enough to send and receive files. Participants were recruited from prostate-cancer-support websites on the Internet. The individuals who were excluded from the study were notified by email that they have not met the criteria for the study in a humane and respectful way, and without introducing stigma to the individual.

Instrumentation

Instrumentation for the study consisted of a demographic questionnaire and an extended online questionnaire.

Study Eligibility Questionnaire

The study eligibility questionnaire requested a birth date rather than an age to ensure compliance with the study requirements. The likelihood of a male participant having had prostate cancer below the age of 18 was remote. The participant was required to be English speaking. I contacted potential participants. At this time, the process for selection was instituted and those not qualifying for the study were eliminated. The exclusion criteria was determined by the study-eligibility questionnaire as to age, whether the participant owned a private computer and had a private email address, if they had been out of treatment for at least 1 year, and if they were willing to write about their experiences. Participants were notified by email that they had not met the criteria for the study in a humane and respectful way without introducing stigma.

Background Questionnaire

The background questionnaire gathered information on age, ethnicity, and religion or spirituality, and included questions that considered support system, recent crisis experiences other than cancer, the stage of cancer diagnosis, the treatment option chosen, how long ago treatment ended, side effects experienced before treatment and now, and experiences and treatment for depression and anxiety, if any (see Appendix C).

Extended Online Questionnaire

Creswell (2014) cited that using an email Internet interview questionnaire is an excellent method enabling the researcher to gain “control over the line of questioning” (p. 191). I used an extended online questionnaire to help eliminate researcher bias (Creswell, 2014). Additional reasons for using an extended online questionnaire were to help in data analysis and interpretation. The data needed to be winnowed down to concentrate on emerging themes (Creswell, 2014); my methodology complied with that requirement. Creswell (2014) also stated that phenomenological research uses the analysis of significant statements, the generation of meaning units and what Moustakas (1994, p. 196) called “an essence description.” According to Moustakas (1994), “when we reflect upon something and arrive at its essence, we have discovered another major component of meaning” (p. 70). Phenomenology, according to Babbie (1998), involves attempting to discover participants lived experiences.

After informed consent was obtained, participants were given the first round of essay questions regarding experiences with meaning in life prior to being diagnosed with prostate cancer. When they completed those questions, they were notified by email and sent the questions for Round 2, which asked about their experiences during their treatment for prostate cancer. After that, they were emailed the questions for Round 3, which addressed their experiences now as survivors and when they had finished the questions in Round 2.

Initial Contact With Potential Participants

Potential participants were identified via flyers posted in support groups as well as oncologist offices and with support-group facilitators. The duration of the process depended on responses to the flyer. This phase varied from a day to 3 weeks. Flyers were posted at various locations and given or mailed to individual facilitators such as those at the Urology Center of Colorado and the Man-to-Man, A Prostate Cancer Support Group, both of which are in northern Colorado, and online at the following sites: Facebook.com, the Healing Well Prostate Cancer Discussion Group, the Cancer Forum’s Prostate Cancer group, and the WebMD Prostate Cancer Support Forum. Communication with potential participants was accomplished by email. I had no previous relationships with any of these entities; therefore, there was no conflict of interest.

Informed Consent and Confidentiality Agreement

The study was conducted electronically and communication took place online (see Appendix B). An email with the demographic questionnaire was sent to all individuals who qualified to be in the study after they completed the informed-consent document; I anticipated this process would take approximately 3 weeks. Essay questions were then be emailed to participants over the span of the research project. The duration of the data-collection events were estimated to be approximately 2 weeks each in length.

I believed that there were no potential psychological risks that might include stress greater than what one would experience in daily life (e.g., materials or topics that could be considered sensitive, offensive, threatening, or degrading); legal risks of exposing criminal behavior; information on workplace performance; or problems with serious injury in the questions or research design posed for this study. Risks were minimized as much as possible. Participants were told in the informed-consent document that they could withdraw from the study at any time and were urged to seek counseling should problems occur during the study, arising from the questions or their answers. Each individual was given a personalized set of three possible clinics near to them that were either low cost, sliding scale, or no cost if they felt the need for help for distress arising from the questionnaires.

I was the only person with access to the data; thus, additional informed-consent forms were not necessary. If psychological problems had arisen for participants during the study, I advised them to seek help through counseling or call 911 if it is an emergency. The informed-consent document stated specifically that no compensation, gifts, or reimbursements would be given for participation in the study. For each participant, local agencies were found that were no fee or low fee in order to provide mental health counseling if needed. I will not use any participant’s personal information for any purposes outside of this research project. Also, I did not include names or other information that could identify participants in the spreadsheets or study reports. Data collected from participants was kept secure on an encrypted flash drive in a locked file cabinet and will be kept for a period of at least 5 years, as required by the university.

Data-Analysis Plan

In this study, data was in the form of participants’ own words through essays written in response various questions. Guidelines for interpretative phenomenological studies used data-analysis structures that include the researcher’s attempt to analyze and comprehend the essence of each participant’s experience, in this case, prostate cancer and its effects on meaning making. Key statements were noted, seeking commonalities and patterns in phrases were repeated, which helped determine codes or themes (Creswell, 2014). Repetitive or overlapping statements were noted to discern saturation, as well as helping determine themes and the essences of the experiences of participants regarding meaning making. Creswell (2014) noted that data from smaller groups may be coded and categorized manually if they are contained in a smaller database.

Data-Analysis Steps

Following data analysis suggestions cited by Smith et al. (2009), the steps that will be employed are as follows:

1. The raw data was collected from participants’ essays and read for overall content. A line-by-line analysis gathered comments from each participant.
2. The data was reread.
3. The researcher made notes to gain familiarity with the information and its contextual meaning, attending to key objects in each writer’s narrative.
4. Excel spreadsheets were used to code the data into themes, categories, descriptions, or definitions, as well as making comments regarding understanding and explanations by participants.
5. The researcher interpreted the meanings aligned with themes.
6. The themes were compared across participants looking for thematic commonalities.

The treatment of discrepant cases was unknown until the data was collected; the definition of a discrepant case for this study could not be defined at this stage. However, I looked for information submitted that contrasted some of the major themes, because the lives of the participants presented perspectives colored by unique experiences that did or did not align with those of other participants (Creswell, 2014).

Issues of Trustworthiness

Increasing Validity/Credibility and Helping Eliminate Bias

According to Foreman-Peck and Winch (2010), research bias is present when researchers allow their own preconceptions, assumptions, and interpretations to color the research study. They recommended researchers thoroughly explore their feelings, preoccupations, and perceptions prior to undertaking the study. Creswell and Miller (2000) advised that to establish validity in qualitative studies or inquiries, researchers use techniques such as data triangulation and audit trails in procedures and subsequent interpretation.

Data Triangulation

Transferability and dependability was addressed through data triangulation and audit trails. Data triangulation was helpful because it helped to eliminate researcher bias (Denzin, 1978). Examples of triangulation are gathering data from different sources using multiple participants, and discerning theories and methods by employing multiple observations and documents (Denzin, 1978).

Audit Trails

An audit trail is documentation that details the researcher’s decisions about the data-collection and analysis processes (Park et al., 2008). Audit trails first were used in qualitative research due to the work of Lincoln and Guba (1985); the authors believed audit trails were one of the best techniques for establishing confirmability. Lincoln and Guba proposed that the following questions needed to be addressed: are the conclusions supported by the data; and has researcher bias been analyzed with thorough assessment?

By using these methods, an auditor can peruse the collected data and make an unbiased judgment as to whether the study's findings can be confirmed.

My audit trail included the following concerns and categories that Halpern (1983) deemed important: (a) data summary and analysis materials including summaries and notes; (b) data synthesis, including themes, definitions, and their relationships; (c) process notes that include research design, collection procedures and rationales, notes relating to credibility, dependability, and confirmability, and audit trail notes; (d) personal notes describing intentions, expectations, and predictions.

Ethical Procedures

Institutional Review Board (IRB) approval was secured from Walden University prior to any data collection. I had taken the required course offered by the National Institutes of Health and the certificate completion number was provided on the IRB application. The IRB approval number is 01-30-14-0230953, expiration date is January 29, 2015.

I secured informed consent from each participant. Ethical concerns related to the protected classes of elderly and terminal patients was addressed in the recruitment materials and excluded them. The data collected was coded with identification numbers to keep the identities of participants anonymous. The study data will be kept for 5 years; it will then be destroyed using appropriate data-removal software such as HDDErase. This software is considered one of the best secure-erase data-destruction programs available, and will destroy the data completely. There were no conflicts of interest between the researcher and the population in the study as I have no relationship with any of the participants, websites, or support groups.

Participants were encouraged that if they felt distressed over the questions asked, they could withdraw from the study at any point. Participants were also encouraged should they experience any adverse events such as intense emotional discomfort during the questionnaire process to stop the process and take appropriate action to relieve discomfort, such as calling their local crisis-counseling center or calling 911, especially if the individual is having suicidal thoughts. An individual list of low cost/no cost clinics in the participant's area is provided in the Consent to Participate in a Research Study Walden University in Appendix B.

Each day, all data collected was stored on a removable flash drive that was password protected and stored in a locked, fireproof, waterproof safe in my personal office. The combination to the safe was sent by way of Federal Express or a similar traceable carrier to my committee chairperson in the event that I was unable to continue the research due to unforeseen reasons. My spouse had the legal rights to dispose of my belongings and these archived materials and they would be sent to the committee chairperson if necessary. All data collected was in an electronic format. At the conclusion of the study, participants will be apprised by email that the study is finished and told they may request a copy of the study summary, which can be emailed to them upon request.

