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Walden University

College of Counselor Education & Supervision

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Luis Lacourt

has been found to be complete and satisfactory in all respects,
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Walden University
2018

Abstract

A Phenomenological Exploration into the Resiliency of Prostate Cancer Survivors

by

Luis E. Lacourt

MS, Wright State University, 1994

BS, Cincinnati Christian University, 1991

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Counselor Education and Supervision

Walden University

March 2018

Abstract

Scholarly articles related to the physical and emotional effects of prostate cancer treatment and survivorship are abundant. However, few researchers have explored resiliency of prostate cancer survivors through their recovery and survivorship experience. There is a gap in the literature regarding resilience through the lived experiences of prostate cancer survivors. Counselor educators could be better prepared to teach counselors to promote the resilience needs of prostate cancer survivors. The purpose of this hermeneutic phenomenological qualitative study was to explore and describe the lived experiences of prostate cancer survivors. Coding analysis of data collected from interviews of 7 participants generated 3 major themes and 30 subthemes of experiences. Themes included experiences and feelings surrounding the cancer diagnosis, descriptions of resilience, and the personal growth the participants gained from their experiences. The results of this study give voice to their challenges and offer insight into how prostate cancer survivors find meaning while adapting constructively to adversity and resilience. A clearer understanding of these experiences may promote understanding of the prostate cancer experience for men, offer insight for promoting resilience among prostate cancer survivors, and give clues to the experiences of other populations responding to cancer.

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Dedication

This paper is dedicated to my Father Luis, my Grandfather Luis, and my Uncle Freddy. They taught me to fight back against prostate cancer with courage and dignity.

Acknowledgments

I would like to thank my wife Chris for her years of patience and support as I have pursued this dream. Thanks as well to our kids, Kaylee, Madeline, Logan, Josephine, and Jason for supporting me through this journey.

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Chapter 1: Introduction to the Study

Scholarly articles related to the physical side effects and emotional effects of prostate cancer treatment and survivorship are abundant; however, few researchers have explored the lived experiences regarding resiliency of prostate cancer survivors through their recovery and survivorship experience. There is a gap in the literature regarding resilience of prostate cancer survivors. Little is known about how prostate cancer survivors experience resilience or posttraumatic growth from their cancer experiences and counselors may promote resilience or beneficial gains for clients. Counselor educators could be better prepared to teach counselors to promote the resilience needs of prostate cancer survivors.

In this chapter, I introduced the reader to the central aspects of this research. The chapter explained the problem, the focus of this study, and the compelling need for this research to be completed. The Background section placed this study in the context of previous research by describing the prevalence of prostate cancer, its social and emotional impact, the presence of depression for prostate cancer survivors, the nature of resilience, and the beneficial aspects of resilience for prostate cancer survivors. Theoretical underpinnings guiding my conceptual framework and study approach are reviewed in the Framework section. The research questions identified the key concepts and phenomenon being investigated and indicate the methodology as qualitative in nature. The Nature of the Study section identified the research approach and offered a rationale and methodology for such approach. The Definitions section explained terms related to the phenomenology that may not be common knowledge.

Problem Statement

Although prostate cancer (PC) is the second most common cancer in men (Siegel, Naishadham, & Jemal, 2013), there is a gap in the literature regarding resilience through the lived experiences of PC survivors. Experiences with cancer have been associated with lower quality of life scores, greater psychological distress, and more mental health needs (Weaver et al., 2012). In addition, cancer survivors have reported experiencing symptoms of depression (Sharpley et al., 2014), anxiety (Pereira, Figueiredo, & Fincham, 2012), despair (Lundquist, 2013), Post Traumatic Stress Disorder (PTSD; Abbey, Thompson, Hickish, & Heathcote, 2015; Rustad, David, & Currier, 2012), and fear of cancer recurrence (Simard et al., 2013). For men, the PC diagnosis and experiences also carry a perceived loss in masculinity (Sharpley, Bitsika, & Denham, 2014; Zaider, Manne, Nelson, Mulhall, & Kissane, 2012), social stigma (Carlsson et al., 2013), and shame (Lehuluante & Fransson, 2014). Improvements in medical treatment, earlier diagnosis, and higher life expectancy rates mean there are more prostate cancer survivors alive today than years ago and it is expected this population will continue to grow (De Moor, 2013; DeSantis et al., 2014). The growing population of prostate cancer survivors reflects a growing need to understand the experiences and needs of these survivors. Understanding this unique population may also contribute to discovering how to promote resilience and post traumatic growth.

Little is known about how PC survivors experience resilience or post-traumatic growth from their cancer experiences, and how counselors may promote resilience or beneficial gains for clients. This gap in the literature poses a problem for counselor

educators because without this information, they are limited in their ability to properly train counselors on how to treat this population more effectively. Current treatment efforts lack the insight of lived experience and are limited. A better understanding of lived experiences will help counselors understand how to better alleviate the suffering of PC survivors by promoting resilience and post-traumatic growth more effectively.

Purpose Statement

The purpose of this hermeneutic phenomenological qualitative study was to reveal the lived experiences of PC survivors and explore the ascribed meanings held by the participants. The results of this study will elucidate the phenomena in the fullness, essence, and meaning intended by the participants. The results will also give voice to PC survivors' challenges and offer insight into how these men found meaning and adapted constructively to their adversity.

Significance

A better understanding of PC survivors' experiences regarding resilience in response to their cancer diagnosis and treatment may offer helpful treatment insights to counselors, counselor educators, urologists, oncologists, and social workers. Participant interview responses may illustrate how resilience interacts with and buffers the negative emotional effects caused by cancer. Exploring survivor experiences may help counselor educators better prepare counselors to promote the resilience of other PC survivors. Awareness and a better understanding of PC survivors' experiences with resilience may also help family members, group leaders, and the public to support and promote similar resilient responses from the PC survivors in their lives. Learning about the resilient

responses and the rich meaning derived by survivors may offer hope and inspiration to other PC survivors. Interviews focusing on resilient responses may help interviewees give voice to their story and reframe their experiences to better reflect the emotions associated with their resilient response. Instead of identifying themselves as victims of their cancer, survivors could experience their stories through the lens of a resilient perspective.

Identifying their stories and themselves with resilience may contribute to an emancipatory freedom that may enable them to better advocate for themselves and give them the desire to promote such in other survivors.

By learning to encourage resilience, counselors may be able to assist PC survivors to engage in personal advocacy and community social action. Social change and community education may prompt men to take proactive steps to practice better self-care, discover and seek treatment for cancer at earlier stages, and experience longer lives.

Background

Selected articles relating to the problem and impact of prostate cancer for men and the nature of resiliency are described here:

Framework

Two frameworks, Heideggerian philosophy and social constructivism theory, offer a contextual lens for this study. Edmund Husserl and Martin Heidegger created phenomenology as a philosophy and methodology for revealing a phenomenon (van Manen, 2014). Husserl (1990) said that phenomenology was the practice of revealing the essence of a phenomenon as it was originally experienced by those describing the phenomenon. Heidegger (2010) said that researchers should understand the phenomena

with the original meaning ascribed to the phenomena by those who initially experienced it. Consistent with Heideggerian philosophy this research approach helps researchers and readers understand and reveal the original essence of a phenomenon from the perspective of those who originally experienced it. Heideggerian philosophy intersects with social constructivism theory in that both perspectives permit participants to construct their own understanding of reality (Lincoln, Lynham, & Guba, 2011).

Participant interviews were consistent with phenomenological inquiry as they sought to learn the essence of a phenomenon from the perspective of those who experienced it (Patton, 2015). The phenomenological inquiry was consistent with the social constructivist theory through open ended questions that did not guide or impose meaning on to their experience. Multiple interviewees yielding varied experiences and different meanings added complexity and depth to the research.

Resilience theories have conceptualized resilience as both trait and process. When described as a trait, Kim and Yoo (2010) list a series of qualities they believe contribute to resilience: Intrapersonal qualities of intimacy, sensitivity, and cooperation. Interpersonal qualities of resilience are positive self-concept, confidence, and optimism (Kim & Yoo, 2010). Coping qualities of resilience are flexibility, responsibility, resourcefulness, and autonomy. Lee and Cranford (2008) however describe resilience more like a process of successful coping. Bonano (2004) supports this notion by describing resilience as a stable equilibrium despite adversity and trauma. Leipold and Greve (2009) also promote that resilience is better described as a process of recovery to

previous functioning. These concepts may illustrate the structure or process of resilience, but they do not capture the raw essence of the survivor's experience.

Research Questions

RQ1: What are the lived experiences regarding resilience for men who are survivors of PC?

RQ2: What does resilience mean to men who are survivors of PC?

RQ3: How do survivors of PC experience post-traumatic growth?

Nature of the Study

Qualitative

This research project was a qualitative hermeneutic phenomenological inquiry into the lived experiences of prostate cancer survivors. Qualitative research focuses on the language, stories, perceptions, and descriptions of the interviewee as such will be appropriate for research that seeks to describe a shared experience (Osborne, 1990). This hermeneutic phenomenological study specifically focused on the participants' interpretation of the phenomena and the meaning of the language used to reveal the essence of the participant's experience. The specific focus of men's response to PC was chosen in hope that it might yield insights into men's experiences of resilience in response to their cancer diagnosis and treatment. The seven participants offered insights into lived experiences surrounding their cancer discovery, treatment decisions, treatment experiences, and adjusting to life after treatment. They discussed resilience at length, reporting how their resilience was encouraged, what they did as a result of resilience, and what resilience looked like or what it meant to them.

Limitations. Several limitations to this study existed. One limitation was that the participants must have experienced the phenomena and be willing to talk about their experiences. PC is a personal experience that men may not be open to discussing. Another limitation of the study was that the interviews focused on the participants' social and emotional experiences regarding their diagnosis and response to PC. The data collection interview with each participant was subject to each participant's time constraints. Due to the smaller sample size and the nature of the data collected, the findings of this study may not be applied universally to all cancer survivors, nor all PC survivors. However, the lived experiences of PC survivors may offer insights into the experiences of other men or women with different cancers or diseases. I provided rich and thorough descriptions of the setting, the participants, their experiences, and the context. Researcher bias is also a threat to the study outcomes. Great care was taken to identify my own biases and open myself up to accountability with my research committee to ensure that I could be a neutral yet active part of the research process.

Assumptions. This section will identify the assumptions that underlie this study. Human beings are unique and have their own personal perspectives. Human beings are free to make choices. Realities are multiple, interrelated, and coexisting within distinct contexts. As in any domain of multiple realities, no single truth can be drawn from the lived experience of any group of PC survivors. Insights into the experiences of men responding to a PC diagnosis can be gained from their own accounts of their lived experiences. Men's responses to PC are personal decisions that will be respected and not judged based on personal values or morality. A decision to not seek treatment is as valid

of a response to PC as a decision to seek treatment. Both responses carry lived experience and meanings for the participant. Finally, it is assumed that the participants in the study will respond honestly.

Possible Types and Sources of Information or Data

Hermeneutic phenomenological research benefits from the recollections and descriptions of individuals who have experienced the phenomena (van Manen, 2015). These firsthand descriptions offer a purer and raw form of data (Osborne, 1990). For the purposes of this study, semistructured in-depth interviews were conducted with PC survivors who were diagnosed with PC more than 6 months prior to the research date but less than 5 years before the research date. I interviewed seven survivors and reached saturation of data. Patton (2015) indicated that “There are no rules for sample size in qualitative inquiry” (p. 184). Participants were invited to participate through a flyer delivered to PC support groups in northeastern Ohio. I conducted in-depth interviews, took field notes (to describe context, affect, etc.), and invited the PC survivors to present any artifacts that exemplified their experiences of resilience.

Possible Analytical Strategies

Interested participants were informed of the nature of the study and invited to complete an informed consent form in order to participate. To preserve privacy, participant names were not used and the participants were assigned and referred to by different first names in the transcriptions. The interviews were recorded with an electronic audio recorder and backed up to a secure server to protect the data from being erased. Transcribed data will be held for 5 years, the minimum required by the university.

The interviews were audiotaped, transcribed, and analyzed with data analysis software. Atlas.ti, a data analysis program, and Prezi, a web-based online presentation tool, were used for coding, analyzing, and organizing the data. Coding and thematic unmasking was an iterative process during which findings were triangulated with additional data and my committee members.

Definitions

The following definitions came from the National Cancer Institute (NCI):

Cancer: A term for diseases in which abnormal cells divide without control and invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems (NCI, 2016a).

Cancer survivor: One who remains alive and continues to function during and after overcoming cancer. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life (NCI, 2016a).

Prostate cancer (PC): Cancer that forms in tissues of the prostate (a gland in the male reproductive system found below the bladder and in front of the rectum). PC usually occurs in older men (NCI, 2016a).

Prostatectomy: Surgery to remove part or all of the prostate and some of the tissue around it. Nearby lymph nodes may also be removed. It may be done through an open prostatectomy, in which an incision is made in the wall of the lower abdomen or the perineum, or by using a laparoscope, a thin, tube-like instrument with a light and lens for viewing (NCI, 2016a).

Prostate Gland: A gland in the male reproductive system. The prostate surrounds the part of the urethra (the tube that empties the bladder) just below the bladder, and produces a fluid that forms part of the semen (NCI, 2016a).

Prostate specific antigen (PSA): A protein made by the prostate gland and found in the blood. Prostate-specific antigen blood levels may be higher than normal in men who have PC, benign prostatic hyperplasia (BPH), or infection or inflammation of the prostate gland (NCI, 2016a).

Summary

This chapter introduced the background, purpose of the study, and theoretical framework for this study regarding the resiliency of PC survivors. The research questions, qualitative research methodology, and definitions were also reviewed. Chapter 2 will provide a review of the literature to identify what has been written about PC, masculinity, resilience, and post-traumatic growth.

Chapter 2: Literature Review

The purpose of this research was to explore and describe the lived experiences of PC survivors. This chapter presents a review of the extant literature associated with this study. Four salient constructs surrounding this phenomenon of PC survivorship are PC, masculinity, resilience, and post-traumatic growth. First, I will provide some background on the nature of PC and its physical and emotional impact on men. Next, I will explore the construct of masculinity through gender development theory and other theories describing masculinity. This will be elucidated through a review of the literature regarding men's beliefs about masculinity and the cultural influences reinforcing their healthcare practices. I will demonstrate how these beliefs and cultural norms contribute to poor health seeking behavior and leave men more vulnerable to the effects of PC. Next, I will identify gaps in the literature with respect to understanding the experiences of PC survivors and how understanding these lived experiences can give clues that will promote resilience in the lives of current survivors. Finally, I will review the research methods used to study resilience and post-traumatic growth in relation to PC survivorship and the literature related to phenomenological research, and promote why hermeneutic phenomenology is the most appropriate approach to answering my research questions.

The relevant literature for this review was discovered and identified through the use of the following online search engines and library databases: Google Scholar, EBSCOhost Multi-Database Search, the Thoreau Multiple Database Search Tool, and Academic Search Complete. The following is a limited list of the key search terms used to review the literature: *Prostate cancer, prostate cancer physical side effects, prostate*

cancer emotional side effects, cancer impact on mental health, prostate cancer impact on masculinity, prostate cancer depression, gender development theories, masculinity resilience, men at risk behaviors, post-traumatic growth cancer, resilience definition, and resilience lived experience. The Zotero browser extension and standalone program were used to save and organize resources. Using Zotero, I created the following folders as main folders with additional sub folders underneath: cancer impact on mental health, cancer population, men, prostate cancer, post-traumatic growth, and resiliency.

My iterative search process was a cyclical four step process of: 1) identifying my key concepts, 2) conducting a search with key terms, 3) analyzing my search results, and 4) revising my search terms to get more specific results. Once I reached a relevant subtopic, I identified the key concepts of that subtopic and begin the process again. For example, a key search term was *prostate cancer*. Next, I searched with Google Scholar, limiting results from the past 6 years. I analyzed the results for relevance and saved the relevant results to Zotero. I continued to get more specific results and filled the gaps in my research by revising my search statements. For example, after searching for prostate cancer, I searched for the mental health impact of prostate cancer by adding the following terms to the words prostate cancer: *emotional side effects, depression, anxiety, and marriage*. Revising my terms gave me more specific subtopics to explore and new opportunities to reidentify the key topics under the subtopics. When a specific search yielded limited results, I altered the search by changing the date limitations, using term synonyms, and trying alternative search engines and databases to intentionally look for different results.

Prostate Cancer

Prostate Gland

In this section, I will offer definitions and background regarding the prostate gland, the nature of PC, its prevalence, treatment, and the residual impact on men. The prostate gland is positioned below the bladder and in front of the rectum. It is one part of the male reproductive system creating semen and operating like a sphincter valve to release either urine or semen through the urethra. Starting at the bladder, the urethra travels through the center of the prostate gland (Guzzo, Malkowicz, Vaughn, & Wein, 2014). Like a female ovary, the prostate is an internal organ with no sensation for men indicating its presence. The prostate gland will generally go unnoticed. As men age, the prostate naturally grows larger, sometimes restricting urine flow through the urethra for older men, a condition called benign prostatic hyperplasia (Guzzo et al., 2014). For many men, this condition may be the first trigger of concern for their prostate gland.