Summary

In Chapter 3, I considered several issues including the methodology was used for this study, and the rationale for use of a qualitative interpretative phenomenological approach, necessary to answer the research questions. Procedures for data collection, recruitment, and participation, along with the issues of trustworthiness such as credibility, transferability, and dependability were presented. Ethical issues with regard to participants’ demographic status were also included. The results garnered from the data after it had been collected and analyzed are included in Chapter 4.

Chapter 4: Results

Introduction

The purpose of this study was to examine how prostate cancer survivors construct meaning from their experiences, and how this meaning influences their life satisfaction.

The research questions for this study were as follows:

1. What is the demographic make-up of prostate cancer survivors with respect to marital status, education, religion/spirituality, type of cancer treatment, experiences with recent crisis, cancer stage at diagnosis, treatment option chosen, side effects, depression, anxiety, and mental health treatments if any?
2. How do prostate survivors define meaning in life?
3. Prior to (a) diagnosis, (b) during treatment, and (c) now as a prostate cancer survivor, do participants report changes over time in terms of how they view themselves, their place in the world, their relationships, their work life, and/or their spirituality?
4. What are the most meaningful or important changes (if any) participants have seen on their journey with prostate cancer before, during, and as a survivor?
5. What are the commonalities and themes (if any) between survivors with respect to meaning in life changes during their journey with prostate cancer?

Chapter 4 consists of the following: (a) examining whether the setting influenced the participants’ answers; (b) examining whether or not the setting influenced the interpretation of the study results; (c) the demographics and characteristics relevant to the study; (d) an explanation of data collection, its frequency, and duration; (e) data analysis;

(f) the evidence of trustworthiness; (g) the results (which are broken down into three categories: before diagnosis, during treatment, and now as a survivor); and (h) the chapter summary.

Setting

The study setting included solicitations that were posted online using Facebook sites and sent to Prostate Cancer support groups that were not online. They included the following Facebook groups: Prostate Cancer Under 50, Prostate Cancer Pony Express, Prostate Cancer Research Center, (Defeat) Prostate Cancer, Prostate Cancer Health & Wellness, Prostate Cancer Community, Prostate Cancer Research Institute (PCRI), Prostate Cancer Awareness, Prostate Cancer Second Chance, Prostate Cancer Survival, Us TOO Prostate Cancer Education & Support Network, Living with Prostate Cancer, Journey of a Prostate Cancer Patient, Gay Men with Prostate Cancer, and Go Balls Out for Prostate Cancer. Study solicitations were sent to prostate support groups that were not online but did not yield any interested participants.

Because the study questions were emailed to participants, they were able to get their answers back in a time frame that suited each individual as well as maintaining their complete privacy. Many of the participants talked very candidly about extremely personal issues including their relationships, sex lives, and their identities as men.

Data Collection

Participant Selection

Solicitation procedure. The online site solicitations yielded an initial group of 18 interested participants. Four of the participants were deemed ineligible, three because they were still receiving treatment and a fourth due to age. One immediately dropped out due to discomfort with the questions. Twelve participants actually completed the informed consent and were sent demographic questionnaires. Ten participants completed the Demographic Questionnaire. A total of seven participants dropped out of the study during various phases due to various reasons, most of which was time; three dropped out after completing the Round 1 questions. Only six individuals completed all three phases of the questions (the full study). The duration of the complete data collection process (from solicitation to collection of all of Round 3 of the extended online questionnaires) was a total of approximately 12 weeks. All of the information provided by participants was then recorded on Excel spreadsheets.

Instrumentation

Three questionnaires were used to elicit the data needed for the study. They were:

Study eligibility questionnaire. All of the participants for the study came from online solicitations. They were asked to fill out the Study Eligibility Form that asked them for contact information, date of birth, whether or not they were English speakers, if they had access to a private email and computer, if they were comfortable writing about themselves, and the date they ceased treatment. Individuals who did not meet the criteria of age and treatment cessation were ineligible for the study and were notified via email of this in a humane and ethical manner. The data were collected according to the methods outlined in Chapter 3 and the IRB application.

Demographic questionnaire. Participants who completed all of the questions on the Demographic Questionnaire (*N*=10) ranged from less than a day to return it to upwards of a week to return their answers.

Round 1, 2, and 3 online extended questionnaires. All of the participants (*N* = 6) wrote answers to the three sets of Online Extended Questionnaires Rounds 1, 2, and 3. One unusual circumstance was encountered in the data collection. This circumstance involved the individual's ability to answer the set of Round 3 questions. One participant emailed and said that he was having issues surrounding his present feelings about his life and his relationships. He asked for more time in which to deal with those issues and then finish the study. I told him to take the time he needed, and when he was contacted 2 weeks later, he was able to finish the study.

Data Variation

The variation in the data collection plan presented in Chapter 3 was that none of the participants came from local support groups. All of the participants were from states other than Colorado. Because of this, a change was filed with the IRB stating that the informed consent form that listed only local Colorado mental health agencies needed to be changed. The change was approved, and a placeholder was decided upon as an addition to original IRB application as well as the Consent to Participate form. Each individual participant was then given the form that included local mental health clinics near the participant's address that was supplied in the contact information.

Study Demographics

Participants resided in a number of different geographic areas including Tennessee, Illinois, California, Wisconsin, Rhode Island, and Canada. In addition, they were from different religious and social backgrounds as well as sexual orientations.

Participant Demographics

These demographics are only for the men who completed the full study, see Table 1 below.

Table 1

Participant Demographics

Age	Average was 59.5; ranging from 55 to 63
Marital Status	Married = 3, Single 1, Divorced = 2
Sexual Orientation	Heterosexual = 5, Gay = 1
Ethnicity	Caucasian = 5, Native American = 1
Religious Service	Catholic = 2, Jewish = 3 , Protestant = 1
Attendance	None = 3, 1x /week = 2, AA Meetings = 1
Education	Some college = 1, Bachelors = 2, Masters = 2, JD = 1

Support System and Treatment Side Effects

Cancer and its treatment side effects (physical and mental), participants reported the following in Table 2 below.

Table 2

Support System and Treatment Statistics

Most important people in support system (most men listed more than one)	Wife (*n*=3), Daughter (*n*=2), Family (*n*=1), Friends (*n*=2), Prostate Support Group (*n*=2), Church (*n*=1), Sister (*n*=1), Niece (*n*=1), Dog (*n*=1), Psychiatrist (*n*=1), brother-in-law (*n*=1), son (*n*=1)
Experienced a recent crisis	(*n* =1) his "entire life crashed," (*n*=1) experienced the death of his parents, a burglary and assault on his partner, and (*n*=1) experienced unemployment for 5 months
Stage Diagnosis	Stage 1 (*n* = 4), Stage 2 (*n* = 2)
Treatment Chosen	(*N*= 6) surgery (a radical prostectomy); (*n*=4) had robotic assisted surgery, and (*n*=1) had surgery plus radiation.
Initial Side Effects	(*n*=6) incontinence; (*n*=1) fatigue; (*n*=1) scar tissue; and (*n*=1) Proctitis (inflammation of the rectum).

Depression and Anxiety

There were eight categories under this section. When asked about depression and anxiety before their diagnosis, four participants answered no, one answered yes, and one did not answer. The next question asked who diagnosed them; the man who answered yes was diagnosed by a psychiatrist and in therapy with a social worker. The men also were asked if they experienced depression and anxiety during treatment. Five participants answered yes and one did not answer. Additionally, the participants were asked if they were still experiencing depression; four said yes; one said no. When asked if they were still in treatment, three answered yes; two answered no. The participants were also asked about whether or not their depression remitted over time. Two participants answered yes, two did not answer; for one the question did not apply; one man treated his depression by going to AA meetings. When asked approximately how long it (depression) took to go away; one man who said no answered that his therapist told him that he has developed an extremely high tolerance for unhappiness. For the final two, one man said it took several months to go away and another man indicated that it took at least 2 years to finally remit, and one did not answer.

Medications

Participants were also asked about the medications they were on presently. Only one man was not on medication. Responses included the following:

- A mixture of three drugs not named,
- Aspirin,
- Bupropion (antidepressant; Drugs.com, 2000/2005d),
- Zoloft (for depression; Drugs.com, 2000/2005j),
- Crestor (lowers high levels of cholesterol and triglycerides; Drugs.com, 2000/2005f),
- Ezetrol (cholesterol lowering; Drugs.com, 2000/2005g),
- Altace (treats high blood pressure; Drugs.com, 2000/2005b), and
- Cialis (erectile dysfunction; Drugs.com, 2000/2005e).

Data Analysis

Per the data analysis plan outlined in Chapter 3 and the suggestions of Smith et al. (2009), the steps that were employed were as follows:

1. The raw data was collected from participants’ essays and read for overall content. A line-by-line analysis was made from each participant’s comments.
2. The data was reread.

3. I made notes to gain familiarity with the information and its contextual meaning, attending to key objects in each writer’s narrative.
4. Excel spread sheets were used to code the data into themes, categories, descriptions, or definitions, as well as to make comments regarding understanding and explanations by participants.
5. I interpreted the meanings aligned with themes.
6. The themes were compared across participants looking for thematic commonalities.

The treatment of discrepant cases was coded into the spreadsheets, and it was decided from the literature to define the first one with regard to situational factors in the essays as the individual’s ability to control or comprehend the situation or event (Park, 2010). The other type of discrepant case included an overall lack of reconciliation between global and situational and was defined as a lack of coping between situation-specific events helps to either dispose individuals to or not to feeling stress in a particular event (Park, 2010). Furthermore, the information submitted was examined in order to look for commonalities as well as contrasts between participants with respect to some of the major themes.