Cancer in the prostate gland. Cancer is caused by the splitting and proliferation of abnormal cells (NCI, 2016a). When these cells split and grow within the prostate gland, it is considered PC. The abnormal cancer cells will group together, creating a tumor growing within the gland. Since early PC development has no accompanying symptoms, it often goes unnoticed for many men. In its first stage (Localized stage) the tumor and its cancer cells are contained or localized to the prostate cancer. At the second stage of cancer development (Regional stage), the tumor's growth will pierce through the outside membrane of the prostate gland, releasing cancer cells to other organs in the

region. The third and final stage (Distant stage) is the continued spread and development of cancer cells through the blood stream into the rest of the body, causing eventual death.

PSA. The healthy prostate gland releases a PSA into the blood system to protect the prostate and help it fight off infection, illness, or cancer. The development of abnormal cancer cells causes the prostate gland to produce more PSA to fight off the intrusion of the abnormal cancer cells. Attained through a standard blood draw and lab measurement, PSA levels have been found to be an effective indicator of prostate health (Guzzo et al., 2014). PSA is a measurement of the number of nanograms of the antigen per milliliter (ng/mL) of blood. A PSA measurement below 4 ng/mL has been associated with a healthier prostate, while a higher score may indicate that the antigen is fighting off an infection or cancer (Thompson et al., 2004). While a higher PSA measurement is generally associated with a higher likelihood of the presence of cancer, the PSA measurement will also vary with age, as it is normal for younger men to have a lower PSA score and for that score to gradually increase with age and the growing size of the gland. The American Cancer Society (ACS, 2013) recommended men get their PSA score checked at the age of 50 and once a year thereafter to establish a baseline score over several years. A baseline score can give the urologist and client a benchmark from which to evaluate future score results in the case the numbers change dramatically. The PSA score can also be influenced by sexual activity, health, and physical activity like riding a bike (ACS, 2013).

PSA controversy. In 2012, the U.S. Preventive Services Task Force (USPSTF) recommended against regular PSA screening for men under 50 and stated that more men

would be harmed by the screening than helped (Moyer, 2012). The USPSTF is an independent volunteer panel of national experts in prevention and evidence-based medicine who offer medical recommendations for Americans. The USPSTF's recommendation was controversial because it was in direct contradiction with the recommendation from the ACS (2012), and the Prostate Cancer Roundtable (2012) who recommended screening should start between the ages of 40 and 45. The ACS (2012) and the Prostate Cancer Round Table (2012) reported that early screening, has led to earlier detection, earlier treatment, and more lives saved from an early death to prostate cancer. They also expressed that the recommended delay in screening would contribute to later detection and deaths among some men, and create confusion about when men should begin getting checked for PC.

Since its discovery, the PSA test has become the most popular indicator of prostate cancer. While deaths from prostate cancer have decreased significantly since the inception of the PSA test, the USPSTF discovered that higher PSA scores have contributed to unnecessary biopsies which have caused needless distress and infection in men from the procedure (Moyer, 2012). While a PSA is not the only screening method, it is more convenient and more often preferred by men than the digital rectal exam (ACS, 2013). The PSA score however is subject to variability from activity, health, and differences in lab procedures. Its validity has met increasing skepticism within the medical community promoting further research to discover more accurate predictors of cancer activity in the prostate gland (Eccleston, 2015). Currently, various other testing

procedures are being explored but none have reached the level of acceptance and widespread support as the PSA test.

Prevalence

PC is the second most common cancer in men (Siegel, Naishadham, & Jemal, 2013), second only to skin cancer. According to the ACS, 1 in 6 men will be diagnosed with PC in their lifetime (ACS, 2013). It was estimated that during 2013, there would be 238,590 new cases of PC and 29,720 deaths from PC in the United States (Siegel, Naishadham, & Jemal, 2013). Worldwide this translates to around 913,000 newly diagnosed cases of PC with around 258,000 deaths per year from PC (Ferlay et al., 2010). Furthermore, it is estimated there are 2.5 million men in the United States who are living survivors of PC (ACS, 2013; De Moor, et al., 2013). This is significant because PC survivors may experience physical side effects, emotional distress, social barriers, and lowered Quality of Life scores (Harden et al., 2013; Kim, Baker, & Spillers, 2007). Understanding their experience; and how to promote a resilience that will help them respond to cancer will be a relevant discovery to them, their partners, medical caregivers, counselors, and counselor educators.

Differences among survivors. *Ethnicity.* While many men have been affected by PC, their experiences with PC are nuanced by their ethnicity, the stage at which they were diagnosed, and their age (ACS, 2013). Differences in incidence and survivability rates based on ethnicity have been identified in the United States. According to the ACS (2013), African American men have a 63% higher incidence rate than non-Hispanic White men and are more than twice as likely to die from PC than White men. Asian

American men have a lower risk of PC than white men, but have a higher risk than their counterparts in living in Asia (ACS, 2013). Hispanics also have a lower incidence rate, and lower death rate than non-Hispanic White males (ACS, 2012). Researchers seem to agree that outside of genetics there is no clear explanation for the variance in the incidence rates (ACS, 2013; Barr, 2014; Peate, 2011).

Stage. The stage at which men were diagnosed may affect their experience with PC. Summary staging, adopted by the American Cancer Society (2015), categorizes the cancers into stages named Localized, Regional, and Distant to reflect the cancers' progress from its point of origin. Localized stage reflects a cancer contained to a specific gland or organ where it began. Regional stage reflects a cancer spread from the primary site to nearby organs or tissues. Distant stage reflects a cancer spread to distant areas of the body away from the original site (National Cancer Institute [NCI], 2015). Research indicates that, regardless of ethnicity, men who are diagnosed with PC at the localized or regional stages have a nearly 100% five-year survivability rate (Siegel, Naishadham, & Jemal, 2013); however, men diagnosed at the distant stage only have around a 30% five-year survivability rate (Siegel, Naishadham, & Jemal, 2013). This indicates that, as with other cancers, early discovery contributes to more effective treatment and recovery.

Age. A man's age at the time of his diagnosis may also affect his experience. Age is the most reliable risk factor for prostate cancer (ACS, 2012). PC is rare among men under 40 years of age but the risk for PC rises as men age. Men in the ages of 40-59 have a 1 in 37 chance of being diagnosed with PC. Men 60-69 have a 1 in 15 chance of being diagnosed and a 1 in 8 chance for men who are 70 or older (Siegel, Naishadham, &

Jemal, 2013). The age at which PC is diagnosed will also affect treatment choice as older men are more likely to be diagnosed with higher risk PC and are more likely to participate in hormone reduction therapy (Bechis, Carroll, & Cooperberg, 2011).

Gay and bisexual men. Prostate cancer remains severely under-researched among the gay, bisexual, and other men who have sex with men (GBM) population (Simon Rosser et al., 2016). Preliminary research indicates that the rate of prostate cancer in GBM is the same as other men; however, GBM appear to be screened for prostate cancer less than their cohorts (Arrington, 2012; Simon Rosser et al., 2016).

Growing trend. Two additional factors affecting the prevalence of PC and the growing need for exploration are life longevity and medical treatment progress. Improvements in medical treatment, earlier diagnosis, and higher life expectancy rates mean there are more cancer survivors alive today than years ago and it is expected this population will continue to grow (DeSantis et al., 2014). While there were less than 4 million Americans with a history of cancer in the U.S. in 1977 (DeMoor 2013), DeSantis (et al., 2014) estimated there would be over 14 million in 2014, and predicted nearly 19 million by 2019. The current 2.5 million prostate cancer survivors in the United States may likely grow by 238,000 new diagnoses per year (ACS, 2013; De Moor, 2013). Considering the longer life expectancy of the current survivors, the number of men with a history of PC promises to continue to grow for many years to come (De Moor, 2013).

As the number of men with PC increases, so does the importance to understand their needs and how they are affected by PC (Guy et al., 2013). Rowland (2008) indicated that being cancer free does not mean being free from the effects of cancer. While the

cancer diagnosis and treatment are stressful, the transition into post-treatment survivorship can also be very stressful (Rowland, 2008). Understanding how men are affected by PC will give insights into their adaptive responses and may reveal clues about their experience with resilience.

Impact on Men

Physical. First, I will briefly review the physical impact of PC, and will then move into the known psychological and emotional side effects of PC. Since many more men died with PC than from PC, it has generally been considered a slow growing cancer (ACS, 2014). If left untreated, however, localized PC is known to progress to regional and distant stages in which it may ultimately cause death. Various treatments are available for prostate cancer but they each have adverse side effects for men to consider in their decision making.

Treatment Options. The most common treatments for PC are radical prostatectomy, radiation therapy, hormone treatment, and active surveillance, though it is not uncommon for certain men to require a combination of multiple treatments (Bolla et al., 2012; Jones et al., 2011; Thompson et al., 2013; Warde et al., 2012). While different forms of treatment may achieve success eradicating cancer, the collateral damage of cancer and its treatment produce unintended often detrimental physical and emotional side effects for men. This is significant to this study, as it underscores the physical and emotional hardship experienced by men with prostate cancer. I will briefly explain these treatments and their side effects below.

A radical prostatectomy is the surgical removal of the prostate gland, seminal vesicles, and sometimes other tissue. This procedure may be the best choice for men whose cancer is localized and contained to the prostate gland. The four main types of radical prostatectomies are 1) open retropubic prostatectomy, 2) open perineal prostatectomy, 3) laparoscopic prostatectomy, and 4) robot-assisted laparoscopic prostatectomy (National Comprehensive Cancer Network, 2015). All of these surgeries remove the prostate gland by cutting the urethra at the base of the bladder (directly above the prostate gland) and at the base of the prostate gland, and by cutting around the gland. If the nerves surrounding the gland are cancer-free, doctors often spare these to preserve the ability for a natural erection and sensation. After removing the prostate, the urethra is reattached to the bladder and a catheter is inserted into the urethra to allow it to heal for 1-2 weeks. The four different surgeries reflect the type of incision, the location of the incision, and how the procedure is done. The two open prostatectomies involve a cut to the belly (retropubic cut is 4-5 inches long) or to the perineum (perineal cut is 2-3 inches long) to access and remove the prostate gland. The physical recovery time for men undergoing an open incision prostatectomy is 4-6 weeks, during which time patients are released to go home with a catheter and are instructed to walk for exercise and rest. The two laparoscopic prostatectomies involve small cuts where tools are inserted to see, cut, and remove tissue. The robotic-assisted laparoscopic procedure allows for more precise cuts. In a study comparing the recovery of patients undergoing an open prostatectomy with those undergoing a robot-assisted radical prostatectomy (RARP), showed that the men who underwent RARP experienced shorter recovery time, faster return of

continence, and more nerve-sparing surgery (Geraerts et al., 2013). With only a 3% likelihood of recurrence after 10 years, this treatment has proven to be very effective at removing localized cancer (Han et al., 2003). However, men who undergo this procedure generally experience urinary incontinence, erectile dysfunction, and penile shortening (Benson, Avern, & Levine 2009; Gontero et al., 2007; Hunter, Glazener, & Moore, 2007; Messaoudi, Menard, Ripert, Parquet, & Staerman, 2011; Resnick et al., 2013). Up to 90% of men who undergo a radical prostatectomy experience erectile dysfunction after surgery (Mullhall, 2009). Other side effects of this procedure may include pain during orgasm, the inability to have an orgasm, limited bladder, and bowel control. Most men experience a reduction of these side effects within months of surgery. The symptom severity and recovery will depend on the patient's age, their condition before surgery, and whether the nerves were damaged or removed during surgery (Frey, Sønksen, Jakobsen, & Fode, 2014; Neff, et al., 2013).

Physical side effects of a prostatectomy are associated with lower quality of life scores, treatment regret, and depression for men (Bill-Axelson et al., 2013; Holm, Fossa, Hedlund, & Dahl, 2013; Ratcliff, Cohen, Pettaway, & Parker, 2013). Holm, Fossa, Hedlund, and Dahl (2013) surveyed 85 patients in treatment for post-prostatectomy incontinence at a median follow-up time of 26 months and discovered that 35% reported poor quality of life that was more strongly associated with depression than with urinary or sexual problems. Hart et al. (2014), surveyed 92 gay men with prostate cancer who reported lower health-related quality of life scores that were associated with “worse

functioning and more severe bother scores on urinary, bowel, (and) hormonal symptom scales” (p. 2308).

Ratcliff, Cohen, Pettaway, & Parker (2013) collected self-report data from 159 men, 3 months before surgery to establish a baseline and 12 months after surgery.

Results indicated that poorer sexual ($\beta = 0.32$, $p = 0.003$) and urinary ($\beta = 0.321$, $p < 0.001$) functioning was associated with poorer MCS (Mental Health Composite Score). Poorer bowel function was associated with poorer PCS (Physical Health Composite Score) ($\beta = 0.306$, $p = 0.001$) (p. 3340).

The multiple regression analyses of Ratcliff, Cohen, Pettaway, & Parker (2013), revealed that among these men, poorer sexual and urinary functioning was associated with poorer mental health composite scores, lower quality of life, and greater treatment regret. Bill-Axelson et al., (2013), conducted an 8-year longitudinal study to compare the symptom burden and distress in men who received radical prostatectomy with those who participated in watchful waiting. Researchers used odds ratios (OR) to compare both populations and revealed that undergoing a radical prostatectomy was associated with more urinary leakage (OR: 8.92; CI, 95%, 5.26–15.1), more difficulties with intercourse (OR: 3.97; 95%, 2.51–6.30), more difficulties with erection (OR: 4.19; CI 95%, 2.63–6.68), and more anger or bitterness (OR: 1.07; CI, 95%, 0.62–1.86) in comparison to the watchful waiting control group. In spite of the differences, both groups reported that cancer contributed to health-related distress and a negative influence on their daily activities.

Radiation therapy is a cancer treatment that kills cancer cells and stops new ones from being made through intense energy waves and energy particles (National Comprehensive Cancer Network, 2015). Radiation treatments can be delivered from an external beam or from seeds that are surgically placed directly into the prostate gland. External beam treatment plans target the tumor through customized dosage, the shape of the radiation beam, and the number of sessions based on the tumor size and location. Patients may undergo 40-45 sessions, at 5-10 minutes per session, one session per day. The seed treatment, known as *brachytherapy* can be delivered as a permanent low-dose rate (LDR) or as a temporary high-dose rate (HDR). The LDR brachytherapy treatment inserts 40-100 seeds containing radiation into the prostate. The seeds release the low-dosage of radiation for weeks or months. The HDR brachytherapy treatment is shorter term radiation that is administered through a catheter over a 1-2 day hospital stay. External beam radiation therapy or brachytherapy have been used alone but the patient survivability rates have seen an increase when the treatments are combined with one another or with hormone therapy (Jones et al., 2011, Warde et al., 2012). Potential side effects associated with radiation therapy are incontinence, erectile dysfunction, bowel complications, penile shortening, urinary incontinence, and urinary obstruction (Fransson & Widmark, 2007; Haliloglu, Baltaci, & Yaman, 2007).

One treatment shown to inhibit the growth of prostate cancer and reduce tumor size is the reduction of testosterone in men (Kumar et al., 2006). This treatment has many forms, but its common purpose in prostate cancer treatment is to stop the testicles from making testosterone. The treatment is effective because prostate cancer grows in the

presence of testosterone (Guzzo, Malkowicz, Vaughn, & Wein, 2014). Hot flashes, loss of libido, fatigue, gynecomastia, anemia, and osteoporosis are recognized side effects of this hormone treatment (Kumar et al., 2006; Saylor & Smith, 2009). Chipperfield et al., (2013) surveyed 377 prostate cancer survivors categorized into four groups based on the treatment they received. All the men had received a form of radiation but different durations of hormone treatment. The results showed that 1) the longer that men were on hormone treatment the more likely they were to report lower quality of life scores and 2) men on hormone treatment for indefinite periods reported the highest scores for depression and anxiety. This is consistent with the findings of Sanda et al., (2008) who recorded the outcome surveys of 1201 patients and 625 spouses and discovered that “Adjuvant hormone therapy was associated with worse outcomes across multiple quality-of-life domains among patients receiving brachytherapy or radiotherapy” (p. 1250).

Finally, active surveillance, also known as *watchful waiting* (WW) is a strategy to monitor the progression of the PC through regular PSA checks and biopsies (Parker, 2004). Other than the potential progression of the disease, there are no physical side effects from active surveillance as it is not a direct treatment but a monitoring procedure. Bill-Axelson et al., (2013) compared the symptoms of burden and distress reported by 136 men who underwent a radical prostatectomy (RP) compared to 136 men who participated in WW over an eight-year period. While the men in the RP group reported urinary incontinence, and erectile dysfunction, the men in the WW group reported symptoms of erectile dysfunction becoming more problematic over time. “Health-related distress, worry, feeling low, and insomnia were consistently reported by approximately

30–40% in both groups” (p. 920). All the men in both groups reported that their cancer negatively influenced their daily activities.

Although different treatment may have different success rates, approaches, and differing side effects, studies comparing the treatments results consistently report that men experience a diminished quality of life scores regardless of the treatment they select (Sanda et al., 2008; Zelefsky et al., 2016). While it is well established in the medical community that PC can have a devastating physical impact on men’s urinary and sexual functioning, its impact on men emotionally is less understood.

Emotional impact. In spite of medical advances in cancer care and improvements in cancer survivability rates, cancer remains one of the most feared diseases and is commonly equated with death across many cultures (Lagnado, 2008). Interviewee, Daniel, explained, “...[cancer] made me face death, although I’m not about to die I think the big C is synonymous with death and you know everybody is wondering whether you are going to die soon or not” (Connerty & Knott, 2013, p.339). Cancer survivors have reported lower quality of life scores, greater psychologic distress, and more mental health needs than their peers without cancer (Weaver et al., 2012). In addition, the cancer experience has been associated with symptoms of depression (Sharpley et al., 2014), anxiety (Pereira, Figueiredo, & Fincham, 2012), despair (Lundquist, 2013), Post Traumatic Stress Disorder (Abbey, Thompson, Hickish, Heathcote, 2015; Rustad, David, Currier, 2012), and fear of cancer recurrence (Simard, et al., 2013). For men, the PC diagnosis and experience contains these same symptoms but also carries a perceived loss in masculinity (Sharpley, Bitsika, & Denham, 2014; Zaidler, Manne, Nelson, Mulhall, &

Kissane, 2012), social stigma (Carlsson et al., 2013), and shame (Lehluante & Fransson, 2014). The following will focus on depression as it is the most prominently researched emotional side effect of PC.

A significant and growing body of research has established that prostate cancer survivors (PCS) have a higher incidence of depression and are at a higher risk for suicide (Bennett & Badger, 2005; Bitsika, Sharpley, & Christie, 2009; Chipperfield, et al., 2013; Jayadevappa, Malkowicz, Chhatre, Johnson, & Gallo, 2012; Sharpley, Bitsika, & Christie, 2013; Sharpley, Bitsika, Wootten, & Christie, 2014). There seems to be a growing interest in research on PCS's experience with depression. A recent Google Scholar search of publications dated from 1991-2000 for the terms "depression" and "prostate cancer" yielded 5,520 articles. Dated from 2001-2010 the same search yielded 18,600 publications. In the shorter and more recent span of 2011-2015, the same search yielded 18,300 publications supporting the premise of a growing interest in and research of the survivors' experience with depression.

In spite of this research, estimates on the incidence of depression in prostate cancer survivors still vary considerably (Jayadevappa Malkowicz, Chhatre, Johnson, & Gallo, 2012; Sharpley, Bitsika, & Christie, 2013c). Jayadevappa et al. (2012) conducted a retrospective cohort design using the Surveillance, Epidemiology, and End Results-Medicare(SEERM) linked database. After reviewing the records of 50,147 prostate cancer patients they discovered 4,285 (8.54%) were diagnosed with depression after treatment. On the other end, Sharpley, Bitsika, and Christie (2013c) conducted a self-report survey of 507 PC survivors where 45.7% of them had responses indicating a

clinically significant score for one of five depression subtypes. Köhler et al., (2014) conducted a multi-center longitudinal study in Germany where 329 PCS completed a Hospital Anxiety and Depression Scale, before a radical prostatectomy, and at 3, 6, and 12 months after surgery. While their study did not reveal a statistical difference in the reported levels anxiety or depression between the PCS and the reference group, they did discover that between 8%-20% of the participants reported psychological distress during two measurement points. Efforts to get a definitive number of PC survivors coping with depression are challenged by the need for honesty in men's self-reports, the fact that all men do not seek treatment, and the lack of research of depression in minority populations. It is important to note, however, that even the lowest estimates of men with this condition present a significant burden on health care resources. Using the SEERM database, Jayadevappa et al. (2012) discovered that men diagnosed with depression were more likely to visit an emergency room, require hospitalization, visit their doctor (outpatient), and more likely to suffer earlier death than the non-depression PC survivors. As a result, the healthcare costs related to depression were higher than the costs for the survivors without depression.

Sharpley, Bitsika, and Christie (2011; 2013a; 2013b) proposed that PC survivors are more likely to present a depression that is characterized by anhedonia. Sharpley, Bitsika, and Christie (2013a) surveyed 526 PC survivors with the Zung Self-Rating Depression Scale and grouped questions into subsets to specifically measure depressed mood and anhedonia or the inability to feel pleasure. Of the 526 participants, 126 met the criteria for clinically significant depression.

Patients (N=152) who fell into this more severe category of depression had a mean score of 1.961 (SD = 0.481) for depressed mood (median = 2.00, mode = 2.00), and a mean score of 3.175 (SD = 0.597) for anhedonia (median = 3.33, mode = 3.33). ... (p. 1722)

The study revealed that, among this group, PC survivors were 25 times more likely to experience anhedonia than depressed mood. Further research into these results (2013c) revealed various subtypes of depression (anhedonia, depressed mood, cognitive, melancholic, and somatic) represented in PC survivors. The many subtypes in existence and their unique pathology suggest they may require subtly different forms of treatment consideration. Furthermore, they recommended that care providers take the time to assess the type of depression and apply an ideographic approach to treatment instead of a one size fits all treatment approach to the depression of PCS.

Bennett and Badger (2005) reviewed the literature on depression and prostate cancer from the 1990s to 2004 and found agreement in the literature about the predictive factors of depression. They explained that PCS were more likely to experience depression if they were in the advanced stage of the disease with prominent cancer symptoms, if they experienced more side-effects from treatment, and if they had a previous history of depression. Bitsika, Sharpley, and Christie (2009) supported these findings in that they determined that coping with the new cancer symptoms was the source of depression for many men. Chipperfield et al. (2013) also discovered that survivors with comorbid physical conditions were more likely to experience anxiety and depression.

Allensworth-Davies et al., (2016) surveyed 111 gay PCS to discover that younger men, in particular, suffered from lower masculine self-esteem scores that the writers believed were associated with loss of sexual function and severe stigma. Thomas, Wootten, and Robinson (2013) explored the experiences of GBM diagnosed with PC through an online focus group to learn that the themes of *incontinence, sexual changes on identity, changed sexual relationships, healthcare professional*, had a connecting subtheme of the *stigma* attached to them.

PC has also been associated with higher risk for suicide ideation and suicide deaths (Carlsson et al., 2013; Lehuluante & Frasson, 2014; Llorente et al., 2005). Based on self-report surveys with 3,165 PCS, Lehuluante and Frasson (2014) revealed a significant relationship between suicide ideation and reduced health-related quality of life. Information from the Prostate Cancer database in Sweden of 105,736 PCS reflected a higher risk of suicide for PCS with metastasized cancer than for those with low-risk cancer (Carlsson et al., 2013). A 2005 retrospective cohort review of men 65 and older in South Florida contrasted prostate cancer-related suicides with the same age and gender-specific suicide rate. Llorente et al., (2005) discovered that of 667 suicides, 20 were related to prostate cancer.

The average annual incidence of suicide for men was 55.32 per 100,000 persons, but for men with prostate cancer, the rate was 274.7 per 100,000. The risk of suicide in men with prostate cancer was 4.24 times that of an age-and-gender specific cohort” (p. 195).

These statistics support the need for further research into how to help these men cope with the emotional impact of PC.

Social impact. Research has shown that PC has not only affected men physically and emotionally but that PC has also affected many men socially. Next, I will explore the research showing how PC has affected men's work, partner relationship, and perception of their own masculinity within the context and implications of the social experience of gender. Research reveals there may be generalized common gender-based social responses to health and a cancer diagnosis which have contributed to social norms for men and women (Saltonstall, 1993; Courtenay, 2009). By contrasting these populations, I hope to offer a background from which to understand the social experience of PCS.

Masculine norms promote isolation over help seeking. In her germinal phenomenological study, Saltonstall (1993) reported that gender was a significant predictor of how we cope and respond to health. According to Saltonstall, women's coping behaviors were associated with traditional feminine caring responses, whereas men's responses were associated with traditional masculine stoic responses. Interview reports of health behaviors were so "colored" (p. 12) by gender, she suggested that health is a form of *doing gender*.

Women have increasingly been associated with prevention and health promotion, while men have been associated with risk-taking health behaviors (Courtenay, 2009). The phrase "boys don't cry" seems to reinforce the norm that men are expected to be strong and not ask for help (Vogel, Heimerdinger-Edwards, Hammer, & Hubbard, 2011). Mahalik, Good, and Englar-Carlson (2003) explained that men may be less likely to seek

help because they may be acting out of a “Strong and Silent Script” (p. 124) of masculinity, or a “Tough-Guy Script” (p. 124) of masculinity. Both of these scripts promote a masculinity of stoicism, and self-denial which may inhibit help seeking.

Further illustrating how stoicism inhibited help seeking, Verdonk, Seesing, and de Rijk (2010) conducted interviews with 13 Dutch male employees about their healthcare beliefs and workplace activities. The men agreed that “men are not whiners, and ideally not vulnerable” (p. 712) and that taking care of one’s health was a feminine endeavour. Ironically, while men have been diagnosed with cancer more than women (ACS, 2012; White et al. 2011) and have poorer prognosis and survival rates than women (White et al. 2011), they are less likely than women to participate in a cancer rehabilitation program (Handberg, Lomborg, Nielsen, Oliffe, and Midtgaard, 2015). In a survey of male prostate and female breast cancer survivors, men reported higher scores of perceived stigma, self-blame, anger, and depressed affect over their diagnosis than the women reported (Else-Quest, LoConte, Schiller, & Hyde, 2009). While offering and seeking support may be consistent with a traditionally feminine role, research shows that many men perceive these behaviors to demonstrations of weakness, dependence, or femininity (Courtenay, 2009; Verdonk, Seesing, & de Rijk, 2010; Vogel, Heimerdinger-Edwards, Hammer, & Hubbard, 2011).

Masculine norms discourage communication, interaction, and education. The traditional masculine stoic norm discourages open disclosure, communication, and help-seeking behavior among men (Courtenay, 2009; Saltonstall, 1993). As a result, men are less likely than women to find a cancer role model (e.g. a prostate cancer survivor) who

may offer advice or influence their beliefs and decisions (OliFFE, et al., 2009). Lack of communication with family and peers promotes an atmosphere in which men cope alone isolated from others with limited guidance or information. In contrast, women have done a much better job of reaching out to and advocating for one another. It may be as a result of this collaboration that women have a stronger media presence and receive more research money (Kedrowski & Sarow, 2007).

Compared to women's cancers, men's cancers are underrepresented in the media (Gough, 2006). Us Too, a national prostate cancer advocacy organization, estimated there have been 2.6 times as many news stories about breast cancer than about prostate cancer. They surveyed and found that between 1996-2006, ABC news aired 895 stories on breast cancer as opposed to 228 stories on prostate cancer. During that same time, CBS news had 498 stories on breast cancer and 174 stories on prostate cancer. While there are more yearly incidences of prostate cancer than breast cancer (ACS, 2012), the NCI spent \$559 million dollars on breast cancer research in 2013 while only spending \$256 million during that same time on prostate cancer (NCI, 2016b). With a stronger media presence and more research, women may have greater access to support, and information than men coping with PC. The lack of communication, interaction, and information contribute to a social norm and offer a context from which to better understand the social challenges faced by survivors of PC. Next, I will review what we know about how PC has affected survivor's experience with their work, their relationship with their partner, and their perception of masculinity.

Work and self-identity. Grunfeld, Drudge-Coates, Rixon, Eaton, and Cooper, (2013) conducted interviews with 50 survivors revealing the effect PC had on their work experience and relationships with co-workers. Fifty men were interviewed post treatment and forty-one of these were again interviewed a year later. The interviews revealed four main themes: 1) *Work and self-identity*, 2) *Work related implications of treatment side effects*, 3) *Disclosure of cancer*, and 4) *Perceptions of future as a cancer survivor*. Many men reported that their work was closely tied to their identity as men so their illness. Men selecting a surgical treatment option reported a 4-8 week interruption from their work to recover. Men selecting radiation treatment option also reported an interruption in their schedule to attend to daily radiation treatment appointments for 4-6 weeks often during work hours. Thus returning to work was described as a return to normal behavior. Upon their return, survivors described concerns with physically performing in their work role while coping with treatment side effects like urinary incontinence. Men explained that returning to work brought apprehensions of how they would be perceived by their peers. Grunfeld, Drudge-Coates, Rixon, Eaton, and Cooper reported a range of responses related to the men's disclosure of cancer with some indicating *reluctance to disclose* their diagnosis out of fear of the stigma of treatment side effects like urinary incontinence or erectile dysfunction. Other men explained they had concerns about their future with the possible recurrence of cancer but also refocused priorities as the experience forced them to consider their own mortality. The authors concluded that the experience of prostate cancer created unique challenges for these men in their social and work experience.

Impact on primary partner relationships. Literature has also shown that the physical effects of PC, erectile dysfunction, urinary incontinence, fatigue and the emotional effects of anxiety, and depression in PCS have a significant effect on the primary partner relationship (Fergus, 2011; Lareyre, de Chalvron, Lafaye, & Cousson-Gelie, 2013; Lim, Shon, Paek, & Daly, 2014; Zaider, Manne, Nelson, Mulhall, & Kissane, 2012; Zhou et al., 2011). Couples have reported initial feelings of shock and crisis with the diagnosis (Gray, Fitch, Phillips, Labrecque, & Klotz, 1999), loss of couple affection (Zaider, Manne, Nelson, Mulhall, & Kissane, 2012), reduced marital satisfaction (Lareyre, de Chalvron, Lafaye, & Cousson-Gelie, 2013; Zhou et al., 2011), increased couple distress and anxiety (Lim, Shon, Paek, & Daly, 2014), and change in their daily lives, their couple relationship, and couple developmental stage (Harden, Northouse, & Mood, 2006). In qualitative interviews, 3 gay couples reported themes indicating their need to *acknowledge*, *accommodate*, and *accept* the changes in their sexual experiences (Hartman et al., 2014). They further identified barriers to accommodating these sexual changes like breakdowns in communication, loss of spontaneity, and experiences of trial and failure. One of the participants described his experience with pro-erectile aids like Viagra and Cialis: “We both knew that I was going to take it. And just nothing would happen, and it just puts me deeper and deeper into depression” (p. 245).

Research indicated that the partner of the PCS is affected significantly by their partners’ diagnosis, treatment, and recovery. Literature reports that the partner may suffer from loneliness (Bruun, Pedersen, Osther, & Wagner, 2010), reduced coping skills,

poorer adaptation (Street et al., 2010), added caregiving responsibilities, caregiving stress (Kim, Baker, & Spillers, 2007), perception of bother, negative appraisal of their caregiving experience (Harden et al., 2013), reluctance to share their feelings with the partner, and lower quality of life (Kim, Baker, & Spillers, 2007). Wooten, Abbott, Farrell, Austin, and Klein (2014) conducted a review of the literature for psychosocial interventions to support partners of PCS and found very limited research. They concluded that the partners of PCS have unmet needs and that considerable research is required to develop and evaluate appropriate strategies for them.

In addition to facing unmet needs, the partner may need to cope with the earlier described social context in which illness and sexual dysfunction are considered signs of weakness, and talking about one's health is discouraged for the male survivor. Without other men to talk to or listen, the immediate partner may be the survivor's sole confidant. This exclusivity may place an added caregiving burden and pressure on the caregiver. After conducting ethnographic interviews with five couples coping with PC, Fergus (2011) accentuated the dyadic coping experience by describing it as a "rupture in the couple's communal bond" (p. 95). Banthia et al., (2003) identified PC's unique impact on the couple by describing it as a "relationship disease" (p. 32). The literature demonstrated that this disease socially affects the survivor's relationship with their immediate partner, and it causes an interruption in their work. Survivors have also reported how PC contributed to a perceived loss of masculinity and feelings of emasculation. I will initially explore their reports from a social perspective followed by a fuller look at the construct of masculinity.