Evidence of Trustworthiness

In Chapter 3, one of the methods described to increase the study’s trustworthiness was audit trails. The audit trail that was employed included the categories that Halpern (1983) deemed important:

1. Data summary and analysis that included summaries and notes;

2. Data synthesis that included themes, definitions, and their relationships; and
3. Notes relating to credibility, dependability, and confirmability.

Personal notes that described intentions, expectations, and predictions were not used as I had no expectations concerning the data nor any predictions about whether the data would agree with any of the theories presented or would provide an entirely new revelation as to the definitions of meaning in life by this particular group of prostate cancer survivors.

As for credibility, site triangulation was achieved by the participation of individuals from different sites or areas in order to help limit the effect that individuals from one particular area may have on the results. Dervin (1983) noted that when similar results emerge from a study, the data may have greater credibility in the eyes of the reader. Data provided from a group of people from different areas may be employed to provide the diversity that underpins Dervin's (1983) concept of "circling reality." She defined this as, "the necessity of obtaining a variety of perspectives in order to get a better, more stable view of 'reality' based on a wide spectrum of observations from a wide base of points in time-space" (Dervin, 1983, p. 7). This was accomplished as the group of men came from different states and backgrounds.

Results

In the following sections, I present the results from the study that are organized by research questions and then by themes. A total of six participants completed the entire study.

Defining Meaning in Life

In this section, I endeavors to answer Research Question 2. This question was designed to have the participant define the term rather than the researcher. The definition used in Chapter 1 of the study was the following: “Meaning in life has been regarded as being a positive state of well-being, indicating an individual’s ability to have goals, be engaged with others, and to be able to maintain strength in the face of challenges” (Steger et al., 2006; Ryff, 2000).

The answers to this question were as follows by participant:

P1: “Sharing intellectual and emotional times with others.”

P2: “Means what gives me purpose, makes me want to keep on going.”

P3: “I derive meaning and purpose from my faith as a Christian, as a husband to my wife, as a father to my children (two of four still live at home) I’m an author and writer with a ministry to those coping with prostate cancer. Finally I’m a businessman who runs two sandwich shops.”

P4: “Conscious living with a focus on meaningful relationships, giving back to others and taking advantage of life's opportunities. My place in the world was that of a caring deep person who modeled how to bounce back from life's challenges, with equanimity, and who was making conscious choices.”

P5:“Intellectually, I define that as being a good person, husband and father, being happy and enjoying the time that we have, and making a positive difference for other people. Emotionally, I have experienced great frustration throughout my life with my inability to understand why I don’t feel like I’m accomplishing any of those things.”

P6:"I have never been able to get a handle on the meaning of life."

A spread sheet was created using the definition above for this question and was divided into four categories. They were coded A = a positive state of well-being; B = individual's ability to have goals; C = being engaged with others; and D = being able to maintain strength in the face of challenges. All of the participants' answers except for one incorporated some or all of the aspects of the definition. This is seen as a validation of the quantitative research of Steger et al. (2006) and Ryff (2000). Of the four categories mentioned above, only one individual included all four aspects of the definition for meaning in life in his response. One other participant had three out of the four aspects, (A, B, & C) and two other participants also had three out of the four but they were different aspects of A, C, and D.

Meaning of life question discrepant case. The discrepant case for this question was the individual who stated, "I have never been able to get a handle on the meaning of life." This statement seems to indicate that the experiences of his journey through prostate cancer have not helped him to elucidate an answer to this question that he feels is satisfactory.

Life Before, During Treatment, and as a Survivor, Major Themes

This section deals with Research Questions 3 and 5. Participants reported changes over time in terms of how they viewed themselves, their place in the world, their relationships, their work life, and their spirituality. This section also deals with the different aspects of life experienced by survivors with respect to life changes noting the categories and commonalities that emerged from the data:

Your Life

Before diagnosis. All of the participants felt that their lives were either happy and life in general was good; none anticipated that their lives would include a diagnosis of cancer.

During and after treatment. After diagnosis, most of the participants became shocked and overwhelmed especially from the side effects of their surgery. One man summed up his feeling this way, “Deep down, I felt like my life as I knew it was ending, and I didn’t know how I was going to live with the consequences of my decision to proceed with the surgery.” Most of the participants did not really realize what their decisions to have a prostectomy really meant for them in the short and long terms.

As a survivor. Now as a survivor Participant 1 handles his life as a gay man differently. He says that he is **“**More selective about sex partners and honest about my situation.” One man feels that he has less motivation for ordinary activities. While he is “functioning,” Participant 6 is not finding joy or satisfaction in most day-to-day activities.” Participant 5 described his life as a survivor this way, “I feel not only like I have undergone decline, but that I am somewhat defective and freakish with such a central bodily function now gone.” Only Participant 3 shared that he is positive about the future saying that “my life, outlook and priorities all shifted for the better as a result of my experience with cancer.”

The Meaning Making Model advocated by Park and Folkman (1997) was ultimately the theoretical construct that most closely mirrored the results of this part of the study. While the other models cited in this study had merit, the Park and Folkman’s

(1997) Meaning Making Model seemed to integrate more of the aspects of the data points than did any of the other theories. The data in this study fit the theory's framework much better with regard to global, situational, and appraised meaning along with looking at the discrepancies in the data of each participant. The data analysis, demonstrated that the data fit this model better than any of the other models presented in Chapter 2.

Sexual Identity

Regardless of sexual orientation, all of the participants in the study wrote about the problems they had with sexual identity and problems with a "relationship with their body" in all three phases (before diagnosis, during treatment, and now as a survivor).

Before diagnosis. Whether the participants were gay or heterosexual, they saw themselves as sexual beings, which helped to define their beliefs about life and their participation in it. All of the participants saw themselves before diagnosis as sexually whole participants with normal lives regardless of the states of their relationships with spouses or partners. Most of the participants did not comment on their sex lives until their experience with prostate cancer. Many of them never gave their sexual identity much of a thought and took it as a rule for granted. Two participants however commented directly on their sex life: Participant 1 said, "I viewed myself as a healthy, happy, sexually active 50-something-year-old gay man" and Participant 3 said,

> My interest in sex was very high. On a 1-10 scale I'd say it was a 9.5 I could and would respond sexually meaning I could obtain an erection as a result of thinking about sex, talking about sex or seeing something sexually exciting…"

Participant 6 said his relationship with his wife “became almost hostile, since she tried to “fix” everything for me, and it was only causing more harm than good.” He went on to say that for him:

> Sex became something to get as much as possible, and at all costs, since I believed that it would be among the last times that it would ever happen. Not surprisingly, that further eroded the relationship with my wife. It became clear to me that I had to be around for her as she grew, even if it meant that the rest of my life would be unhappy. My wife tried to attend to me as much as possible, but I was feeling regret and profound sadness for what I had done. I was withdrawn and just wanted to be left alone.

During and after treatment. Many of the men in this study had so many embarrassing problems with incontinence and erectile dysfunction that during and after treatment the physical problems continued to be problematic to the point that their self-esteem and their mental health were affected.

Participant 6 said that he began spiraling down to hopelessness during his treatment and said,:

> I felt like my ability to exist and function as a man was gone forever, and that my sex life was over. I felt that I had been dealt a blow from which I might not be able to recover. The question of “why?” kept coming up, but there were no answers. Absolute hopelessness…

His comments suggest that the depth of his depression was very serious. His erectile dysfunction had affected his entire self image and he has still not recovered four years later.

Participant 4’s problems were so dramatic that his mother and his girlfriend made him promise that he would attend a prostate support group. At one of the meetings he experienced a very unhelpful discussion regarding the restoration of sexual functioning that was very disappointing to him and is evidenced by his comments:

> The speaker was a reconstruction Dr. I remember him saying I don't do treatment anymore.... They all lie to you and he went through the steps of trying to restore a functioning sex life. Not a pretty picture. He said he could restore a sex life but it would never be close to being the same. I never went back.

Participant 3 said that during and after his treatment, he was extremely depressed and that..

> Losing the ability to have a spontaneous erection was for me a devastating loss. Losing my desire for sex was another. I became so depressed I considered myself useless and thought my wife would be better off without me. I withdrew from her emotionally and physically. Her satisfaction in our relationship took a plunge and I was too depressed to care.

He also felt that “the loss of the ability to ejaculate hit me hard--it made me feel that my place in the world had been altered such that I no longer was like the other guys.” He tended to sum up the feelings most of the participants felt during and after treatment.

Many of the participants reported having problems with their relationship to their bodies. In many respects their bodies were not responding as before. Participant 4 noted: “My relationship with my own body was the first relationship change I had to deal with.

Losing the ability to have a spontaneous erection was for me a devastating loss. Losing my desire for sex was another.” Other men had similar reactions. Participant 5 who also had a heart attack previous to his prostate cancer said, “... all in all I felt that I had no control over my future in terms of health and that overall I was in decline.”

Some of the participants definitely wondered if they had done the right thing having surgery.

Participant 3 remarked that,

> It took close to 4 months before I regained urinary control. I’d need a pad for occasional leaks for a total of 19 months, but I did feel like I’d got my life back. Now I was ready to resume a physical relationship with my wife. I had no idea I was heading for a second emotional cliff and another bout with deep depression.

As a survivor. As their journey progressed into survivorship, participants continued to report problems with their bodies. Many overcame the problem of incontinence but the problems with erectile dysfunction continued for most of the participants.

Participant 2 reported that his attitude concerning his body and the cancer had changed. He remarked, “it’s almost like I never even had it (cancer); the only reminder of it is, unfortunately, my issues with erectile dysfunction. (Never had issues prior to my surgery).” For most of the men in this study issues such as erectile dysfunction were problematic during treatment and are now as survivors.

Problems with sexual identity began after surgery and for most of the participants have continued into survivorship. The comments provided by all of the participants demonstrate just how important their sexuality was to them before diagnosis and how different it is now as a survivor. Participant 4 actually used the word “eunuch.” He explained it this way: “I felt like I had become a eunuch. I felt that my life was over.” He felt that new relationships were definitely problematic. He said, “I tried dating... a couple of times... It did not work. There is not a lot of use for a 54 year old eunuch. It doesn't matter how good you look, how much you make. Physical performance is expected.”

Participant 5 felt that even though he has returned to normal which he defines as “no incontinence” and “return to sexual function,” he does not feel “triumphant” but rather that his former “masculine identity” has been stripped away due to his inability to ejaculate. Additionally he felt that he is constantly reminded of his cancer due to his ED (erectile dysfunction) issues that continue to be a problem.

He also said this about his problems with his sexuality:

> Perhaps because I feel less in control over my health, I tend to be a bit less tolerant of not having control in my relationships. As well, I feel that my wife wants me to want sex with her as if I still were 25 and that I'm meant to step up and perform, when in a way I'd rather be left alone in that area of my life.

Participant 5 also felt that perhaps an extra marital affair might be the answer explaining that his sexual relationship with his wife has become “distant and frustrating.” Sex with her has become less frequent due to these reasons:

> she is now in menopause and simply doesn't have the desire; it is less physically satisfying for me, and it takes far more stimulation than before the surgery; [and]

> it has become something that I need to prove to myself that I can still do (with varying degrees of success).

Relationships

During the period from diagnosis to survivorship, some of the participants lost businesses, family members, were victims of crime, spent time in jail, and had serious side effects from medications they were on during surgery and treatment. These participants' comments indicate that many feelings still remain problematic due to coping with a new "normal."

With spouses/partners and family. For some of the participants, problems in their relationships became more accentuated due to the diagnosis, treatment, and side effects of curing their cancer. While spouses and children tried to be supportive, the problems grew unabated anyway.

Before diagnosis. Most of the participants remarked that their relationships with family, friends, and coworkers were fine although several participants reported failed or failing relationships with a spouse/partner. Half of the participants who were married found their relationships with their wives were severely strained to the point of either considering divorce or an extra marital affair even before they were diagnosed or treatment began. For example, Participant 3 said that while his family could be described as a "typical family with two grown daughters, both doing well," his relationship with his wife " of 35 years" was "no real relationship" and "at times we were distant caused by the stress of work, but still hung together for whatever reason."

During and after treatment. Comments from the participants indicated that relationships with their wives were especially problematic after treatment such as “Our sex life went out the window because I was constantly dripping urine, and I was totally disgusted with this fact. I abandoned my wife both emotionally and physically.” Even after treatment life seemed to get better but not back to the way it was as indicated by the same participant and this comment,

Participant 3 felt that after treatment, “My marriage was very stressed and I was deeply convinced my wife would be much better off without me.” He also explained that after surgery his relationship ended: “The one area of my life that was lacking was my love life which had pretty much come to a roaring halt after the end of a 19 year relationship.”

Participant 5 saw all of his close relationships were affected by his cancer and that his family, especially the relationship with his children, would be different going forward:

> I also feel that this health event has set up a bit of a barrier in my close relationships because the reality is nobody wants to hear-or really could handle-the expression of the sorts of thoughts and feelings I have described even in answering these study questions. I also have been telling my children that they may not be able to count on me indefinitely to support their post-secondary education-that I may want to retire and that I don't want to work just to pay for their house down payments and/or to give them fancy weddings--it is time to look more after me.

Participant 6 described his relationship with his wife as having become more difficult during treatment:

> My relationship with my wife has become more distant and frustrating. She doesn't understand why the prostate cancer and the surgical treatment have affected me so adversely. She just thinks that I should be grateful that it was found and treated early.

However, Participant 1 talked about his family relationship in general, that he looked forward to “more years of good living…”

As a survivor. One participant explained that while his relationship issues started before he even got married and that they are still problematic today:

> I married my wife over 22 years ago, probably to avoid being lonely, since I apparently believed that I would never be able to find anyone else. My wife could never understand why I couldn’t do that [be closer to his stepdaughter], and it has been a point of contention throughout our entire marriage. We’ve given up trying to resolve that difference. At this point, the marriage will probably continue as-is, since neither of us have the energy nor desire to start over. How very sad for both of us…

Participant 3 saw a definite positive move for the better in his life after surgery. He was a Psychiatric Social Worker and his wife had experience as an Oncology nurse which helped both of them deal with the mental and physical issues surrounding his cancer and recovery. He deemed their experiences as being helpful while trying to cope with his cancer experience saying that:

> It’s been a much difficult journey than I ever expected and the impact of surgery still has some negative impact on our lives, BUT I believe my life, outlook and priorities all shifted for the better as a result of my experience with cancer.

Most of the participants had problematic relationships with their spouse or partners before their diagnoses of prostate cancer. The cancer in most of these instances exacerbated already fragile relationships, dissolving some and making others even more problematic. Only one individual seemed to have developed a more positive view of living with his spouse.

With friends, acquaintances, and coworkers. Relationships with friends, acquaintances and coworker were very problematic for most of the participants in this study. They found that being able to talk freely about their experiences was extremely difficult even though individuals faced with cancer really needed more support rather than less support.

Participant 4 said that his circle of friends was greatly “diminished” but that he thought it might be due to his realization of alcoholism and attending Alcoholics Anonymous. Just when individuals who are fighting cancer need support the most, many times people will draw back not wanting to really hear the truth that is expressed in the person’s feelings.

Participant 5 described it this way:

> [It] has set up a bit of a barrier in my close relationships because the reality is nobody wants to hear-or really could handle-the expression of the sorts of thoughts and feelings I have described even in answering these study questions.

Before diagnosis. As for these relationships with their acquaintances and friends, before diagnosis, they were described as being good. Their comments about friends and coworkers were mixed as well. Participant 3 remarked that he wanted to, “Spend more time with my wife, family and friends” however in the next section those relationships were problematic. Participant 1 felt that before diagnosis he had an, “Excellent support system with family and friends” and that did not change over time.

During and after treatment. Participant 3 said that he was a virtual recluse after his surgery and summed up his feelings this way:

> I had zero use for healthy friends and family. They were too busy being happy and grateful I was cured to understand how and why I was depressed. I didn’t want to see or speak with anyone outside the family for the time I was in diapers.

He continued describing his relationships with his family as a “bright spot” in his life but stated that his relationship with friends was definitely problematic after treatment.

As a survivor. Participant 4 explained about his relationship with his friends in this way, “My circle of friends has diminished greatly” however, he was not sure if it was due to his prostate cancer or his drinking. He also related that he had “grown closer to the family dog” after treatment and now as a survivor.

Feelings of not being able to talk openly with others came up in Participant 5’s comments. He related that he feels “in less in control over my health” and that he has tended to “be a bit less tolerant of not having control in my relationships.” Additionally, he felt that:

> [This] health event has set up a bit of a barrier in my close relationships because the reality is nobody wants to hear-or really could handle-the expression of the sorts of thoughts and feelings I have described even in answering these study questions.

After diagnosis, during treatment and even as a survivor, relationships with friends and coworkers changed from the way they were prior to diagnosis. Informing other people of their diagnosis was a challenge for many. Participant 5 summed up the problems encountered by many cancer patients. People who are healthy only want to hear good news; being able to talk freely about what the individual is experiencing that does not fit this criteria is extremely hard.

Work Life

On this question the group was split concerning job satisfaction and enjoyment before, during, and now as a survivor. For some of the participants, their relationships at work changed as well.

Before diagnosis. Not only was Participant 5 diagnosed with prostate cancer, he also had a heart attack before his diagnosis. While he recovered from both, he felt that his fellow coworkers viewed him very differently from before his health problems. Participant 4 said that "At the time I viewed my work as my work as scary but one hell of a lot of fun. I was calling the shots. I was applying all those things I had learned inside the corporation."

Two individuals felt their work was stagnated and they were extremely dissatisfied with it; Participant 2 commented that "My job, for the most part, has been simply a means to an end. I don't find it all that rewarding" while Participant 6 also felt dissatisfied as well before his diagnosis:

> For the last 10 years, I feel like I have been stagnating professionally and I don't know how to affect any changes. Overall, I have been frustrated that my career has been reduced to a pay-check with very little professional satisfaction.

During and after treatment. Participant 2 said that his boss made his recovery somewhat problematic saying:

> I got two months off from work after my surgery. I completely enjoyed the time to myself. At one point before my surgery my boss told me that she had looked online how long the recovery time for my surgery was simply six weeks; my urologist had told me I'd be out for eight to twelve weeks. I didn't like her doubting either my word or my doctor's. I have to say I did not miss my job or work while I was out on recovery.

After surgery, Participant 6 went back to work after only a week of recovery. While he was doing desk duty, he said that his relationship with his coworkers consisted of not having much interaction with them "other than to tell them I was OK (which may have been true physically, but certainly not emotionally)." During this time, he was under more stress when the company he was working for was bought out and many of his coworkers were let go without severance; fortunately he was not one of them. However, he went on to say that "it seemed like everything I had been working so hard to save was crumbling."

As a survivor. Work life changed again for some of the participants as they moved into survivorship. One individual was able to quit his full time job and get a part time job he loved; another man ran his own business saying that it "gave me flexible time to be with and enjoy time with his family." Another individual said that his work was something he "really looked forward to going to work or working on the projects that came my way."