Perceived loss of masculinity. Male survivors of PC have described their perception of masculinity by listing traits that if lost or gained, contribute to a perceived presence of masculinity or perceived loss in masculinity. Qualitative interviews with cancer survivors revealed the following traits contributed to their perception of their male identity; work, physical strength, sports, active, socializing with other men, not going to the doctor, not paying attention to health, and the belief that “It won’t happen to me” (Mesquita, Moreira, & Maliski, 2011). Gannon, Guerro-Blanco, Patel, and Abel, (2010) interviewed seven men following a prostatectomy who reported they equated masculinity with mental resilience, emotional control, rationality, and penetrative sex. Kelly (2008), conducted ethnographic research with 14 prostate cancer survivors and explained that these men saw physical strength and independence as masculine traits. Chapple and Ziebland (2002) interviewed 52 men who had received treatment for prostate cancer and concluded that the psychological treatment side effects reduced “men’s sense of masculinity” (p 821). One interviewee (80 years old) receiving ADT reported that the injections not only affected him physically but psychologically as well:

I think being impotent is a, you don’t know it but I think it psychologically affects you. (...) I mean I feel that I’ve lost all masculinity, I’m not a man anymore. I mean I’m just not. I mean if I were walking along with my wife, very slowly these days, and somebody accosted her I would sort of run away. I have no masculinity left. (...) I think that really, that is the worst side effect by far (...) I no longer fulfill my function as a husband you know (pp 833-834).

A younger interviewee (58 years old) described his experience with hormone treatment explaining that the drugs “attack a man in every department you know where he feels that he is a man” (p. 834). Thomas, Wootten, and Robinson (2013) told of a gay man participating in their online focus group undergoing hormone treatment who reported he “felt that his male identity had been altered markedly. As well as having great issues with anxiety and mood fluctuations, this patient thought of himself as experiencing female menopause in a male body” (p. 525).

While these qualitative studies, with a small sample size of a specific population, dealing with a specific disease, have limited transferability, they are consistent with themes of perceived loss of traditional hegemonic masculinity. Data collected from 1070 patients in the TROG 03.04 (RADAR) trial were used to explore the factors that contributed to a perceived loss of masculinity in prostate cancer survivors (Sharpley, Bitsika, & Denham, 2014). They discovered that the presence of depression and anxiety symptoms was the most consistent difference between men who reported a perceived loss of masculinity and those who did not. The data revealed that symptoms of depression and anxiety “made the largest significant contribution to perceived loss in masculinity ($B = .347, t = 9.701, p < .001$)” (p. 526), than sexual problems and urinary dysfunction for their sample. The men also reported they associated their feelings of tension, irritability, depression, and worry about a perceived loss of their masculinity (Sharpley, Bitsika, & Denham, 2014). Consistently through these studies, the researchers reported that men equated the perceived loss of masculinity less with the ability to engage in penetrative sex but more with psychological and emotional traits associated with traditional masculinity

(Sharpley, Bitsika, & Denham, 2014). The men generally reported they experienced more masculinity when they felt traits of resilience, strength, emotional control, rationality, independence, and libido. They reported they felt a loss in masculinity when these traits were absent or when they experienced feelings of depression, anxiety, emotionality, irrationality, frailty, and lack of libido (Sharpley, Bitsika, & Denham, 2014).

Stigma. Disease stigma and self-blame have been determined to be barriers to health promotion (Corrigan, 2004). Previous research has also established that people who felt blamed or ashamed of their disease scored worse on mental health outcome scales (Bennett, Compas, Beckjord, & Glinder, 2005; Friedman et al., 2007; Li & Lambert, 2007). Else-Quest, LoConte, Schiller, and Hyde (2009), surveyed 43 PCS and discovered that self-blame was a mediating factor between perceived stigma, self-esteem, and anxiety and were linked to poorer psychological adjustment in PCS. As such, stigma remains an important experience to consider as it may contribute to the PCS's disease adjustment, attempts to pursue care, self-esteem, anxiety, and overall mental health.

Cushman, Phillips, and Wassersug (2010) explored the media in modern Western culture to learn how their language contributed to feelings of stigma and emasculation for PC survivors. The researchers investigated the use of words such as castrate, emasculate, neuter, impotent, and eunuch in their hermeneutical context to identify common themes promoted to the readers. They searched nonmedical usage of the key terms and their common derivatives on the Google search engine and performed various Boolean search strategies to separate medical and anatomical usage of the terms from non-medical, metaphorical usage. This expansive search included websites, articles, magazines, news

stories, books, jokes, and films with a publication range from the 1960s to 2005.

Admittedly, their approach to their large data set was semi-quantitative as it was based on the number of Google hits and it did not seem to adhere to the strictest standards of quantitative research. Their research, however “confirmed that terms of emasculation were typically employed to criticize and denigrate within domains that are traditionally associated with masculinity and power, and therefore used to signify loss of maleness and authority” (p. 10).

The following examples illustrate the findings of Cushman, Phillips, and Wassersug (2010). They found the term *impotence*, which on its own means powerlessness, was also linked with words like aged, pain, apathy, and futility. Although the National Institute of Health and the medical profession have stopped defining penile failure as impotence but instead erectile dysfunction, the authors found that the usage of the term was equated with both political and sexual powerlessness. The term *emasculate*, was often used metaphorically to describe an attack (“military emasculated...” or “emasculating of Bible English”). The term *neuter* was often used to denigrate (e.g., “Microsoft neuters Bluetooth”; “neutering of politics”). The use of the word *castration* also carried a negative connotation as it was used most frequently to describe the castration of animals, the punishment for sexual offenders, or as a term of mockery in the headlines like “Guess who castrated FEMA?” (Drum, 2005). The writers found that the language promoted and reinforced the public perception that power and strength were masculine traits. This association excluded females from possessing those strengths and denigrated men who somehow did not exhibit the same traits.

Cushman, Phillips, and Wassersug (2010), concluded that men who are androgen-deprived, suffering from erectile dysfunction, and other symptoms of PC treatment may be at risk for stigmatization, shame, and the anxiety of how they will be perceived by their family, friends, and medical providers. “When faced with this language about themselves, PC patients are likely to internalize negative self-conceptions and feel obsolete” (Cushman, Phillips, & Wassersug, 2010, p. 20). The gay and bisexual population are particularly vulnerable to stigma as many have rejected traditional hegemonic values and are considered by many to be a deviant form of masculinity (Dean, 2013). Research has shown that this stigma inhibits them from revealing their sexual orientation to their doctor and may contribute to help-seeking delays (Allensworth-Davies et al., 2016).

Literature seems to reflect that men surviving PC clearly face significant challenges physically, emotionally, and socially. PC is distinguished from most other cancers faced by men by its impact on the survivors’ sexual performance and their perception of their own masculinity. The prostate gland is a sexual organ, so its dysfunction and treatment directly affected the survivors’ sexual performance, and for many men, contributed to a perceived loss of their masculinity (Sharpley, Bitsika, & Denham, 2014). To better understand the experience of men with prostate cancer, I will explore the construct of masculinity, its relationship with sexual performance, culture, and men’s health as central themes to this research.

Masculinity

The literature on the construct of masculinity reflect a wide range of theories and perspectives that emerged in a historical context from the seeds of gender development theories. In the following section, I will review the literature on gender development and descriptions of masculinity in their historical and cultural context. I hope to demonstrate that as society has changed the construct of masculinity and public perception of it have also changed. Connell (1987) described, that masculinity is a social construct that is linked to its historical time period, culture, and geographical location. In the spirit of phenomenological research, I will explain my pursuit of an integrated perspective of masculine development that accounts for biological, psychological, and sociological influences. Lastly, this section will review the literature describing the relationship between traditional masculinity towards health with research of men's beliefs about health, their health seeking behaviors, and how these may or may not affect men's overall health.

Gender Development

Early literature on gender development historically focused on biological theories and psychological theories (Money & Ehrhardt, 1972; Moynihan, 1988; Quadagno, Briscoe, & Quadagno, 1977). Biological theorists held to the belief that the primary source for gender differences was in the biological composition up of men and women (Moynihan, 1988; Hare-Mustin & Marecek, 1988). Medical discoveries in the early 1900s of the *x* and *y* chromosomes and in the 1920s-30s of estrogen in women and testosterone in men promoted the biological determinism that sex and gender were one in

the same construct (McLeod, 2014). The positivist notion was that men and women were physically different, consequently, their expression of gender will also be different (McLeod, 2014; Moynihan, 1988). Concurrent with these medical discoveries, Freud developed the first psychological theories explaining gender development (Freud 1916/1963). He proposed that gender development took place in the early in childhood through a process he called identification where the young child would assume the traits of their same-sex parent and thus resolve their erotic attachment with their opposite-sex parent.

New theories emerged in the 1960s during a period of significant social change in the United States. Maccoby's (1966) *The Development of Sex Differences*, promoted the idea that social learning influences (Mischel, 1966), and cognitive developmental influences (Kohlberg, 1966) contributed to gender development. These writings were pivotal in the field of psychology at a time when the social roles of men and women were receiving increasing attention and scrutiny. Based on their work with intersex patients, Mooney and Ehrhardt (1972) concluded that social influences were more important than biological ones in the experience of gender and brought more attention to the nature vs nurture debate. They were also the first to distinguish a gender identity as one's personal experience in gender and gender role as one's social expression of gender. Maccoby's and Jacklin's (1974) work promoted further debate by arguing there were actually very few differences between men and women, citing research that revealed more differences within the same gender than those between the genders. They challenged the notion that parents were the primary source of socialization but argued that children assume

gendered behavior through the process of play and self-socialization. While these ideas were revolutionary for the field of psychology, they were in harmony with the social movements of the late 1960s and early 1970s in the United States.

The growth and change in the research on gender development were paralleled by the growth of the feminist movement and feminist writers (Gardiner, 2005). Founded in 1966, the National Organization for Women educated the public of prejudices that promoted gender discrimination and sought gender equity through changes in the law. Feminist literature addressed the inequities and injustices faced by women on a personal level, community level, and national level while exposing the mechanisms that men have used to advance and preserve their power (Friedan, 1963; hooks, 1984; LeGuin, 1974). Certain behaviors, language, and aggressions practiced by men may have been socially accepted displays of normative masculinity at one time but were exposed for their repressive, intimidating, or hurtful effect on women, and minorities. The public perception of traditional masculinity changed as the feminist movement and scholarly writers promoted gender equality and alternative forms of masculinity (Connell, 1977; Connell, 1987; Gardiner, 2005).

The most important accomplishment of 20th-century feminist theory is the concept of gender as a social construction; that is, the idea that masculinity and femininity are loosely defined, historically variable, and interrelated social ascriptions to persons with certain kinds of bodies—not the natural, necessary, or ideal characteristics of people with similar genitals. (Gardiner, 2005, p. 35)

While feminist theory's most important accomplishment may be debated, the quote indicates the change in perception of masculinity and one writer's perception of Feminism's role in that change. The movement promoted legal, social, and personal changes. The national dialogue, combined with innovative research on the social influence of gender development, inspired richer exploration of gender and the construct of masculinity.

Theorists Kohlberg, Chodorow, Bandura, and many others contributed to this new era by exploring factors that contributed to the manifestation of gender. Kohlberg (1966) proposed *gender constancy* as a process by which children achieve gender identity as a permanent attribute determined by their biological properties and not dependent on their external characteristics like their clothes, choice of play, or length of hair. Chodorow (1999) described that boys may initially identify with their mothers as they grow older they increasingly define themselves in terms of their difference from their mothers. Bandura (1999) created a social cognitive theory of gender conception that integrated social experiences and relationships with internal self-regulatory and motivational mechanisms that guided gendered conduct through life. While the field became more populated with theories describing gender and its development, generally current theories emerged out of biological, psychological, sociological theories or a combination thereof (Bussey & Bandura, 1999).

Descriptive Theories

Theories describing masculinity are generally anchored in and may be better understood from the background of gender development theories. The descriptive

theories like positivist, social constructionist, postmodernist, feminist, and hegemonic theory will each offer a different frame of reference from which masculinity has been understood and explored.

Positivist. Grounded in science and objective neutral reasoning, the positivist theory holds that masculinity is a reflection of a biological reality (Hare-Mustin & Marecek, 1988). It asserts that male anatomy is the ultimate signifier of gender and determinant of that person's social role. Supported by the understanding that men had higher testosterone levels, and testosterone's association with aggression (Batrinos, 2012), men were expected to be naturally aggressive, independent, in control, reasoned, and successful (Moynihan, 1988). Other signifiers that were perceived as fixed masculine characteristics were: inexpressiveness, ambitious, and stoic (Moynihan, 1998).

Predominant in the 19th and early 20th century, the positivist theory held that masculinity and its characteristics were a biologically fixed and static construct (Chapple & Ziebland, 2002). These beliefs contributed to the social expectation of roles that were to be performed by men. Natural experiences of failure, weakness, pain, fears, or illness were subjugated to promote a suffering in silence or stoic persona. In the 1960s and 70s, social theorists and the emerging feminist movement promoted the idea that masculine and feminine gender were largely social constructions born out of cultural practices and beliefs (Chapple & Ziebland, 2002). They opened the door for new ways of looking at gender.

Social constructionist. In direct contrast to positivist thought which deems that information is objective and external to the knower, the constructionist thought is internal

to the knower and determined by that person's perception (Watzlawick, 1984). In social constructionist thought then the construct of gender was created by the social conscious, so masculinity or femininity are what the culture deem them to be (Moynihan, 1988; Connell, 2008; Courtenay, 2000). Each culture may have their own characteristics determining the norms of masculinity and femininity. In this model, gender is constructed and reproduced through interactions, relationships, and actions. This model holds that from birth, individuals see gender interacted all around them, adopt those practices, and contribute to a culture reinforcing others to practice the same. Connell (2008) for example defines masculinity as a social construct but links it to a specific time in history, culture, and location. Steadfast social constructionists deny there is a biological essence of masculinity or femininity influencing gendered behavior but instead focus entirely on the social influence that reinforces the cultural norms (Chapple & Ziebland, 2002; Moynihan 1998; Hare-Mustin & Marecek, 1988).

Postmodernist. Consistent with social constructionists, postmodern theorists promote the idea that sex and gender cannot be defined definitively for all but that instead individuals create their own definition based in their reality (Docherty, 1993). In this tradition, Moynihan (1998) offered floating signifiers to expand the medical profession's traditional view of masculinity and improve their understanding and treatment. She indicated that a man may be stoic while seeking comfort: "for example, refusing psychotropic drugs while holding his teddy bear" (p. 1073). A man may show strength and weakness: "for example, accepting a chemotherapy regimen and crying because he feels sick" (p. 1073). Finally, a man may be aggressive and gentle: "for example,

shouting at his doctor while cradling his baby” (p. 1073). This model does not assign traits as masculine or feminine but instead promotes differences that are based on our diverse experiences and realities (Docherty, 1993).

Feminist. Feminist theories historically focused on the differences between men and women to identify social inequities, promote positive feminine qualities, and expose the process by which men used social power (Scott, 1985; Connell, 2014; Connell & Messerschmidt, 2005; Hare-Mustin & Marecek, 1988). Feminist theorists are credited for coining the terms “patriarchal masculinity” (hooks, 2000; Nall, 2010) and “hegemonic masculinity” (Connell, 1987; Connell & Messerschmidt, 2005). Theorists described masculinity in relation to its subjugation of women through aggression, oppression, and control (Adams & Coltrane, 2005; hooks, 2000; Connell, 1987; Connell & Messerschmidt, 2005). Masculinity, “teaches men that [men’s] sense of self and identity, their reason for being, resides in their capacity to dominate others” (hooks, 2000, p. 70). Cornell (1998) advanced psychoanalytic theories of Jaques Lacan arguing that masculinity is defined by unconscious fears of castration which fuel fantasies of superiority. Feminist scholars have also described masculinity in terms of sexual force and violence perpetrated against women (MacKinnon, 1987), or reasoned that masculine competition and attempts to dominate would ultimately lead to depletion of the earth’s natural resources (Seager, 1999). While some of these descriptions may have pushed the cultural boundaries, feminist theorists and activists successfully brought attention to the harm caused by masculine aggression, educated the public at large, and contributed to more social equity through-out the world. Stoltenberg (1989) seemed to offer a male’s

apology for these harms by promoting his position of anti-masculine feminism in his book *Refusing to Be a Man*. Feminist theorists have also promoted language that eliminated the construct of gender altogether. Lorber (1994) indicated that gender equality would not take place in a culture with two genders but instead could be grasped in a culture with many forms of sexuality where gender is invisible. “When the information about genitalia is as irrelevant as the color of the child’s eyes . . . then and only then will women and men be socially interchangeable and really equal” (p. 302).

Hegemonic Masculinity. The concept of hegemonic masculinity was coined by Connell in 1987 while conducting social research of bullying behaviors among high school boys in Australia (Connell, 1987). Since its inception, the concept has received broad acceptance as well as critique. Multiple scholarly interdisciplinary conferences have been devoted to the subject of hegemonic masculinity. A Google scholar search of *hegemonic masculinity* returned 110,000 hits indicating its wide acceptance. Approaching masculinity from a sociological perspective, the concept of hegemonic masculinity “was understood as the pattern of practice (things done, not just a set of role expectations or an identity) that allowed men’s dominance over women to continue” (Connell & Messerschmidt, 2005). The concept was described as a normative practice for some men and the ideal for many others to follow. Within the scope of Connell’s theory, she described that because most men cannot meet the ideal of hegemonic masculinity, the majority of men participate in some form of subordinate masculinity. According to Connell, many men contribute to a complicit masculinity promoting the status of another to position themselves to gain rank and benefits from the patriarchal strategy. Within the

ranks of hegemonic masculinity, Connell described homosexuality as a deviant masculinity.