Participant 6 who became unemployed felt when he became employed again:

> I was unemployed for about 5 months last year when the start-up company for which I was working went out of business. I finally found a new job 9 months ago, but I am not enjoying the work or the company environment. It has become solely a pay check and something to occupy my time. I am frustrated and sad that my career has deteriorated in this way. I have been looking for a new job, but my heart just isn't in it.

Just as in some of the other relationships, a number of participants were reported Being dissatisfied with their jobs as well. For men who are already experiencing problems with their identity as men, encountering problems with work compounds these difficult experiences. It is as if they cannot seem to get any balance back into their lives. Participant 6's comment that his "heart just isn't in it" referred to finding a new job; many of the men seem to be struggling with this kind of lack of interest or enthusiasm in many areas of their lives.

Your Place in the World

Most of the participants in this study had their places in the world change through the experience. They saw themselves as different people before their diagnosis. All of them had satisfying sex lives. Their work lives although not perfect were places that defined their abilities to gain notoriety and accomplishment. As Participant 5 explained it, “life was good.” Life certainly did not include a cancer diagnosis. The average age of the participants was not considered to be old; three were in their fifties and three were in their early sixties.

Before diagnosis. Participant 3 saw his place in the world and his life through the lens of his spirituality defining it this way:

> I’ve been a Christian for close to 30 years now and my understanding of my place in the world was based upon my biblical world view. I always believed God had a plan and purpose through my life. While I’ve made a few attempts to go in other directions than being a business owner those doors always seem to close, so it’s been my belief owning a business and having an opportunity to speak into the lives of my employees was a major part of my God ordained place in the world.

Participant 5 summed up his feelings about his place in the world with this comment: “I felt like my place in the world was that of a caring deep person who modeled how to bounce back from life's challenges, with equanimity, and who was making conscious choices.” Participant 5 also said this concerning his place in the world previous to his diagnosis:

> I sensed early on that I had a special place in the family. Yet it was a source of anxiety as well. Instead of being the long awaited son for my father, it felt as if I was my mother's male gift to her own father-his heir. It felt a little bit like she was The Queen and my father the non-royal Prince Phillip, with me as the royal heir by virtue of her status. It felt a little undeserved, as if I had somehow usurped my father's rightful place.

Other participants saw their lives as having and experiencing:

- P4 said, “If I worked hard or harder than most and played it smart life was pretty much set. I was finally going to get to build my vacation home on a piece of land I bought in Missouri.”
- P5 said, “I had an unexpected heart attack and cardiac arrest which I was lucky to survive. In the immediate aftermath I felt somewhat relieved as if this event would now exempt me from life's pressures including the career struggle. And I had an expectation that as someone who spent a lot of my time looking after others, now others would look after me.”
- P3 said, “I always believed God had a plan and purpose through this life.“

Only Participant 2 seemed to have a problem with envisioning his place in the world as indicated by the following:

> I am really not sure of the meaning of my life. Nine years ago I made an attempt to end my life, unsuccessfully, and was quite angry at not feeling like I had the choice of being in control of my life.

During and after treatment. While most of the participants actually considered their place in the world as changing, Participant 2 did not give it much consideration during his treatment and concentrated instead on survival. Participant 3 actually saw a theme running through his experiences and how he saw his place in the world. He thought his suffering was something he had to go through in order to give meaning to his experience and to help others:

> At some point in my deepest depression I became absolutely convinced I was going through a trial by fire in order to know, understand and help other men and couples cope with life after prostate surgery. This gave my suffering meaning and purpose. Even during dark times I found myself able to relate to other men in helpful ways as they experienced their dark times.

Participant 5 also saw his place in the world as only a challenge that was meaningful as well:

> I felt that I was going through a second life challenge and that all the work I had done since the first such challenge would serve me well, as indeed it did. I again resolved to "give back" by way of being a role model and volunteer with newly diagnosed men, and this indeed has happened.

In contrast, Participant 6’s experience lacked meaning and purpose during treatment: “[I felt] that I had been dealt a blow from which I might not be able to recover. The question of “why?” kept coming up, but there were no answers. Absolute hopelessness…”

As a survivor. Participant 5, who felt he had usurped his father's place before diagnosis, expressed that as a survivor even though he has triumphed over a heart attack and cancer, he felt defective and freakish:

> While to date I have been described as a "Triple Crown" winner on the basis of cancer control, no incontinence and return of sexual function, it doesn't quite feel that triumphant to me. I feel like the loss of the ability to ejaculate has taken away a part of my masculine identity. Whereas when I had a heart attack I viewed myself as a lucky survivor and resolved to change as many things for the better as I could, in this case I came away feeling a bit defeated and as if lifestyle changes I might make had no point to them. I feel not only like I have undergone decline, but that I am somewhat defective and freakish with such a central bodily function now gone.

Participant 6 felt very similarly saying that he finds he has "less motivation for ordinary activities;" although while he is "functioning," he still is "not finding joy or satisfaction in most day-to-day activities." Participant 4 was also having problems with functioning; while he wished to be "more compassionate and understanding," he realized that he has always had trust and boundary issues. As a survivor, he felt that "Lately my survival skills have kicked in and my level of trusting anybody has went to nil."

Spiritual Life

Before diagnosis. Participants showed a broad range of comments regarding spirituality. For example, Participant 1 stated: "At the time I was diagnosed, I felt a kinship with a higher power but was a lapsed Catholic. I have since returned to the

Church” while another individual noted, “I attend a gay friendly Catholic Church. I feel it is more social than spiritual. Others commented saying:

> P3: Living our lives consistent with biblical principles and maintaining a Christian model of family living and parenting has always been a defining role in our lives both before and after the diagnosis of prostate cancer.
>
> P4: My spiritual life was pretty much solid. I did not go to church regularly but prayed daily and said my thanks. I said lots of thanks. I thought all the crap I had learned and practiced growing up was paying off.

During and after treatment. For some individuals, spirituality did not change while for others it changed in ways such as getting closer to God. Participant 4 remarked that “I feel I am closer to God. I don't look at him as a punishing God anymore but one who just wants you to try to play nice and give thanks.” He went on to say, “I really did feel like I had discovered the roses and that I lived every day to its fullest with a full appreciation for what I was experiencing. Participant 2 expressed it this way:

> My faith has grown both stronger and deeper. When you come to grips with your own mortality and you realize it’s not just other people who die, and death becomes very personal and very real, your values and faith is tested in a new way.

As a survivor. Participant 6 expressed that while he was raised in the Jewish faith, today his faith is “non-existent.” He also said that he has not missed having a spiritual and religious life. Participant 5 spoke only of himself and no spiritual or religious entity. He said that he “felt like my place in the world was that of a caring deep person who modeled how to bounce back from life's challenges, with equanimity, and who was making conscious choices.“

While spirituality was one of the major themes it did not seem to be as important as one might have thought when facing such a major health incident. Only one of the men in the study felt guided by his spirituality and felt that it gave his life meaning even though he was facing this major health crisis. Most of the participants had spiritual backgrounds that were tentative at best and problematic at most in that some felt the religion they grew up with was not helpful.

Meaningful or Important Changes

This section deals with answering Research Question Four. While one participant became closer to friends and family and now treasures every day, others felt angry, sad, guilty, and reported having a difficult time just making it through a day. Participant 6’s comments indicated his inability to be sure about his inner self. He was not sure if much of his problem was due to previous self-esteem issues or whether it is the result of his experiences with prostate cancer. Some of the other participants are moving ahead and sharing their stories with others through interviews, articles, and websites.

Biggest Hurdle

This section was a subcategory of Research Question Four having to do with what participants saw as the biggest hurdle they faced. It produced a variety of responses. Two participants said their biggest hurdle was psychological. Both are still struggling with negative feelings and are trying to stay positive. Participant 6 said, “Trying to maintain a positive attitude has always been a significant struggle for me.” He went on to say that, “I hate what I've become, and I haven't found anyone or anything that has been able to help. I'm just tired of fighting.” This suggests that he would like to be helped but has not found anyone or anything that he feels will help him.

The final two participants commented that their biggest hurdle continues to be their ED. Erectile dysfunction was problematic with all of the participants in the beginning but other participants have either come to terms with it or it has resolved itself into an issue they can live with. These two participants listed it as their greatest hurdle.

For this question overall, the results were indicative of a struggle that continues years after being diagnosed. While some of the physical side effects have receded or discontinued, the mental, psychological, and emotional scars remain. While the shock of the diagnosis and treatment is less, the “new normal” is nothing like the “old normal.” These men are continually reminded that they have lost a piece of themselves because of this disease.

Summary

While the mental-emotional status of most of the men that participated in this study before surgery was good, for some of the others who had previous bouts of depression and even suicide attempts, the rigors of the physical, mental, and emotional side effects they experienced was overwhelming. At a time when these men needed to get closer to the individuals in their support systems, some found that it was just not possible. Others, however, found that their support systems stayed intact and actually were very beneficial.

Regardless of the research questions asked there were themes and commonalities that surfaced again and again in the writings of the study participants. The decision to have surgery not only removed the cancer but it also redefined these participants' sexual identity, their self-esteem and self-identity. Before surgery, their lives were basically good in a general sense. After surgery however, they all suffered indignities, mental and emotional strains, grief and loss. Some of them have been able to overcome many of the physical and mental problems presented by the disease but others have become stuck and have not moved on.

When these individuals did their research with respect to surgery and recovery, they did not anticipate many of the side effects to be as physically and mentally taxing as they were, especially concerning their sexual identities. These men did not think that after their surgery they would suffer in the ways that they have and as survivors would still be dealing with the issues years after surgery. As for being understood by people with whom they were closely related, some of the participants indicated that those people did not understand why they were not bouncing back to their former lives after their surgery. All of the participants commented that their experience with prostate cancer has changed them in different ways and some men have changed in many areas of their lives.

Additionally, these men did not feel that the possible mental and emotional side effects of surgery were adequately explained to them. While most of the men had positive attitudes going into surgery, the side effects quickly eroded that positivity. The reality of losing sexual function was one of the most important identity losses these men suffered. They really had no idea how much of their lives as men were based on that identity.

Many of their relationships have changed, but unfortunately not for the better throughout their experiences. While some reported their relationships becoming stronger, some of their relationships were not able to survive through problems such as depression.

This disease has significantly affected their relationships with their own bodies, as well as their personal and professional relationships with the people in their lives in ways not realized until after surgery. While many of the participants are still in relationships with their spouses, some are not. Those who still are in primary relationships note that their relationships have changed and that very few of the relationships improved throughout their experiences with prostate cancer.

In general, their relationships with family changed as well; some were better than before their diagnosis but not all. The participants felt that their acquaintances, friends, and coworker relationships were somewhat strained due to their diagnosis. Not being able to share their real feelings about what they were going through was problematic and resulted in more superficial relationships. Coworkers for some treated the men very differently than before their diagnosis.

Their work lives and work relationships were different as well. While most of the men stayed employed, their work lives were not satisfactory. A few of the men tried burying themselves in their work to avoid thinking about their lives during treatment and now as survivors. However, they tended to find this avoidance behavior to be unsatisfactory as well. Only a couple of men moved on to different work situations feeling better about their work lives in general; the majority of men however seemed stagnated in their employment and unable to move on to something that might provide more satisfaction.

For some men, their spiritual lives changed as well. While some made their way back to church and some kind of spiritual participation, others did not. And while the majority of men have begun to move forward in many aspects of their lives, others have not and now have non-existent faith lives.

Before diagnosis many of the men saw their place in the world very differently than after treatment and now as a survivor. Because they seemed to see themselves through the lens of their sexual identities, many of the participants' new "normal" is unfamiliar and unsatisfactory. They tended to look back at their previous lives as feeling more in control and intact.

The meaningful changes and biggest hurdles for many of the participants will be to try to retool and reimagine their lives in a more positive frame of reference. Presently, most of the men seem to be anchored to their experiences seeing only what they have lost and not what they have gained. Becoming whole physically as well as psychologically has been extremely challenging for most of the men.

Chapter Five will provide an interpretation of the findings with regard to the literature review in Chapter Two and will detail whether or not those findings support or diverge from the earlier research presented. Additionally, the final chapter will also discuss limitations of the study, implications for future research and implications for positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Previous quantitative research designs examining the construct of meaning in life have attempted to create a more uniform approach to assessing an individual’s view of meaning and the process of meaning making. In a review of the literature, the data gathered have not been able to adequately capture the complexity of the phenomenon of meaning in life. However, qualitative research is better able to delve more deeply into the subjective experiences of individuals (Park, 2010). The research with regard to meaning in life with prostate cancer survivors is limited at best, and the literature review revealed very few qualitative studies. This study was unique in its design in that it specifically considered men who are prostate cancer survivors, delving deeply into their descriptions of meaning, as well as exploring and comparing the differences and similarities across participants’ responses. The interpretation of the findings for Research Questions 2 through 5 are below.

Interpretation of the Findings

Research Question 2: Meaning in Life

Research Question 2 asked, “How do prostate survivors define meaning in life?” The main theme for the participants in answering this question was the importance of relationships although one participant reported being unable to define it throughout his life. Life roles such as being father, husband, friend, and work roles defined what meaning entailed for participants. The answers to this question also included beliefs regarding the importance of spirituality.

In the literature review in Chapter 2 regarding the theoretical constructs of meaning in life, meaning was described in terms of two broad categories (a) global meaning, which looks at the perceptions individuals use to determine their place in the world overall, and (b) situational meaning, which includes the perceptions individuals use to determine how to interpret situations (Skaggs & Barron, 2006). With respect to this theoretical construct, the participants' definitions for this question definitely fell into the global meaning category with regard to their relationships with family members, friends, acquaintances, and coworkers.

Skaggs and Barron (2006) suggested that for individuals who cannot determine what meaning in life means to them personally, there can be an initial stagnation due to an incomplete appraisal of global meaning. As a result, the process of analyzing the meaning in a particular situation is impeded, which may result in the inability to create more positive outcomes. This was true for the participant who could not define meaning in life initially in that the mental health questions showed he was definitely experiencing diminished psychological well-being.

Research Question 3

Research Question 3 asked the following: Prior to (a) diagnosis, (b) during treatment, and (c) now as a prostate cancer survivor, do participants report changes over time in terms of how they view themselves, their place in the world, their relationships, their work life, and/or their spirituality?

Six themes emerged from the data. They concerned life in general, sexual identity, relationships with others, work life, place in the world, and spiritual life.

Life before diagnosis centered on participants' reporting living relatively normal lives with the general ups and downs of daily living before their diagnosis. After diagnosis, the men's worlds were changed completely with most of the participants experiencing feelings of being shocked and overwhelmed. As survivors, while many of the men had worked through the physical and mental side effects associated with the disease, some were still reporting psychological problems, in particular depression.

Sexual identity was the most prominent theme, garnering significantly more data than any of the other categories or themes that emerged. All of the participants described their sexual lives before their diagnosis as normal. Their abilities to have erections and ejaculations were normal and they could have them as desired. After diagnosis, problems with incontinence, erections, ejaculations along with fatigue, embarrassment, and frustration became the norm for their sexual lives. These side effects took a great toll on the mental and emotional lives of the men. Even as survivors, some of the men have continued to have problems mentally and physically stemming in large part from their decision to have their prostates removed. Most of these men have come to regret this decision, despite knowing that their lives were likely saved by the procedure. Many felt that they were not apprised of how seriously the prostatectomy might contribute to these long-lasting side effects, leading them to feel they had been betrayed by their physicians.

While many of the physical side effects have gone away now that the men are survivors, they appear to still be grieving the loss of the identity they had of themselves before diagnosis. Some of the men believe they are now only partially men, feeling in some cases that they are "freaks," with little or no desire for sex or even intimacy. One can infer from what participants shared that this loss of sexual identity for the majority of these men constitutes an ongoing struggle to make meaning out of their cancer experience and their lives in general.

As noted above, participants' sexual identity problems also made some of their relationships problematic or exacerbated difficulties that were already present before diagnosis, in some cases ending the relationship altogether. The additional emotional toll this took was considerable. Some of the men could not accept help from their spouses, and some resented the expectations by spouses and friends that after surgery they should be happy, physically the same, and completely healthy mentally. Because this was not the case, many of the men began withdrawing further into themselves leaving their relationships to languish and in some cases die. Most of the participants' relationships with regard to other family members such as parents and children fared much better in that the support was typically given without expectations.

There were some complete changes in work lives as well. Some of the men lost jobs, found new ones, or came to the conclusion that their work lives were less than satisfactory. Relationships with coworkers for some were problematic and had definitely changed over the period of diagnosis and treatment. As survivors, some of the men felt as though their jobs had become joyless and a means to an end with regard to making money. Some men felt that the attitudes of coworkers and bosses had changed toward them because of their illness, and some felt unappreciated for the work they were doing or left out of consideration for projects or promotions.

Before diagnosis, they felt their position in life was relatively secure. After diagnosis and during treatment, however, the theme for most of the participants became survival. Surviving their disease was their primary goal and took much of their mental and emotional energy and time.

Now as survivors, for some of the participants, their place in the world has changed for the better relating that they have more feelings of compassion and empathy, and their goals in life have changed. Their perceptions of what was important about life shifted more to relationships. For many of the participants, a great epiphany with regard to their spiritual lives did not occur. Some did indeed decide to go back to the faith of their youth and attend religious services, but others did not see the value in having a spiritual life. For the ones who abandoned the religion they grew up with, they did not find solace in going back to that religion. For one participant whose faith played a major part in his life, he continued on as before in his faith and decided to make his experience a life's goal to help others. His cancer experience helped him to grow in his faith and to move confidently into the future.

As previously discussed in Chapter 2, the theoretical constructs of the meaning making model as proposed by Park and Folkman (1997) were particularly evident when examining the individual participants' comments regarding their relationships. According to Harper et al. (2007), the process of meaning making can be flexible in the beginning, but it can also turn into dysfunctional behaviors if the meanings are not productive (Harper et al., 2007). This process described by Harper et al. (2007) was seen in the answers from several of the participants, especially in the survivor phase; they were not able to reconstruct a sense of meaning in life and their answers showed the type of negative thoughts without finding meaning which indicated negative outcomes (Harper et al., 2007). There were many negative comments from the “during treatment” phase, which according to Harper et al. (2007), are to be expected; however, many of them continued into the “survivor” phase, which demonstrated that the making meaning process had not moved into the meaning made process.

Additionally, as discussed in Chapter 2, an individual’s adjustment to illness as proposed by Bloch et al. (2007) showed that adjustment to illness is a complicated issue. The present study also found that each of the men’s adjustment to their illness was clearly complicated by the impact of their diagnosis, treatment decisions, and side effects associated with the treatment. Quality of life issues regarding sexual identity, incontinence, and other issues produced additional confirmation of the study by Eton and Lepore (2002), who found that depending upon the type of treatment chosen, adjustment to the disease of prostate cancer was more difficult for men who chose surgery, as the men in this study did, due to the long lasting effects upon sexual function and identity that tend to persist over time.