Created by Gramsci, hegemony is the process of winning and holding onto social power to establish domination over others (Connell, 1987). It is typified by the movie quote of George C. Scott in the role of George S. Patton when he said, “Now I want you to remember that no bastard ever won a war by dying for his country. He won it by making the other poor dumb bastard die for his country” (McCarthy and Schaffner, 1970). This pattern of domineering and subjugating others, women or men, was the central characteristic of hegemonic masculinity.

Creation and promotion of the concept of hegemony were intended to put a spotlight on the injury caused by the domination and the loss privilege to others (Connell and Messerschmidt, 2005). Stressing the need for change, writers produced research supporting the existence and impact of the construct in various areas of society. The concept was applied in education to explain classroom dynamics among students (Skelton, 1993), in criminology to explain why men commit more violent crimes (Messerschmidt, 1993), in sports media to demonstrate the over-representation of masculinity in sports (Messner, 1992), and in organization studies to identify the gendered nature of bureaucracy (Cockburn, 1991). The concept of hegemonic masculinity has also drawn criticism that it characterizes men as unsympathetic, uncaring, self-centered, aggressive, and criminal (Collier, 1998; Martin, 1998). Collier goes on to explain that it does not account for the positive behaviors that many men

engage in such as demonstrating initiative at work, working to provide an income for a family, and being a father.

Towards a working definition. Moving past her definition of hegemonic masculinity, Connell promoted that masculinity should be more than a static concept, or a physiological birthright but described it as a much more complicated social construct.

Rather than attempting to define masculinity as an object (a natural character type, a behavioural average, a norm), we need to focus on the processes and relationships through which men and women conduct gendered lives.

‘Masculinity’, to the extent to which the term can be defined at all, is simultaneously a place in gender relations, the practices through which men and women engage that place in gender, and the effects of these practices in bodily experience, personality and culture (Connell, 1995, p. 71).

Leading authority on the study of masculinity, Kimmel (2004) supported the complexity of masculinity as a social construct but promoted the contribution of history, culture, and differentiation to his definition.

Manhood is neither static nor timeless; it is historical. Manhood is not the manifestation of an inner essence; it is socially constructed. Manhood does not bubble up to consciousness from our biological makeup; it is created in culture. Manhood means different things at different times to different people. We come to know what it means to be a man in our culture by setting our definitions in opposition to a set of ‘others’—racial minorities, sexual minorities, and above all, women (p. 81).

This “setting our definitions in opposition to” is in contrast to psychoanalytic theory’s process of gender identification with the same-sex parent (Freud 1916) and social cognitive theory’s tenets that children model their behavior after their same-sex counterparts (Bussey & Bandura, 1999). It does, however, allow for a social constructionist perspective where “manhood means different things at different times to different people” (Kimmel, 2004, p. 82). If gender is “something that one does and does recurrently, in interactions with others” (West & Zimmerman, 1987, p. 140), then perhaps gender and masculinity are not static containers but are better understood as a dynamic construct, or as a verb in the context of a larger social structure.

Ultimately, however, understanding the essence masculinity through men’s experiences will offer the best insight into the survivor’s experience with prostate cancer. The following paragraphs summarize different research attempts to learn more about how men describe masculinity and what meaning they ascribe to their experience of gender.

How men describe masculinity. Martin and Harris’ (2006) interviews with 27 college-age African American student-athletes with an academic 2.8 grade point average or above from four different universities revealed interesting themes of what masculinity meant to them. The participants identified masculinity with having upstanding moral character, integrity, and the courage to do what is right. One of the interviewees indicated, “Masculinity, to me, is knowing that as a man you have to make decisions that are going to be different from everybody else and being comfortable with who you are as man, regardless of what other people say” (p 368). Their findings are consistent with the

themes of stoicism and self-denial that reinforce the “Strong and Silent Script” and the “Tough Guy Script” (Mahalik, Good, and Englar-Carlson, 2003).

Sloan, Gough, and Conner (2010) interviewed 10 healthy men to learn how they describe masculinity in relation to their health choices. In response to being asked if it is masculine to be concerned about his health, one participant, Josh responded:

“traditionally no, it is seen as more of a feminine trait to be concerned about your health or fitness” (p 793). Themes of autonomy and self-reliance demonstrated that some men preferred to preserve their autonomy and make unhealthy choices than to relinquish their autonomy while making healthy choices. Other men described themselves as autonomous because they were “standing their ground” (p 795) in support of healthy choices. They explained they were being rebels for making healthy choices instead of “getting bacon sandwiches” (p 795) like the others. Some men described healthy choices as feminine while others described healthy choices as masculine rebellion. Whether pursuing healthy or unhealthy choices, the men in both groups described themselves as autonomous, drawing on themes of choice, competition, and control to illustrate how they described their health choices in relation to their masculinity.

O’Brien, Hunt, Hart (2005) conducted 14 focus groups with 55 men to explore their perception of masculinity and help seeking. They cited the following quotes from men describing masculinity in relation to help seeking.

- “Aye that’s just a man thing. ‘I’m hard, I’m daft, I’ll cut my arm off and just grow another one back’” (p. 508).

- “males don’t tend to talk about what’s bothering them or why they’re depressed because they’re all man-like (smirking). It’s true though, they tend to keep quiet about it” (p. 511).
- “You don’t like to make a fuss because it’s a macho thing just to say you’re being the strong silent type. You’ll endure it, you can take it. So if there is something wrong you won’t talk to anyone about it. You have to be bed-ridden or half dead before you’ll go (to the doctor’s)” (p. 508)
- "the whole idea about what constitutes a man. A real man puts up with pain and doesn't complain" (p 508).
- “the more masculine man is defined by a man who doesn’t share stuff with other people.” (p. 510).

In this study, the men used themes of strength, autonomy, and self-reliance to describe themselves and compare themselves with other men.

Comparing themselves to one another in competition for masculinity is also an important practice of masculinity.

I have a standing bet with a friend that I can walk into any playground in America where six-year-old boys are happily playing and by asking one question, I can provoke a fight. That question is simple: “Who’s a sissy around here?” Once posed the challenge is made (Kimmel, 2004, p.83).

Kimmel used this story to explain the comparisons among boys and how there is shame in looking like the sissy. Capraro (2000), drew from this dynamic of men in comparison to one another to explain alcohol consumption among college males. He explained that

men in college were “drinking because men are supposed to drink . . . If they don’t they feel inadequate, . . . a sense of falling short of the cultural ideal of manhood” (p. 310). Capraro’s research illustrates one way that men compare themselves to one another in pursuit of an ideal masculinity.

Although “...what it means to be a man has never had a simple, coherent meaning...” (Watson, 2000, p. 35) the various men represented in the different studies seem to have cohesive concepts that represent the essence of their experience of masculinity. The men in the aforementioned studies reflected that themes of autonomy, strength, and choice are consistent with how they experience and live out masculinity. This is an important insight as I seek to understand how masculinity and its essential themes are experienced by the prostate cancer survivor. It also seems significant that the themes that men attribute towards masculinity, of autonomy, strength, and choice are also consistent with themes of resilience and post-traumatic growth. Both of these constructs will be explored in-depth later in this chapter. Sociological theorists hold that the consistent themes in the different studies may be a reflection of how culture has contributed towards a masculine code by socializing men “to project strength, individuality, dominance, stoicism, and physical aggression, and to avoid demonstrations of vulnerability” (Williams, 2003, p. 726). The following section will reflect what we know about men’s healthcare choices and how according to research culture has influenced men’s beliefs and healthcare decisions.

Relationship to Health

Exploring men's health behaviors and their reported values towards health and health-care may offer insight into the experience of prostate cancer diagnosis, treatment, and recovery. I will review current data illustrating men's health outcomes, explore behaviors that may be contributing to poorer health outcomes, and present research showing how men's perceived normative health behaviors, and perceived social role contributed to the phenomena of poorer health outcomes among men. The Health, Illness, Men and Masculinities Model (HIMM) (Evans, Frank, Oliffe, & Gregory, 2010) as well as a Communities of Practice Perspective (Creighton & Oliffe, 2010; Paechter, 2003) will be presented as two theoretical frameworks offering insight into how social influences contribute towards men's relationship with their health. These will offer a framework from which to understand how unhealthy behaviors are promoted, healthy behaviors are discouraged, and the adjustment men make to reframe healthy behaviors as masculine.

Health outcomes. It has been well researched and documented that men have considerably worse health outcomes than women. Nearly half of all men in the United States will have cancer during their lifetimes while only one-third of all women will be diagnosed (ACS, 2015). Men are more likely to be diagnosed with and die from cancers like stomach, lung, liver, brain, skin, lip, larynx, esophagus, and bladder and non-Hodgkin's lymphoma (DeSantis et al., 2014; Stewart, & Wild, 2015). Men have a shortened lifespan, by 5.4 years and die at higher rates in 12 of 15 leading causes of death which include cardiovascular disease, liver disease, suicide, and motor vehicle accidents (Barr, 2014; Bilkser, Goldenberg, & Davidson, 2010; Ross, Masters, & Hummer, 2012).

Gender has been identified by the American Cancer Society (2015), World Health Organization (2000), and Canadian health researchers (Raphael, 2008) as a significant health predictor in need of further research. It may be argued that men may have worse health outcomes because, consistent with themes of self-reliance and autonomy, they have not sought medical attention or preventive health care. This underscores paradoxical challenge in that while it is the men who have worse health outcomes than women, men need more health care, yet, it is the men who seem to be less likely to seek help for health care.

Behavioral factors. In his seminal work on behavioral factors associated with disease and death, Courtenay (2000) identified 30 behaviors that men are more likely to engage in that increase their risk for disease, injury, and death. Among the behaviors he listed were: not utilizing health care, not participating in preventive care, not using sunscreen, not taking vitamins or medicine, not using a seat belt, not using a helmet, use and abuse of alcohol, tobacco, anabolic steroids, engaging in risky behavior like reckless driving, driving while intoxicated, criminal activity, and fighting. Additional researchers have explored and affirmed the same findings (Creighton, Oliffe, Matthews, & Saewyc, 2016; De Visser, 2009; Levant, Wimer, Williams, Smalley, & Noronha, 2009; O'Brien, Hunt, & Hart, 2005; Verdonk, Seesing, & de Rijk, 2010; Vogel, Heimerdinger-Edwards, Hammer, & Hubbard, 2011).

Alcohol abuse. Capraro (2000) explored men's problem drinking at the college level and suggested that there is a strong link between social construction of masculinity and alcohol consumption.

When we look for connections between drinking, men, and masculinity, we observe that the most prominent feature on the social landscape of drinking is that drinking is a male domain. By male domain I suggest that drinking is male dominated, male identified, and male centered (p. 308).

While not specific to college students, the National Alcohol Survey revealed men consumed more alcohol, and reported more frequent yearly and monthly drunkenness than women in the same survey (Witbrodt, Mulia, Zemore, and Kerr, 2014). This is the epitome of a behavioral factor clearly affecting health as chronic heavy alcohol consumption is linked to anemia, cancer, cardiovascular disease, cirrhosis, dementia, depression, seizures, gout, high blood pressure, infectious disease, nerve damage, and pancreatitis (Freeman, 2016).

Creighton, Oliffe, Matthews, and Saewyc (2016) interviewed 57 men in individual semi-structured interviews to explore how young men used alcohol in the grief process after the accidental death of a male friend. Out of the transcribed interviews emerged themes of 1) using alcohol to dull the pain, and 2) using alcohol to purge sadness. The men reported they used alcohol to help them preserve an image of masculinity, as it seemed to dampen the pain but it also gave them temporary permission to demonstrate non-masculine expressions of grief that could be blamed on the drunkenness. One participant reported:

But I don't think that anybody is like, 'Well I'm going to get hammered for [my friend's] wake because I want to be able to express my emotions and whatnot.'

It's like, 'Oh I'm going to go celebrate [my friends] life and get hammered with all the boys' (p. 57).

The researchers summarized that overuse of alcohol in grief was a "masculine practice" (p. 59) used to cope with emotions and connect with peers.

Help seeking. The research on men's help-seeking behavior draws particular concern since many illnesses can be discovered with preventive screening and treated more successfully after early discovery. The Centers for Disease Control (2014) reported that men are 80% less likely than women to access regular health care services. Nearly 25% of men surveyed had not seen a medical professional in over a year compared to just over 87% of women who had accessed medical help within the past year. Galdas, Cheater, and Marshall (2005) conducted a review of the medical literature on men and their help-seeking behavior. They found numerous articles confirming the trend that men "delayed help-seeking when they become ill" (p. 616). In addition, there is evidence that men delay preventive health services as well. The American Academy of Family Physicians' (2007) online survey of 1,111 men indicated that 55% of them had not gotten a preventive physical exam from their primary doctor in over a year. Weinrich, Weinrich, Priest, and Fodi (2003) interviewed men who declined a prostate cancer screening to discover their most common response for not participating in the cancer screening was a time and scheduling problem. A focus group interview study of Australian men's willingness to perform a self-exam for testicular cancer showed that the men's responses reflected attitudes of stoicism and avoidance (Singleton, 2008). In summary, many men visited their doctors less than women, they engaged in riskier more dangerous behavior,

and received worse health outcomes than women. In relation to prostate cancer, these behaviors may contribute to delayed discovery of prostate cancer which may necessitate more aggressive treatment resulting in potentially poorer health outcomes maybe even death. The following will review the research into and explanations for this phenomenon, which has generally focused on culture, social norms, and stigma faced by men.

Sociocultural influence on health behaviors. Various studies have explored the degree of influence culture and social relationships have had on men's health choices (Courtenay, 2000; Mahalik, Burns, & Syzdek, 2007; Vogel, Heimerdinger-Edwards, Hammer, & Hubbard, 2011). The following will review how dominant masculine norms, perceived normative behaviors, and social relationships appear to influence health behaviors.

Promoting the concept that masculinity, as a social construct, contributed negatively towards men's health Courtenay (2000) explained "The activities that men and women are engaged in, and their gendered cognitions, are a form of currency in transactions that are continually enacted in the demonstration of gender" (p. 1388). He held that activities like eating, exercise, self-care, or play offer each gender an opportunity to demonstrate and enact representations of gender. Like play or exercise, health behavior "can be invoked as a practice through which masculinities (and men and women) are differentiated from one another" (Messerschmidt, 1993, p. 85). This differentiation may also be negotiated in part through the power and microaggressions that demonstrate dominance by subordinating another (women or lower status male). Courtenay held that practices, consistent with hegemonic masculinity, like "denial of

weakness or vulnerability, emotional and physical control, the appearance of being strong and robust, dismissal of any need for help, a ceaseless interest in sex, the display of aggressive behavior, and physical dominance” (p. 1389) were putting men at significant risk to their health.

Mahalik, Burns, and Syzdek, (2007) explored whether the normative behaviors expected of masculinity could be a predictor of men’s health behaviors. They explained, “The link between normative behavior and one’s own behavior is illustrated when a man perceives that his male friends are trying to quit smoking and believing this to be a normative behavior, attempts to do the same” (p. 2203). The researchers recruited 140 men to complete a 1) Masculinity: The Conformity to Masculinity Norms Inventory (Mahalik et al., 2003), 2) a scale surveying their participation in 8 health promoting behaviors, and 3) a 48 question questionnaire indicating their perception of the normativeness of the 8 health promoting behaviors. “Results indicated that men scoring higher on masculinity reported lower frequencies of health promoting behavior” (p. 2206). The men in the study that demonstrated greater frequency of health promoting behaviors reported they conformed to less traditional masculine norms and reported a perception that other men were also engaging in healthy behaviors. The writers concluded that men’s perception of other men’s normative health behaviors were influenced by socialization with other men and was an accurate predictor of the participants own health behaviors.