Research Question 4 and 5

Research Question 4 asked the following: “What are the most meaningful or important changes (if any) participants have seen on their journey with prostate cancer before, during, and as a survivor?” Research Question 5 asked, “What are the commonalities and themes (if any) between survivors with respect to meaning in life changes during their journey with prostate cancer?”

The data from these questions were mixed. While some of the participants felt that they were able to reframe their experiences with prostate cancer more positively, others were much more negative, being at times overwhelmed by feelings of anger, sadness, and guilt. Most of the men felt lucky their cancer had been caught early, but the most important change for all the men again was the negative alterations in their sexual identity. This theme returned again and again in all of the questions.

When asked specifically about the "biggest hurdle" they had experienced, most reported that it was dealing with the experience psychologically, feeling that they were unable to stay positive and felt demoralized due to the short and long-term side effects. Feelings of lack of control, the inability to feel joy, and feelings that nothing was worth fighting for anymore were all experienced (and for many, continue to be experienced) as major hurdles.

In the literature review, appraised meaning, which is the assignment of meaning to a particular experience or event, was considered an integral construct of situational meaning. Each individual's experience with prostate cancer in this study was examined from the standpoint of whether or not the event was able to be influenced by the participant or whether their fear of the disease or threat from the disease (as in the case of side effects) produced problems that tended to predict the individual's ability to take back their lives and move on into the future (Aldwin, 2009; Sweeney, 2008).

Sweeney (2008) proposed that individuals make predictions through a lens appraising their situation and the people involved in those situations during the process of meaning making when they encounter "negative life events." The comments detailed in

Chapter 4, especially with regard to each man’s relationships and the hurdles they faced, demonstrated the interplay of the people in their lives to the elements of the negative life event, prostate cancer.

The different comments with respect to the themes and commonalities of the individual men and then the group as a whole demonstrated the automatic versus deliberate processes which are an integral part of the meaning-making model proposed by Park (2010) by demonstrating how each individual was able/unable to make meaning from their ability or lack thereof to cope with the disease and treatment. The recurring themes and commonalities showed the recurrence of troubling issues and thoughts in all of the comments made by the participants; it also showed their ability or inability to accept their situation as it progressed and whether they were able or not to move on with their lives.

The automatic or unconscious processing involved in meaning making has been suspected to help in reducing discrepant thoughts concerning events that are extremely intense such as trauma or disease. Examples of this are invasive thoughts or thought patterns that recur with frequency while individuals are trying to reconcile their appraised meaning regarding the stressful event such as cancer, the beliefs they hold about global meaning, and the beliefs they hold about life and the universe in general but also including their personal life goals (Lepore, 2001). On the other hand, the deliberate or conscious meaning making deals with situations from a more focused conventional coping style includes using “positive reappraisal,” goal revision and planning, as well as accessing past experiences and spiritual beliefs (Folkman, 1997).

While their sense of purpose and previous life goals shifted during the process, many of the men were able to accept the changes and move on. Those who were not able to move on demonstrated that they were not able to reconcile their present lives and relationships with their past. The goal of returning to their previously normal lives became blocked, making the process of acceptance and reframing difficult for most of the participants (Park, 2010).

Limitations of the Study

As discussed in Chapter 1, there were several limitations in this study: (a) lack of generalizability owing to the small sample size and age of participants; (b) potential that participants' memories were unreliable; (c) findings that may not generalize to other depressed men diagnosed with prostate cancer. Two additional limitations that were not mentioned in Chapter 1 are (a) that this study eliminated individuals diagnosed with Stage 4 or terminal cancer diagnoses. These individuals are in a protected class, and it was decided only to use individuals who were not considered to be terminal. Because of this limitation, the results may only apply to individuals who were diagnosed as Stages 1 or 2; (b) the group of participants in this study were all Caucasian, and it is therefore unclear the extent to which the results are applicable to other racial/ethnic groups.

Recommendations for Further Research

One suggestion for future research would be to conduct a similar study but follow participants for an extended period (e.g., 5 years) to examine whether participants' meaning-making continues to evolve over time. An example of why extending the study might be important can be found in the work of Park, Edmonson, Fenster, and Blank

(2008). While these researchers spoke of people reaching a “meaning made” stage, the data in the present study suggest that participants had not yet moved through the meaning-making process into Park et al.’s (2010) meanings made stages. Undertaking additional studies focused on the themes that emerged in this study (e.g., spirituality, sexual identity, and the emotional toll associated with the disease and its treatment) is recommended.

Larger groups of men, and especially men from other ethnicities, would provide a more rounded perspective of the issues presented in this study and new issues which might come to the forefront. The men in this study caught their cancer early because of screenings. Preventative care such as prostate exams and PSA tests for underserved minorities are some of the additional issues that could be explored with further research. Unfortunately, the U.S. Preventive Services Task Force has not recommended that PSA screenings be paid for as preventative tests in the Affordable Care Act (Hsieh, 2012). This will affect many minority men who cannot afford the cost of the screening and one of the major benefits, early detection, may be lost (National Cancer Institute, 2014). Their cancer may not be caught as quickly, which may lead to more mental and emotional distress for them and their families. This is an important issue that needs to be explored as well.

Implications

Positive Social Change

The participants in this study were very interested to know if the findings of this study could be provided to them. Some of them wanted to share the findings with other survivors as well as those who were facing a new diagnosis. The positive social impact of sharing feelings and experiences is a major value provided by this study. Not only does it provide a way to initiate conversations about the results of the study, it can also open up discussions on very personal issues that are of importance not only to individuals, but family members, organizations such as churches, and society as a whole.

This is the area in which social workers, therapists, psychologists, and other mental health professionals can begin to open a dialogue with clients and patients dealing with a diagnosis or the results of the treatments for this disease. The recommendations coming out of this study are to talk not just about the physical repercussions of the disease but the potential psychological and emotional toll the disease can take on the individual and others. Men want to talk and need to talk, but they may not know how to begin the discussion. Their feelings may be so intense that they will need the mental health practitioner to help start the discussion for them. The research questions that were asked and answered in this study create an excellent starting point in helping clients and patients sort through these feelings and put them into words. They also may provide a way to begin a discussion with spouses, partners, families, and friends.

One of the participants in this study spoke specifically about the expectations of the people around him. Because the cancer was gone, the expectations were that everything should be fine with him never realizing that the side effects of his treatment and the emotions that were swirling within him could possibly be problematic. They expected him to be happy and back to his “old self” by the time he came back to work. These expectations can set up a tremendous amount of psychological and emotional pain in the individual which ends up negatively impacting other relationships. Many times when family and friends see that the person is not responding in the ways they expected, they can react with impatience and judgment, even to the point of condemnation.

Therefore, based on these findings that prostate cancer and its treatment can give rise to a number of intra- as well as inter-personal challenges, one positive social change recommendation would be that psychoeducational classes focused on the myriad psychological and relational issues that can arise as a consequence of the disease and its treatment be made more readily available to patients as well as family members.

Conclusion

While the answers from the participants did not reference meaning in life directly, it was clear that they were speaking about issues that were meaningful to them. Additionally, their comments do speak to some of the components outlined in the theories presented in Chapter 2 and detail the issues the men had separately as well as corporately with regard to their experiences with prostate cancer. The Meaning Making Model advocated by Park and Folkman (1997) was ultimately the theoretical construct that most closely mirrored the results of this study. One important issue that emerged from participants' sharing was the psychological and emotional issues surrounding prostate cancer specifically and cancer in general. Further, the men in this study felt that they were not provided with this information from their physicians. Whether or not physicians need to provide this information or give patients access to mental health professionals to provide this information is something for the medical community to decide. However, the present study's findings suggest there is a clear need for this information to be provided to patients after diagnosis and before treatment as well as during the ensuing years of survivorship.

All of the men in this study needed and wanted to talk about the issues presented here and their feelings about those issues. They were given the opportunity to do just that in a nonjudgmental way through writing essays. These men were not interviewed in person so they were able to speak in a way that they could not speak with their most intimate companions or friends. They were able to express their thoughts and feelings firsthand in a confidential and profound way. I feel privileged to have been a part of these men's very personal revelations.

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Appendix A: Study Eligibility Questionnaire

Name: ____________________________________

Phone number: _______________________

Email address: ____________________________________

Date of Birth: ________________

1. Is English your first language: Yes/No
2. Do you have private access to a computer and to email (meaning not in a public place such as a library and not sharing with others)? Yes/No
3. Are you comfortable writing fairly extensive essays about yourself and your feelings? Yes/No
4. What date did you cease treatment for prostate cancer? _________________

Appendix B: Consent to Participate in a Research Study, Walden University

TITLE OF STUDY: The Impact of Prostate Cancer on Survivors' Sense of Meaning in Life

1. **PRINCIPAL INVESTIGATOR:** Carol Brady, a doctoral student at Walden University.

2. **WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH?** You are being invited to take part in this research because you are an adult, between the ages of 18 and 65, who accessed this survey through a solicitation by the researcher and has had prostate cancer.

3. **WHO IS DOING THE STUDY?** Carol Brady is conducting this research study.

4. **WHAT IS THE PURPOSE OF THIS STUDY?** The purpose of this study is to better understand what makes people's lives feel meaningful by asking people about their experiences in life with regard to their diagnosis and survivorship of prostate cancer.

5. **WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?** This study will take place by answering questions which will be emailed to you. You will be asked to complete three groups of essay questions, and the total amount of time should be no longer than two hours.