Vogel, Heimerdinger-Edwards, Hammer, and Hubbard (2011) conducted online surveys with 4773 men to examine the links between the endorsement of masculine

norms, self-stigma, and help-seeking attitudes among men with diverse backgrounds. The participants reported their own conformity to dominant male gender role norms through the Conformity to Masculine Norms Inventory (CMNI-22; Mahalik et al., 2003). A higher score reflected more participant support for dominant male norms. Research has shown that some men may be more likely to internalize public stigma than women (Vogel, Wade, & Hackler, 2007) so they measured self-stigma as a possible mediating factor using the Self-Stigma of Seeking Help scale (SSOSH; Vogel, Wade, & Haake, 2006). Help-seeking was assessed using the Attitudes Towards Seeking Professional Psychological Help Scale (ATSPPHS-SF; Fischer & Farina, 1995). Men's level of depressive symptoms was assessed through the Center for Epistemological Studies Depression scale (CES-D; Radloff, 1977). Examination of the correlations among the variables revealed a positive correlation between masculinity norms and self-stigma ($r = .41, p < .001$), a negative correlation between masculinity norms and attitudes towards counseling ($r = -.41, p < .001$), and a negative correlation between self-stigma and attitudes toward counseling ($r = -.63, p < .001$). This showed a stronger adherence to masculine norms reflected higher levels of self-stigma. Higher levels of stigma were related to lower levels of positive attitudes towards counseling. The results showed that "men with higher endorsement of masculine beliefs have less favorable attitudes towards seeking psychological help" (p.375). They also discovered that while masculine norms contribute to more self-stigma, self-stigma was a stronger indicator; than masculine norms; of help-seeking attitudes.

This attitude towards help seeking is consistent with focus group interviews conducted with fifty-five men in Scotland in which the men endorsed a “hegemonic view that men should be reluctant to seek help” (O’Brien, Hunt, and Hart, 2005, p 503), unless they were restoring or preserving a masculine role like working as a firefighter or other masculine role or function. In other words, men believed they should not ask for help unless the help restored some sense of idealized masculinity. While masculinity has been associated with poor health choices, many men pursuing healthy lifestyles frame their choices in masculine terms. As demonstrated earlier, Sloan, Gough, and Conner (2010) interviewed healthy men and learned that they framed their healthy lifestyles in masculine sports language of performance, competition, and success. These masculine constructions suggested the participants were concerned of being socially construed as feminine because of their healthy lifestyles and underscored the impact of social expectations, roles, and self-stigma on health choices (Sloan, Gough, & Conner, 2010).

Theoretical Frameworks. Few theories conceptualize the interaction between men’s health behavior and men’s conception of masculinity from a social constructivist perspective. Two theories offering some insight are the HIMM framework (Evans, Frank, Oliffe, & Gregory, 2010), and the Communities of Practice Model (Creighton & Oliffe, 2010; Paechter, 2003). The HIMM framework conceptualized how masculinity was “a social determinant of health” (Evans, Frank, Oliffe, & Gregory, 2010 p. 10) that interacted with other known determinants of health like socio-economic status, race, ethnicity, and sexuality. Social influences to masculinity were explored through the lifespan by addressing masculinity in youth, middle years, and later life. They explained

that hegemonic masculinity was promoted when boys were told not to cry, to ‘take it like a man,’ be tough, and compete. Physical risk was encouraged and “...sport injury reflects the gendering of sport in the form of...” (p. 11) injuries that were endured, shown off like trophies, and considered badges of manhood. Team sports competitions and team achievement rankings promoted ideals of ascending over others to be successful and playing through the pain to not let the team down. During the middle years of life men “construct their masculinity in relation to the physicality of their work and level of income their labor produces” (p. 12). The writers identified that performing higher risk work or work that may be more physically demanding offered men the opportunity to demonstrate masculinity through risk taking, denial of bodily pain, or stoicism. Another social concept is that of the “hardy man- a personality style characterized by commitment, rather than alienation, control, rather than powerlessness, and challenge rather than threat” (p. 12). These behaviors potentially created a social feedback loop that reinforced unhealthy behavior and promoted how men should define themselves in terms of others around them.

Evans, Frank, Oliffe, and Gregory (2010) explained that this process influenced how men addressed illness, hardship, and the uncertainty of midlife experiences. The authors expressed the need for men to normalize the experience of depression among one another to discourage silent suffering. Finally, they described masculinity in later life as an area in need for further exploration expressing concern that older men may have lost abilities idealized in hegemonic masculinity and have lost their contributing role to the community. Furthermore, the writers expressed concern to explore how men socially

define themselves in light of a diminishing same age social group, diminishing health, and in the context of an idealized masculine culture. The HIMM framework offered developmental insights that contributed to understanding how masculinity's social conception contributes to men's health (Evans, Frank, Oliffe & Gregory, 2010).

Creighton and Oliffe (2010), and Paechter (2003) used the Communities of Practice theory to describe how social relationships create a community where members learn, practice, and promote forms of gendered identity. "The term community of practice was coined to refer to the community that acts as a living curriculum for the apprentice" (Wenger, 2009, p 3). Adapted from the work of Wenger (1998), Communities of Practice was a social learning theory describing how people with a common interest engaged in activities related to their interest, learned from one another, gained collective knowledge, and developed a shared repertoire. A community of practice could be as narrow as members of a local athletic team or as broad as people with a shared interest. Members of a community may participate in the following activities to improve their practice: 1) Problem solving, 2) Requests for information, 3) Seeking experience; 4) Reusing assets; 5) Visiting together; and 6) Sharing knowledge (Wenger, 2009). Wenger promoted that the community member as an apprentice may not only gain new knowledge, expertise, and membership into a community but that apprentice could also gain a sense of identity. He stated, "we define who we are by the ways we experience ourselves through participation as well as by the ways we and others reify ourselves" (Wenger, 1998, p. 149). Paechter (2003) positioned gender identity as a community of practice to explore "how and why" (p. 69) men and women develop, practice, and promote gendered

behavior. She held that boys and girls may gain a gendered identity by participating in, identifying with, and learning from a community of the same gender. As Wenger held that the apprentice's identity was influenced by negotiated experiences, community membership, and assumed learning trajectories, so Paechter explained that these also contributed to the apprentice's identification with and "learning of particular forms of masculinity and femininity practice." (p. 69).

Creighton and Oliffe (2010) drew from this positioning of gender as a community of practice to explore the cultural norms surrounding men's health and illness practices. They concluded that hegemonic ideals of independence, control, and power persist within men's communities perpetuating practices of risk taking and delayed help seeking among men. They advocated that understanding the problem from this social perspective and leveraging change through communities of practice, members and leaders may offer alternative solutions that alleviate the pressure felt by men to perform while also promoting diverse masculine norms.

As already discussed, prostate cancer has a devastating medical, emotional, and social impact on men. Many PCS have characterized these experiences as losing masculine traits and masculine identity while gaining feminine traits. Medical advances have made cancer much more treatable so consequently, there are more living cancer survivors in need of medical and emotional support today than ever before. However, all cancer experiences have not been described as negative. Many cancer and prostate cancer survivors report positive growth, enrichment, and renewed personal relationships as a direct result of their cancer experiences. The following section will review the literature

for the reported positive experiences of prostate cancer survivors and present these through the lens of two salutogenic constructs; resilience and post-traumatic growth.

Post-traumatic Growth and Resilience

Although the cancer diagnosis may be associated with psychological trauma, functional difficulties, and death, 60-90% of cancer survivors reported that the diagnosis and treatment experience brought beneficial aspects (Mystakidou et al., 2015). These positive aspects of cancer offer a salutogenic perspective which is in direct contrast to the traditional medical model. While the medical model and traditional psychology have focused on pathology, the subdisciplines of salutogenesis and positive psychology focused on factors contributing to health and wellness (Tedeschi & Calhoun, 2004; Lopez & Snyder, 2011). These subdisciplines contributed to current understanding of resilience and post-traumatic growth (PTG) and will offer a salient frame from which to understand the experience of the PCS.

Post-traumatic Growth.

It has been an appealing and long-held notion that trauma and suffering have a silver lining, and that people may grow to higher levels of functioning after trauma. Original literature from the Judeo-Christian tradition convey themes of growth after overcoming suffering (Isaiah 61:3, Job 19:25). More recent writings of Victor Frankl, Mahatma Gandhi, Kahlil Gibran, and Mother Theresa conveyed a similar message of hope and meaning to people in times of suffering. Defined as positive psychological growth after a trauma (Tedeschi & Calhoun, 1995), PTG theories were developed in the early 1990s and continue to be an emerging field of study (Walsh, 2015). Tedeschi and

Calhoun's (1995) Transformational Model of growth, the most widely researched and used model, conceptualized PTG into five dimensions of beneficial life change: "perceived changes in self; developing closer relationships; changing life philosophy/increased existential awareness; changed priorities and enhanced spiritual beliefs" (p. 5). Their theory led the development the Post-Traumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) that measures these five domains with a 21 item inventory and remains widely used today (Wilson, Morris, Chambers, 2014; Mystakidou, et al., 2015). The following will offer a sample of qualitative research on PTG, research indicating possible concerns with PTG theories, and the PTG research with PCS.

Qualitative Research. Connerty and Knott (2013) explored the PTG construct through qualitative group interviews with cancer survivors. After inquiring about the positive aspects of the cancer experience 4 themes of beneficial change emerged from the transcribed interview data: "change in world view, areas of positive change, supportive relationships, and the notion that doing creates meaning" (p. 338). Also named "Shattered Assumptions" (p. 338) the *change in world view* was the recognition that core beliefs about themselves and the world had been altered. Interview participant, Ava, explained:

I was very set in my ways, so letting go of things a little bit and not always having to strive. I've discovered . . .you don't have to be perfect . . . Be a bit kinder on yourself; that's a big message I think; don't always try to be perfect (p. 339).

This theme seems consistent with the domain measured on the PTGI named *changing life philosophy/increased existential awareness* (Tedeschi & Calhoun, 1996). The theme *areas of positive change* was consistent with the PTGI domain named *perceived changes*

in self as well as the domain *changed priorities* as the participants reflected gratitude for positive changes in their life and in their values. Emily explained: “The need was to focus on the important things in my life and important people in my life . . . I think you work out your priorities when you’re in the situation” (p. 339). Subthemes in this area were not taking life for granted, valuing relationships, self-awareness, and spirituality. The third theme was that of *supportive relationships*. Participants identified how much they appreciated the support they received from friends, family, and partners in their life. They explained the need to make improvements to current relationships, and a deepened sense of appreciation for the relationships they have. This is consistent with the PTGI domain of *developing closer relationships* (Tedeschi & Calhoun, 1996). The final theme the participants raised was the importance of activities that promoted positive change in their own health. Many participants “obtained a sense of personal control” (p. 340) and contributed towards their own care by educating themselves, attending a program, or asking more questions. “People have to take control . . . you’ve got to look into what the possibilities are and investigate and research and take control” Andrew (p. 340). Jennifer explained, “After diagnosis and treatment I made a concerted attempt to eat healthily . . . and I really made an effort . . . and still do it today” (p. 341). The survivors identified that although the cancer experience was difficult and “traumatic” (p. 337) they valued the beneficial growth they saw in their own lives as a result.

Research indicating concerns with PTG. Hobfoll et al., (2007) offered an insightful critique of PTG based on the results of a series of five research studies conducted through structured phone interviews with Jews and Arabs living in Israel

undergoing terrorism, trauma, war, and loss. Based on conservation of resources theory (COR), the five inquiries explored participants' reported exposure to traumatic events, PTSD symptoms, PTG, self-efficacy, resource loss, and social justice. They found the following:

- As expected, they discovered that those “who experienced greater psychological resource loss and greater PTG reported greater PTSD” (p. 352). This is consistent with COR theory that someone who experienced more significant trauma has greater potential for growth and development than someone who experienced minimal trauma and needed minimal change to return to normal functioning.
- They were however surprised to find in some of the studies that PTG was related to worse outcomes: “Put another way, the data clearly indicate that those who have greater exposure and who are not using PTG avenues for coping are having decidedly better outcomes (than others using PTG)” (p. 354). To explain these findings, the writers discussed the concerns, expressed in other research (Taylor & Brown, 1994; Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000), that PTG may create an illusory perception and palliative thoughts that may not produce meaningful growth.
- Lastly, telephone interviews with Gaza settlers who refused evacuation revealed that PTG may have protected them from a probable PTSD diagnosis. This supported the writer's belief that when PTG was accompanied by meaningful action, PTG became a protective factor from PTSD symptoms.

While Hobfoll et al., (2007) did not make the direct assertion that PTG did not exist, their research raised the question of the validity of PTG when it was not accompanied by positive actions demonstrating the growth of PTG.

Research into PTG with PCS. Research into the PTG of PCS has been scarce but there are some studies that seem to indicate that PCS may benefit from interventions that facilitate PTG. Guðbjartsdóttir (2012), conducted a three-month longitudinal study in Iceland where participants completed a Hospital Anxiety and Depression Scale (HADS), and Impact of Event Scale-Revised (IES-R) shortly after a prostate cancer diagnosis to establish a baseline score. At the three-month follow-up, the participants again completed the HADS and a PTGI to assess perceived areas of growth since the diagnosis. The results demonstrated that “the interaction between post-traumatic stress and post-traumatic growth was a significant predictor of both anxiety and depression, the higher the level of post-traumatic growth the lower the effect of post-traumatic stress on depression and anxiety” (p. 48). While more research is needed, this suggests that PTG may be a meaningful construct to alleviate post-traumatic stress for PCS.

Morris, Wilson, and Chambers (2013) conducted a cross-sectional mail-in survey of 514 PCS to explore gains in compassion as a result of prostate cancer that may not be measured using the PTGI. The participants completed a PTGI and a Dispositional Positive Emotional Scale (DEPS). A Principal Component Analysis revealed that the construct of compassion accounted for 48% of the variance in the data while the overall model accounted for 79.9% of the model. Confirmatory factor analysis validated the compassion as a salient domain of PTG among the sample of PCS. A consideration of

this study is that the participants were more than 7 years post diagnosis and may be removed from the trauma, but may also have the reflective perspective of their experience. This confirmed previous qualitative research where compassion was identified as a newfound or improved quality after a cancer diagnosis (Morris, Shakespeare-Finch, & Scott, 2012). One of the participants explained, “[I now] have great empathy and understanding of how others feel when given a diagnosis of cancer” (p. 792). Morris, Wilson, and Chambers (2014) had also surveyed the earlier 514 PCS to learn that the survivors’ appraisal of cancer as a challenge, their change in core beliefs, and their experience with cancer-related rumination were all associated with PTG.

Thorton and Perez (2006) surveyed 104 PCS with a PTGI, and a Rand 36-Item Health Survey 1.0 a year after radical prostatectomy treatment to explore the relationship between quality of life and PTGI. They discovered that PCS had experienced a modest degree of PTG 1 year after treatment but that their PTG was not related to participants’ quality of life scores. Furthermore, they compared the male PTG scores with documented PTG scores for female breast cancer survivors and found that women reported higher levels of PTG in comparison.

Walsh (2015) conducted qualitative interviews with 18 PCS as part of a larger study to explore the psychometric soundness of the Physical Post-traumatic Growth Inventory (P-PTGI). The participants’ responses demonstrated evidence of “post-traumatic growth in traditionally defined areas ... (e.g., perceived changes in self; developing closer relationships; changed life philosophy/increased existential awareness and changed priorities)” (p. 82). The interviews, however, revealed 4 central themes of

the survivorship experience with the latter two more closely reflecting themes of PTG: *Acceptance, Secrecy vs Support, New Awareness, and Resilience*. *New Awareness* theme reflected the participants' renewed appreciation for their own health and their reported decisions to engage in new healthier behaviors. One participant described:

...my style of eating has changed. I am now more healthy, because I know we have our own lettuce and veg. It's so much fresher, it's nicer to eat, we have fresh eggs, we eat a lot of stir fries now than what we used to (p. 81).

The theme of *Resilience* was accompanied by sub-themes of survival instinct and active coping. The survival instinct sub-theme was characterized by the participants' focus on survival to overcome the disease. Being aware of the side effects one of the participants indicated he would still pursue the prostatectomy "because I think that when there is something bad inside, you get it out as quickly as possible" (p. 71). The active coping sub-theme was characterized by participants who took an active role in educating themselves, remaining engaged with treatment, talking with other patients, and participating in social awareness efforts. For the purposes of this research, PTG will be conceptualized as any positive psychological growth after a trauma (Tedeschi & Calhoun, 1995). The construct of resilience will be more closely reviewed in the next section.

Resilience

When diagnosed, cancer survivors were confronted with a life-altering and potentially life-threatening diagnosis. For some, the diagnosis may have been accompanied by thoughts of dread, fear, and anxiety, but ultimately the diagnosis was followed by decisions of treatment, reflection, and for many, new perspectives of

themselves and their surroundings. For many, the classification of “cancer survivor” is evidence of resilience as it carries the connotation an internal force pushing back against fear and hopelessness to survive (Richardson, 2002). An anticipated phenomenon in data collection interviews and the focus of this study will be the concept of resilience. The lived experiences of PCS may reflect their struggle to cope with and respond to the PC diagnosis and its treatment. Their stories may reflect themes and reflections consistent with the construct of resilience. How prostate cancer survivors experienced resilience, what influenced that experience, and what meaning they derived out of those experiences will be central to the phenomenological inquiry. As resilience is tied to PC survival there is a need to explore the literature for established definitions of resilience. The following review of the literature will explore accepted definitions of resilience, overview the commonalities and differences, and will synthesize the concepts to offer an inclusive definition that will be conducive to phenomenological inquiry.

Commonly accepted as the act of, or ability to, bounce back (Rutter, 1985), the definition of resilience lacks consensus in the literature. As a popular term, the construct has received broad attention from researchers in diverse disciplines such as psychology, neuroscience, sociology, endocrinology, epigenetics, and psychiatry. Discrepancies in the definition make the term more difficult to research as it hinders evaluation and comparison but a broad understanding of the different elements of resilience offer the reader a fuller understanding of the construct. While, ultimately, it is the participants’ experiences with, and understanding of resilience that will guide the inquiry, broader conceptualization of resilience may offer more inclusiveness to participant experiences.

Definitions. The following definitions from the field of mental health will illuminate the common ideas around the concept of resilience but will also illustrate diversity in the conceptualization: (Terms underlined for emphasis)

- "the protective factors and processes or mechanisms that contribute to a good outcome, despite experiences with stressors shown to carry significant risk for developing psychopathology" (Hjemedal, Friborg, & Stiles, 2006, p. 84).
- "a dynamic process of positive adaptation in the context of significant adversity" (Luthar, & Cicchetti, 2000, p. 858).
- "embodies the personal characteristics that enable one to thrive in the face of adversity. ... the multi-dimensional characteristic that varies with context, time, age, gender and cultural origin, as well as within an individual subject to different life circumstances" (Connor, & Davidson, 2003, p. 76).
- "an interactive concept that refers to relative resistance to environmental risks or overcoming stress or adversity" (Rutter, 2006, p. 1).
- "The process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances" (Masten, Best, & Garnezy, 1990, p. 426).
- "The ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event such as the death of a close relation or a violent or life-threatening situation to maintain

relatively stable, healthy levels of psychological and physical functioning, as well as the capacity for generative experiences and positive emotions" (Bonanno, 2004, pp. 20–21).

- "the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of stress" (APA, 2016, para. 4).
- "a process to harness resources to sustain well-being" (Panter-Brick & Leckman, 2013, p. 333).

The definitions seem to be in agreement that resilience has a preceding potentially traumatic event (PTE), consequences, essential attributes, and a response trajectory towards previous levels of functioning (Earvolino-Ramirez, 2007; Fletcher & Sarkar, 2013; Herrman et al., 2011). However, as illustrated in the underlined words, researchers disagree whether resilience is a trait, a process, an outcome, or a mechanism.

When represented as a trait, the literature suggested that resilience is a cluster of characteristics assisting the individual to adapt to the PTE (Connor & Davidson, 2003). Those traits included but are not limited to commitment, hardiness, self-efficacy, past successes, sense of humor, benefit finding, meaning making, and optimism (Earvolino-Ramirez, 2007; Fletcher & Sarkar, 2013; Herrman et al., 2011). Trait-based resilience may be quantitatively measured and researched using the 25 item Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003). When conceived as a process, the literature stresses the beneficial impact of relationships, the stress process, and the selection of and development of coping strategies (Earvolino-Ramirez, 2007; Fletcher & Sarkar, 2013; Herrman et al., 2011). Rutter (2013) made a strong case that resilience is an

interactive phenomenon influenced by a variety of features like the nature of the potentially traumatic event (PTE), the inoculation effect of previous stressors, cognitive coping skills, social relationships, genetic and biological predispositions.

Bonanno conceptualized resilience as an outcome by defining resilience as “a stable trajectory of healthy functioning after a highly adverse event” (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014, p. 2). Bonanno holds that trauma elicits four distinct trajectories of coping patterns that have been confirmed in studies of participant responses to grief (Bonanno et al., 2002), cancer surgery (Lam et al., 2010), traumatic injury (deRoon-Cassini, Mancini, Rusch & Bonanno, 2010), and terror attack (Bonanno, Rennieke, & Dekel, 2005). He described that the mapped trajectory responses of chronic, delayed, recovery, and resilient each represented heterogenic coping patterns among the participants in separate studies. Bonanno (2012) argued that resilience was not a personality trait, not the absence of pathology, and not an average of the typical response to trauma but instead a distinct trajectory more akin to the preservation of homeostasis.

Richardson’s (2002) metatheory of resilience took into account the traits and the process, listed above. He offered a model demonstrating four typical responses to PTEs and promoted a postmodern definition for resilience. He explained that individuals create and maintain a biopsychospiritual homeostasis based on current life circumstances by coping with stressors based on the skills they possess. When a PTE interrupts that homeostasis, he argued there are four outcomes: 1) Resilient reintegration occurs when the participant adapts to the stressor, makes changes, grows, develops new skills, and

returns to higher level of homeostasis. 2) Reintegration back to homeostasis occurs when the participant returns to previous level of functioning. 3) Recovery with loss occurs when the participant returns to lower level of homeostasis. 4) Dysfunctional reintegration occurs when the participant uses of maladaptive strategies to cope with stressors.

Furthermore, he described his resilience theory as a “force within everyone that drives them to seek self-actualization, altruism, wisdom, and harmony with a spiritual source of strength” (p. 313). Under this perspective, as a force, resilience may be the effort moving the person towards reintegration, or resilience may be the well-intended efforts of the individual trying to restore homeostasis through maladaptive strategies. This inclusive model was the result of what Richardson called “three waves of resiliency inquiry” (p. 308) identifying traits, explaining a process with 4 outcomes, and offering a postmodern definition of resilience. The definitions offer a broad reference point from which to understand whether the lived experiences of PCS reflect an experience or theme consistent with resilience.

Components of resilience. Earvolino-Ramirez (2007) conducted a concept analysis of resilience by reviewing the literature and identified characteristics that have been consistently used to describe resiliency. She listed the repeated characteristics and identified them as “defining attributes” (p. 76) of resilience: 1) rebounding/reintegration, 2) high expectancy/self-determination, 3) positive relationships/social support, 4) flexibility, 5) sense of humor, and 6) self-esteem/self-efficacy. These are among items considered to be protective factors in that they ameliorate or shield a person from

potentially negative effects of the PTE (Rutter, 1985). These are also among attributes considered robust predictors of resilience (Rutter, 1993).

Richardson (2002), promoted two resilience postulates in his third wave of resilience inquiry. “Postulate 1: A source for actuating resilience comes from one’s ecosystem” (p. 314). Citing perspectives from nature, the existence of energy at a molecular level, concepts from Eastern medicine, and the philosophical belief in a higher power, he argued that internally people have the ecological sources to provide or trigger resilience. He summarized resilience by describing it as a “force that drives a person from survival to self-actualization” (p. 315). His second postulate was that “Resilience is a capacity in every soul” (p. 315). In this, he argued that while everyone has that capacity, he believed the field of mental health should come to a broader understanding of the soul to be a synergistic experience of the body, mind, and human spirit. He promoted a Transpersonal psychology for “understanding beyond the ego” (p. 315) and a fuller understanding of and access to the energy sources that he defined as resilience.

Working definition of resilience. While the literature reveals disagreement in the definition, there is agreement in the conceptualization of resilience that includes a preceding PTE, a disruption in the life of the participant, and a response that moves the person towards previous levels of functioning (Earvolino-Ramirez, 2007; Fletcher & Sarkar, 2013; Herrman et al., 2011). As demonstrated, there exists support in the literature for resiliency to be conceptualized as a trait, as a process, as an outcome, as a force, or as a combination of these. A synthesized definition that includes these alternatives will allow for a fuller range of reported experiences and offer room for the

participants of this study to explain their experience with resilience in language that remains true to their experience. For the purposes of this research, resilience will be conceptualized as the traits, process, or force returning individuals towards previous levels of psychological functioning after a traumatic event.

Inverse relationship between PTG and resilience. Levine, Laufer, Stein, Hamama-Raz, and Solomon (2009), conducted studies of Israeli teens exposed to terror (N=2908) and Israeli citizens (N=588). Measuring resiliency as the absence of PTSD symptoms after trauma, they used a Child Post-Traumatic Stress Reaction Index (CPTSD-RI; Steinberg, Brymer, Decker, & Pynoos, 2004) with the adolescents and a DSM based PTSD Inventory (Solomon & Dekel; 2007) with the adults. To measure post-traumatic growth, they used the PTGI with both populations. Their results in both studies showed that a lack of PTSD (higher resilience) was associated with the least PTG. This indicated that highly resilient people are more likely to experience lower levels of PTG after a PTE while less resilient people are more likely to experience higher levels of PTG after a similar PTE. Levine, Laufer, Stein, Hamama-Raz, and Solomon (2009), explained that highly resilient people may experience less disturbance to homeostasis as they are more likely to adapt and cope with the stressors, consequently they would experience less PTG. Inversely the person with lower resiliency in the same PTE may experience more disturbance, lack the same coping skills, but may also experience greater gains afterwards in the form of learned skills, insight, and confidence in their ability to cope with future events.

For purposes of this research, PTG and resilience will be understood as two separate constructs. Resilience will be conceptualized as the traits, process, or force returning individuals towards previous levels of psychological functioning after a traumatic event. PTG will be conceptualized as positive psychological growth after a trauma. Distinction in the two may be found in that resilience is defined more by the components of a response process while PTG is defined more by the consequential gains out of the process. Resilience may be characterized by process-based questions like “What sustained you along the experience? What helped you cope after the trauma?” PTG may be characterized by questions of gain or growth like “How have you grown as a result of ___?” “What new insights did you gain as a result of ___?”

Related concepts. Related to resilience are two additional concepts deserving attention, hardiness and thriving. Hardiness, to most people, most closely reflects resilience as it refers to the ability to withstand adversity (Kobasa, 1979; Maddi, 2006). Two important distinctions are that hardiness is a personality trait (Bonanno, 2004) and that “resilience results in an improved or enhanced adaptive outcome, whereas hardiness allows individuals to endure significant adversity but there is not necessarily a positive change or outcome” (Earvolino-Ramirez, 2007, p. 80). Thriving is typically referred to as the PTG that takes the person to a higher level of functioning than they previously experienced through the acquisition of skills, knowledge, confidence, or improved relationships (Carver, 1998).

Resilience and prostate cancer. Scarce research has been done to assess the resilience of and the benefits to prostate cancer survivors. A 2016 Google Scholar search

for *resiliency prostate cancer* in the title revealed 0 results. A similar search for the terms *resilience prostate cancer* in the title revealed 11 results, 1 that was listed twice and 3 were citations of work that was already on the list. The following will provide an overview of the studies listed.

Ranganarsdottir (2012), conducted a longitudinal study of 44 PCS who completed an HADS, Impact of Event Scale-Revised (IES-R; Weiss & Marmar, 1997), and a Connor-Davidson Resilience Scale (CD-RISC-10; Campbell-Sills and Stein, 2007), around the time of diagnosis, three months after diagnosis, and six months after diagnosis. He discovered that lower resiliency scores were associated with higher levels of intrusive thoughts and higher levels of anxiety. Conversely, he also found that higher levels of resiliency were associated with lower levels of intrusive thoughts, and lower levels of anxiety.

Sharpley, Wootten, Bitsika, and Christie (2013) explored whether resilience may be a buffer to depression in the first five years after initial diagnosis with 255 PCS. They measured depression using the self-report Patient Health Questionnaire-9 (PHQ9; Kroenke, Spitzer & Williams, 2001), and measured resilience with the CD-RISC. The findings confirmed a buffering effect of resilience on depression and revealed a significant inverse relationship between resilience and depression. Most of the effect in that relationship was accounted for by one factor from the resilience scale (“Confidence to cope with change”). “It is clear from these data that having the confidence to cope with change was a powerful attribute for dealing effectively with the challenging side effects...” (p. 419). The authors concluded that an important take away from this research

was the importance of developing focused interventions to promote confidence and resilience of PCS.

Sharpley, Bitsika, Wooten, and Christie (2014), investigated the effects of resilience on anxiety and depression in 425 PCS from two different sites. As in the prior research they measured depression using the self-report Patient Health Questionnaire-9 (PHQ9; Kroenke, Spitzer, Williams, 2001), and measured resilience with the CD-RISC. They found that again resilience was a significant buffer to depression. The same factor of questions measuring “Confidence to cope with change” significantly predicted depression. While the value of resiliency to PCS has been quantitatively measured, the research does not represent rich first-hand descriptions of their experiences with resilience or PTG. Qualitative inquiry may offer additional insight into how components of this factor contribute to resilience and may buffer from depression. These results heighten the need for rich descriptive data that may offer indications that will help counselors promote resilience and PTG in PCS.

Conclusion

As the second most common cancer faced by men, prostate cancer offers significant physical, emotional, and social challenges to men. The disease has a devastating physical impact on sexual and urinary functioning which contribute to emotional and social distress among men and their partners. Although prostate cancer has been associated with psychological trauma, functional difficulties, and death, the majority of cancer survivors reported that the diagnosis and treatment experience brought beneficial aspects. Two constructs that may account for the reported beneficial aspects of

cancer are resilience and PTG. The research on resilience or PTG in prostate cancer survivors was scarce. There have not been any published studies exploring resilience with PTG in prostate cancer survivors from a phenomenological perspective.

The central research questions for this research will be: 1) What are the lived experiences of resilience for men who are survivors of prostate cancer? 2) What does resilience mean to men who are survivors of prostate cancer? 3) How do survivors of prostate cancer experience post-traumatic growth? A hermeneutic phenomenological study will specifically focus on the participants' interpretation of the phenomena and the meaning of the language used to reveal the essence of the participant's experience. By learning more about the essence of their experience the intent of this study will be to provide insight that may help professionals promote resilience and PTG to other men suffering from prostate cancer.

Chapter 3: Research Method

Introduction

The purpose of this qualitative hermeneutic phenomenological research was to explore the lived experiences of resilience of PC survivors. The results of this study gave voice to participants, offered a rich description of the participants' everyday experiences, and explored their attributed meaning of resilience that resulted from coping with the adversity of prostate cancer. This research addressed a gap in the literature related to resilience for PC survivors. In turn, counselor educators and supervisors may be more equipped to prepare counselors to understand the experience of the PC survivor and promote resilience in the lives of future survivors. This chapter presents the hermeneutic phenomenological approach, rationale, researcher role, and methodology for this study. A hermeneutic phenomenological study design allowed me to focus on the prostate cancer survivors' interpretation of their resilience experiences and the meaning of the language used to reveal the essence of their experience.

Research Design and Rationale

Central Research Questions

RQ1: What are the lived experiences of resilience for men who are survivors of PC?

RQ2: What does resilience mean to men who are survivors of PC?

RQ3: How do survivors of PC experience post-traumatic growth?

Central Concepts/Phenomena

The central phenomenon was the lived experiences of resilience for men who were survivors of PC. Additional constructs influencing and interacting with the

phenomenon were PC and masculinity. Resilience will be understood as the traits, processes, or forces returning individuals towards previous levels of psychological functioning after a traumatic event. PC is the splitting and proliferation of abnormal cells in the prostate gland (NCI, 2014). Masculinity is a dynamic social construct of gender. Chapter 2 documented how these constructs have interacted with one another. PC and its treatment have been shown to have an adverse effect on the recipients' gendered masculine self-perception. Resilience has been shown to be an adaptive response to this adversity.

Research Tradition and Rationale

Research design and methodology should be driven by the research questions (Patton, 2015). This research gave voice to PC survivors' experiences with resilience and elucidated their definition of resilience. Understanding men's experiences with PC is made more difficult by the various conceptualizations of resilience, the shifting social definitions of masculinity, the reconstruction and maintenance of a man's sense of self after PC treatment, and the social promotion of stoicism over self-disclosure for men. Qualitative research was more appropriate as it pursues in-depth information, yields data that is more descriptive in nature (van Manen, 2015), and promotes the exploration of a phenomenon with "empathic understanding [...] of human behavior and the subjective aspects of the human experience" (Frankfort-Nachmias & Nachmias, 2008, p. 256). The research design of qualitative hermeneutic phenomenology is most closely aligned with the research question, as it gives an opportunity for in-depth information gathering of a

subjective phenomenon, with a view that embraces lived experiences and the participants' perceived meaning of their experiences (van Manen, 2015).

Heidegger, Stambaugh, and Schmidt (2010) defined phenomenology as “to let what shows itself be seen from itself, just as it shows itself from itself” (p. 32). A central challenge of phenomenological research is to reveal something for what it is. In this form of inquiry, I will explore “What is this experience like?” Participants' reflections regarding their everyday experiences with the phenomena will reveal the ascribed meanings they held. A core strategy of this phenomenological inquiry will be retrospectively revealing and describing the fullness, essence, and meaning of an experience as it was actually lived and originally perceived with the recognition that any description will be a reduction of the complex and intricate original (van Manen, 2015). While various strands of phenomenological research have emerged, Giorgi (1989) described four consistent characteristics among them: Researchers will provide rigorous descriptions, use phenomenological reductions, explore relationships between persons and situations, and disclose the essences, or structures, of meaning contained in human experiences. Ultimately, “a good phenomenological description is collected by lived experience and recollects lived experience-is validated by lived experience and it validates lived experience [*sic*]” (van Manen, 2015, p. 27).