6. **WHAT WILL I BE ASKED TO DO?** In this research, you will be asked to complete a background/demographic questionnaire and essay questions regarding meaning in life, your relationships, and your experiences with prostate cancer.

7. **STUDY CRITERIA:** You should not take part in this study if you are older than 65 and younger than 18 years old, have not been out of treatment for prostate cancer for at least 1 year, do not have access to a private email address and a private computer or if you believe that answering questions about your experiences will distress you.

8. **WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?** There are no foreseeable risks other than possible discomfort in answering personal questions. If you are uncomfortable answering any question, you may skip it or stop participation at any time. There may also be unforeseen risks. The following clinic contacts have been provided in case you should experience any discomfort during or at the end of the study. Please print out this list for future reference:

All these clinics are no fee for service or sliding scale:

[PLACE HOLDER FOR CLINICS LOCAL TO PARTICIPANT]

9. **ARE THERE ANY BENEFITS FROM TAKING PART IN THIS STUDY?** The possible benefits of this study include improved understanding of what makes people's lives feel meaningful and helping other survivors through the gathering of these data. The information collected may not benefit you directly.

10. **AM I REQUIRED TO TAKE PART IN THE STUDY?** No, your participation in this research is completely voluntary. If you decide to participate in the study, you may withdraw your consent and stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

11. **PRIVACY: WHO WILL SEE THE INFORMATION THAT I GIVE?** Your information will be combined with information from other people taking part in the study. If the researcher writes about the study to share it with other researchers, it will involve the combined information that has been gathered. You will not be identified in these written materials. The researcher may publish the results of this study and will keep any possible identifying information private. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure on an encrypted hard drive in a locked file cabinet. Data will be kept for a period of at least 5 years, as required by the university.

12. **WHAT IF I HAVE QUESTIONS?** Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Carol Brady. If you would like to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her number is 1-800-925-3368, extension 3121210. Walden University's approval number for this study is 01-30-14-0230953 and it expires on January 29, 2015.

13. **WHAT ELSE DO I NEED TO KNOW?** If you agree to participate in this study please reply to this e-mail with the words "I Consent." This acknowledges that you have read the information stated and willingly sign this form giving your consent to participate in this study and you may print a copy of this document at this time for your records.

Appendix C: Demographic/Background Questionnaire

Please answer the following questions and email them back to: Thank you!

Name:

Address: **City:** **State:** **Zip:**

Phone number:

Email address:

Marital Status: Single/Married/Divorced/Separated/Widower/Partner (circle)

Ethnic background:

African American/ Asian/ Caucasian/ Hispanic / Native American / Other please state: ____________

What is your highest grade of education/degree?

____

Religion/Spirituality:

1. What is your religious/spiritual orientation?
2. Do you attend regular services? Y/N
3. If so how many times per week.

Questions concerning your cancer and its treatment:

1. Who do you consider to be the most important people in your support system and why? If you do not have a support system, please explain why.
2. Have you experienced a recent crisis (such as a fire, death in your family, crime, or anything that would cause mental distress)?
3. What stage were you when you were first diagnosed as having prostate cancer? I/ II/ III/ IV

4. What kind of treatment for your cancer did you choose?
5. Did you experience any side effects? If so what were they (physically, emotionally, and mentally)? Please explain all in as much detail as possible.
6. Are you still experiencing side effects from your treatment? If so, please explain them in detail.
7. What has been the biggest hurdle(s) for you during treatment and now as a survivor?
8. Have you experienced depression or anxiety previous to your cancer diagnosis? Yes/No
    a. If yes, were you diagnosed with depression by a mental health professional or medical doctor? Yes/No If yes, which one diagnosed you?
    b. Were you treated for your depression? Yes/No
    If yes, please indicate the treatment (such as counseling, medication, in-patient care etc).
9. Have you experienced depression during your cancer experience? Yes/No
If yes, were you diagnosed with depression by a mental health professional or medical doctor? Yes/No If yes, which one diagnosed you?
    a. Were you treated for your depression? Yes/No
        i. If yes, please indicate the treatment (such as counseling, medication, in-patient care etc).

        - ii. If you were not treated for your depression are you still depressed?

          Yes/No

    - b. If you were not treated for your depression, did it go away over time?

      Yes/No

        - i. If yes, approximately how long did it take to go away?

10. Are you on medications presently? Yes/No

    - a. If yes, please state name of medication and dosage.

Appendix D: Extended Online Questionnaire Rounds 1, 2, & 3

Round 1:

The questions are as follows:

1. How would you define the term “meaning in life” today?

Before your diagnosis.

1. Please tell me the story of your life before you were diagnosed. Please include these following sections in your essay:
    a. How did you view yourself before your diagnosis?
    b. How did you view your relationships?
    c. How did you view your work?
    d. How did you view your understanding of your life and your place in the world?
    e. How did you view your spiritual life if any?

Round 2: During Treatment

1. Please tell me about your experiences and the impact of those experience during this period of time. Please include these following sections in your essay:
    a. How did you view yourself while in treatment?
    b. How did you view your relationships while in treatment did they change?
    c. If you were able to work during treatment how did you view your work?
    d. How did you view your understanding of your life and your place in the world during treatment?

   e. How did you view your spiritual life if any during treatment?

Round 3: Now as a survivor.

1. Now that you are living as a cancer survivor:
   a. Do you feel anything about you has changed? If so, in what ways?
   b. Do you feel anything about your relationships has changed? If so, in what ways?
   c. Do you feel anything about your work has changed? If so, in what ways?
   d. Do you feel anything about your understanding of your life and your place in the world has changed? If so, in what ways?
   e. Do you feel anything about your spiritual life has changed? If so, in what ways?
2. Do you feel that what you consider most meaningful or important has changed at all since going through cancer diagnosis and treatment? If so, in what ways?
3. What have been the biggest hurdle(s) for you now as a survivor?

Curriculum Vitae

Carol L. Brady, M.A.

EDUCATION

Expected 2016	Doctor of Philosophy – Clinical Psychology, ***Walden University,*** *Minneapolis, Minnesota*
2009	Master of Arts – Counseling, ***Colorado Christian University,*** *Denver, CO*
2002	Bachelor of Science – Business, ***Bellevue University,*** *Bellevue, NE*

RELEVANT PROFESSIONAL EXPERIENCE

April 2014 ***Guest Lecturer***
Liberty University

In January, I was asked by a Dr. Ray Crawford, a professor at Liberty University to be a guest lecturer for his undergraduate class in Research Design. The lecture was on the qualitative research, why it is important, and how to design a qualitative research study.

2013 – Present ***Principal Investigator***

The project concerns, The Impact of Prostate Cancer on Survivors' Sense of Meaning in Life. It is a qualitative study examining how the encounter with prostate cancer impacts a man's sense of well-being and what they consider valuable, important and meaningful in life. This project is in the data analysis phase presently.

2013 – Present ***Principal Investigator***

The project concerns Anxiety, Depression, and Quality of Life Satisfaction in Occupational Retirees, which is a quantitative study that will use a Manova statistical analysis design to determine what if any relationships there are between anxiety, depression and the quality of life satisfaction in individuals over 65 who cannot retire due to various circumstances. Presently, this study is in the proposal phase.

2011-2012 ***Research Assistant***

The project was Enhancing System Integration of Families as Change Agents. Principal investigator: Donna M. L. Heretick, Ph.D. $10,000 Funded grant through Walden Faculty Initiative Grant (FRIG), 2011. Survey and focus group investigation of processes of developing and enhancing vocal empowerment for individuals involved in advocacy work on behalf of families, in accordance with Colorado HB-1451. It was a joint project with the Colorado Collaborative Management Program and the Colorado Federation of Families for Children's Mental Health.

ASSOCIATED PROFESSIONAL EXPERIENCE

2008-2009 ***Substance Abuse Counselor***
Creative Counseling Services

Responsible for completing intakes for court mandated substance abuse offenders. Individual therapy one-on-one with mental health clients that included case management of client's files determining the best route of therapy for each client. Interface with court system, probation, and parole officers; performed testing and assessments using the SASI, ASI (Addiction Severity Index), and performed breathalyzers on clients and dispensed anabuse to clients.

MEMBERSHIPS IN PROFESSIONAL ORGANIZATIONS

American Psychological Association, Student Member
American Psychological Association Division 12, Student Member
Society of Clinical Geropsychology, Student Member
International Psycho-Oncology Society, Member in Training
International Positive Psychology Association, Charter Member
Gerontological Society of America, Member
Western Psychological Association, Member

HONORS AND AWARDS

Psi Chi Honor Society, Walden University
Laude Honors: Summa Cum Laude, Bellevue University

PROFESSIONAL WORKSHOPS

- CAC1 Workshop: Addictions Counseling for Substance Abuse Clients, April, 2008
- PTSD & Co-Occurring Addiction Symposium, February 8, 2010
- Co-Occurring Training Series, Contingency Management, September 28, 2010

ADDITIONAL EDUCATION CLASSES

- Psychology of Aging
- Psychology of Death and Dying
- Cognitive Behavioral Therapy and the Elderly
- Dementia and Neuropsychological Disorders
- Clinical Geropsychology
- Public Policy and the Elderly
- Special Topics in Gerontology

- Multicultural Aspects of Aging
- Long-Term Care and the Elderly

CERTIFICATIONS:

Certification in Gerontology (44 hours), July, 2012

CEUs

Nutrition and Physical Activity Guidelines for Cancer Survivors

PUBLICATIONS

Brady, C. L. (2013). Understanding learning styles. *International Journal of Childbirth Education*, 28(2), 17-19.