Gadamer was a student of Heidegger and expanded the philosophy of phenomenology with a focus towards a contextual human understanding that he called hermeneutic phenomenology (van Manen, 2014). Van Manen explained, “Phenomenology becomes hermeneutical when its method is taken to be essentially

interpretive and primarily oriented to the interpretation of texts” (2014, p. 132). While similar to phenomenology, hermeneutic phenomenology promotes the idea that lived experiences should be interpreted in the context of the participants’ historical experiences and pre-understandings. One’s collection of experiences, insights, and values creates a historicity so deeply engrained in the individual that Gadamer (1975) believed lived experiences could not be removed from their historical context.

Gadamer (1975) held that the researcher must not only attend to participants’ preconceptions but also to their own preconceived notions. He argued that researchers should not set aside their own experiences or preexisting beliefs, but instead bring these to the foreground to more clearly distinguish what belongs to the researcher and what belongs to the participants. To bring the researcher’s historicity to the foreground, the researcher must be willing to participate in rigorous self-reflection. According to Finlay (2008), researchers need to bring a “critical self-awareness of their own subjectivity, vested interests, predilections and assumptions and to be conscious of how these might impact on the research process and findings” (p. 17). This awareness allows the researchers to place their own presuppositions in temporary abeyance to fully explore the participants’ experiences in their full context. Two important constructs of hermeneutic phenomenology are: The epoché and the reduction. The essence of experiencing the world of another free from presuppositions is the epoché (van Manen, 2014). Reduction is gaining “access, via the epoché and the vocative, to the world of prereflective experience-as-lived in order to mine its meanings” (van Manen, 2014, p. 221).

The researcher biases and presuppositions are “not bracketed or set aside, but rather are embedded and essential to interpretive process” (Laverty, 2003, p. 28). The researcher must give considerable thought to their own experiences to identify how their experiences relate to the issues being researched. The researcher’s experiences and presuppositions offer a position of meaning in relation to the other person (Gadamer, 1975). They offer a place from which to experience empathy for the participants (Finlay, 2005; Wertz, 2005) and an opportunity for intersubjective space, experiences, and insights between the researcher and participants (Finlay, 2005).

A cyclical process called the hermeneutic loop may be applied to promote the researcher’s understanding of the phenomena’s parts in the context of the whole, and exploring the whole with reference to the parts (Conroy, 2003). Both the whole and the parts give reference to one another and offer richer context for understanding. Gadamer (1975) explained that looking at the part was like studying a musical note or an athlete. On their own, the note and the athlete have their own qualities, but when looked at as part of a whole, the musical note becomes part of a piece of music and the athlete is a member of a team. In this metaphor then, the part (the athlete) may be studied with reference to the whole (the team), or the whole may be studied with reference to the part. Each frame of reference offers richer understanding and additional data from which to continue the cyclical exploration.

Hermeneutic phenomenology is a strong match for this research as it elucidates lived experience in such a way as to resonate with lived life of men responding to prostate cancer (van Manen, 2014), and it offers the researcher an opportunity to use his

experiences as an added frame of reference and reflection. Richer understanding of the lived experience of resilience for prostate cancer survivors that is congruent and true to their experience may offer insights that will help mental health professionals understand and promote this resilience in other survivors.

Role of the Researcher

In the qualitative tradition, “the researcher is the instrument of the research” (Maxwell, 2005, p. 37). This means that instead of using a standardized test to measure and interpret data, it is the researcher who plays the role of data collection and interpretation (Patton, 2015). While this offers the advantage of researching a concept that the researcher feels passionate about and has an affinity towards, this also presents a challenge of coping with researcher bias and its influence on the process. This section will attempt to explain the researcher’s history, promote researcher posture of empathic neutrality and critical subjectivity, and put forth strategies to achieve such roles.

Researcher History

In 2012, at the age of 43, I was diagnosed with prostate cancer and underwent a robotic-assisted radical prostatectomy. This was the first major illness and medical procedure I had ever experienced so the experience was shocking and overwhelming. I had decided to get screened regularly starting at the age of 40 as my paternal grandfather had been diagnosed with prostate cancer, and his two sons (my Father, and Uncle) were also diagnosed with prostate cancer. Although my cancer was discovered at an early stage, I decided to pursue surgery in an effort to “get cancer out of me” as soon as possible. My urologist patiently answered all of my questions, performed the procedure,

and has continued to provide aftercare support, monitoring side effects as well as bloodwork for recurrence of cancer. At the time of the cancer disruption, I was a husband and father to 5 children still living at home and my feelings of shock had been accompanied by confusion, fear, and uncertainty. I spent time in reflection and prayer seeking to find order, meaning, and benefit out of the experience. I found order, meaning, and benefit by turning the situation into an opportunity to help others while teaching my kids how to deal with adversity. I believed that “God allowed this to create an opportunity to help others,” so I explored avenues for constructive social change. Conducting a social awareness campaign at our local high school during a high school football game became an effective opportunity to raise awareness among the general public, bring other survivors together, and raise money towards a good cause (Lacourt, 2014). Since the initial event, I have conducted additional awareness events and have facilitated a monthly prostate cancer support group.

As a direct result of my experiences, I carry presuppositions that I need to be aware of as a researcher. I will list some of these beliefs below:

- Positive bias towards the use of spirituality for coping.
- Positive bias towards the medical field and its medical treatment of prostate cancer.
- Positive bias towards and empathy for prostate cancer survivors.
- A belief that because I share common experiences with other prostate cancer survivors we may also share in similar feelings, values, and beliefs.

As a researcher, it is imperative that I am aware of these biases to protect the data and my research from being skewed by my own perceptions and to ensure that the experiences of my participants are truly represented. It is important for consumers of this research to understand my potential biases in accordance with van Manen's recommendations promoting self-awareness and reflection (2015). Lipp (2007) promoted a framework for "...deeper and broader dimension of reflection..." (p.18) through the use of reflexive prompts which I will use as a guide for journaling and ongoing reflection to promote self-awareness. I will also explore my biases by completing the Researcher Identity Memo (Maxwell, 2005) self-awareness exercise. My dissertation committee will also serve as peer reviewers offering objective feedback on the process and the findings of this study.

Research Posture

My research posture was characterized by interrelated concepts of empathetic neutrality, critical subjectivity, openness, and wonder. Patton (1990) used the term "empathetic neutrality" (p. 55) to describe a stance in which as a researcher I experience the Rogerian empathy of "entering the private world of the other and becoming thoroughly at home in it" (Rogers, 1975, p. 3), but I preserve neutrality by not proving "a particular perspective or manipulating the data to arrive at predisposed truths" (p. 56). In this posture, the investigator is not detached but does maintain a level of cognitive and emotional understanding of the phenomena that may be a valuable resource in the research process. Reason (1988) described "critical subjectivity" as

a quality of awareness in which we do not suppress our primary experience; nor do we allow ourselves to be swept away and overwhelmed by it; rather we raise it to consciousness and use it as a part of the inquiry process (1988, p. 12).

This ability to perceive the experiences of another while also preserving our own is described by Gadamer (1975) as openness.

This openness always includes our situating the other meaning in relation to the whole of our own meanings or ourselves in relation to it ... This kind of sensitivity involves neither “neutrality” with respect to content nor the extinction of one’s self, but the foregrounding and appropriation of one’s own fore-meanings and prejudices. The important thing is to be aware of one’s own bias, so that the text can present itself in all its otherness and thus assert its own truth against one’s own fore-meanings (pp. 268-269).

Van Manen (2015) argued that researchers should maintain a sense of wonder about their study, requiring a humility to learn from the participants and let the participant’s experiences speak for themselves. This position implies a level of neutrality that carries a deep respect for the data with a fascination for the emerging insights. These concepts share a common sense of respect for the research process, promoting the integrity of the data while also permitting the researcher to carefully include their own experience as a source of data. I strove to maintain such a posture of respect for the data in this research process.

Strategy

To maintain such a research posture, I completed and included the results of the Researcher Identity Memo (Maxwell, 2005) in the Appendix. I also used the Lipp (2007) framework for reflection, and sought peer review from my dissertation committee. The Researcher Identity Memo was designed to help the researcher examine their “goals, experiences, assumptions, feelings, and values” (p. 27) associated with their research. Lipp’s framework of reflexive prompts offered valuable direction to my reflection and journaling. The prompts include the following questions:

What impact am I having on the process?

What impact is this process having on me?

What are my personal responses?

What are the interpersonal dynamics?

What are my motivations?

What are my biases?

What impact has the process, methods and outcomes had on the topic?

What has arisen from my reflexive narrative of the process? (p. 22)

I also engage in journaling to document my experiences with the participants, personal feelings, biases, and changes in perspectives. This study was also be guided by the expertise of dissertation committee members functioning as peer reviewers. Their feedback, questions, and comments will help this researcher identify areas of misappropriated bias and will enhance the trustworthiness of the research.

Prostate cancer survivors were invited to participate in the research through a flyer handed out at a local prostate cancer support group. I recruited participants that I had not previously met to keep personal or power influence from affecting the participants or the research. I had access to volunteer names and demographic information prior to selecting the participants to help me ensure that I had not met the volunteers previously.

Methodology

Participant Selection

Purposive Sampling Polkinghorne (2005) explained that researchers should select “fertile exemplars of the experience for study” (p. 140). In order to do so, this study was conducted with 7 prostate cancer survivors who were between 6 months and 5 years after their initial diagnosis. This purposive sampling will ensure that all participants had experienced the phenomena being studied and could represent the phenomena being studied. The time range of 6 months to 5 years post diagnosis ensured that the participants had a close proximity to their post-diagnosis response. The time range also excluded survivors with less than 6 months to give them time to respond to their diagnosis and determine initial treatment decisions. None of the potential participants demonstrated active psychological distress. Active psychological distress would have disqualified volunteers from participating and would have triggered a referral to a local mental health provider for support services.

Sample Size Patton (2015) stated: “There are no rules for sample size in qualitative inquiry” (p. 184). Sample size will depend on what the researcher seeks to

explore and how broadly that information will be applied (Patton, 2015). If the researcher only hopes to describe the surveyed population then that size will suffice. Patton (2015) confirmed that “The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities of the researcher than with the sample size” (p. 185). Connelly (2010) stated “In phenomenology, sample sizes often will be relatively small and purposeful” (p. 127) and cited a phenomenological study with only 7 participants. Their rationale was that a large volume of information that would be gained by an in-depth interview.

In this research, interviews were conducted until saturation occurred in the data. Upon completing 7 interviews, I observed significant commonalities in the men’s reports and minimal new insights or information. I determined the data was saturated when no new themes emerged and the data demonstrated patterns of redundancy.

Participation The participants were invited to participate from participants at a local prostate cancer support group. This pool of potential participants was appropriate as they experienced the phenomena of prostate cancer survivorship and could speak to their lived experiences with the disease. This group offered a typical representation of the setting, experiences, activities, and decisions faced by prostate cancer survivors. The flyer (Attached in the Appendix) included information about who was qualified to participate, what was required of those who participated (time commitment), why they should consider participating, how this research had been approved under university supervision, and how to contact me to be considered or to learn more about the study. I

handed out the flyer to the attendees of a prostate cancer support group in northeastern Ohio.

Interested attendees were invited to complete a demographic questionnaire that confirmed the type of cancer and the date of diagnosis to ensure they met the criterion. The initial responders meeting the criterion were called by phone to review the purpose of the study, confirm their understanding, and willingness to participate. A meeting time and location convenient to the participants was also selected. I sought to conduct the interviews in locations that offered privacy but also “feels right” (van Manen, 2014, p, 315) to the interviewee. These locations included the participants’ home, a quiet coffee shop, and a library conference room. The location was determined on a case by case basis based on participant comfortability and privacy. After the phone call I e-mailed the participants a blank informed consent form to give them a chance to read it prior to meeting with them.

Consistent with Rubin and Rubin (2005), I will strove to demonstrate warmth, acceptance, and respect to gain the confidence and trust of the interviewee from the beginning of the initial phone call and throughout the interview. At the outset of each interview, I discussed the informed consent process and collected their signature on an informed consent form. As part of the informed consent process, participants were also be informed that they were not under obligation to answer any question that made them feel uncomfortable and that they were permitted to end the interview at any time. Relaxed, semi-structured interviews lasted an average of 54 minutes with the longest interview lasting 86 minutes and the shortest interview lasting 39 minutes. All interviews

were audio-taped with an Olympus Digital Voice Recorder (VN-721PC) which automatically saved the audio interview into an electronic audio MP3 format.

At the interview, each participant received a \$20 gift card from a major retail store as a thank you for their time, future contact information to follow-up on the research, a list of local counseling resources, and local prostate cancer support group information. The participants were invited to contact me in the event they would want to contribute additional relevant information that they may recall after the interview was over. I sent the completed transcripts to the participants via e-mail 6-8 weeks after the actual interview to verify accuracy. In the e-mail I invited the men to participate in on-going dialogue with me about any insights they gained or feedback they had about the experience. About 12 weeks after the interviews, I sent the participants an early draft of the findings to invite feedback and confirm the validity of the results. I received affirming responses from 3 of the participants but I did not receive additional insights.

Instrumentation

Data sources. The principal data collection instruments were the semi-structured interviews, field notes, and a reflective journal. The semi-structured interview followed an interview guide approach (Patton, 2015) in which prewritten researcher produced questions will served as a guide for an open conversational discussion. Questions were generally asked in sequence depending on the discussion at the time. The prewritten questions encouraged the participants to tell their stories by bringing them closer to their lived experiences. “As we interview others about their experience of a certain phenomenon, it is imperative to stay close to the experience lived ... then explore the

whole experience to the fullest” (van Manen, 2015, p. 67). The narrative content served as a source for richer understanding of the phenomenon and it drew out reflective insights from participants about the meaning they had ascribed to their experiences. Field notes structured after Janesick’s (2004) sample in Figure 2.1 (p. 20) collected in the moment Notes to self as well as Observations that contributed to later data analysis. A reflective journal offered a place to explore my thoughts, reactions, and insights to the research experience. This has been shown to be a helpful tool to separate researcher’s beliefs and biases from that of the participants and provide more integrity to the data collection process (Janesick, 2004). Most of the interview locations were approximately 45 minutes away. I used the 45 minute drive to the interview to mentally prepare for the experience, and I used the drive back home to reflect on the content and experience.

Interview questions. The interview questions were derived from the central research questions with a focus on promoting disclosure of the participant’s narrative (van Manen, 2015). The first central research question inquired about the actual experiences of the men, so narrative responses were connected to that research question. The second question inquired about the meaning derived from the phenomenon so the interview data reflecting their opinions, beliefs, values was connected to that question. The following interview questions promoted narrative discussion, reflection, and expanded on these central questions with a role to explore, explain, and describe the phenomenon:

1. What was it like when you learned you were diagnosed with prostate cancer?
(Explore)

2. What is your most vivid recollection of that period? (Explore)
3. What experiences are most vivid for you? (Explore)
4. What was it like to disclose your diagnosis to others in your life? (Explore)
5. How did this discovery affect you? (Explore)
6. What were the different ways you responded to this diagnosis? (Explain)
7. Where in this process did you first become aware of your resilience?
(Explain/Describe)
8. How was this experience different than other moments when you have felt resilience? (Explore)
9. What was that like to discover your resilience? (Explain/Describe)
10. Where in your body do you feel your resilience most? What do you mean by that?
(Explore/Explain)
11. How or what did you feel as you experienced your own resilience? (Describe)
12. What did you do as a result of your resilience? (Explore/Describe)
13. What experiences have caused you to feel more resilient? (Explain)
14. What experiences have caused you to feel less resilient? (Explain)
15. What role, if any, did resilience play to affect your prostate cancer experience?
(Explain)
16. What role, if any, did resilience play to affect the meaning of your prostate cancer experience? (Explain)
17. What gains, residual benefits, or insights do you feel like you have discovered as a result of your experiences? (Explain)

18. What changes in your self have you experienced as a result of your experience?

(Explain)

19. What changes have you experienced in your close relationships? (Explain)

20. What changes have you experienced in your philosophy, or spirituality as a result of your experiences? (Explain)

21. How have your priorities changed as a result of these experiences?

(Explaining/Describe)

22. How do you see yourself differently as a result of your experiences? (Describe)

23. What advice would you offer other men to help them be more resilient through their experiences of prostate cancer diagnosis and treatment? (Explain)

The following open-ended prompts were used to probe further and facilitate discussion:

1. Tell me more about that...
2. Could you give me an example?
3. Could you explain that further?
4. What do you mean by that?
5. How so?

The questions possess content validity by consistently naming the construct, seeking to explore it, explain it, and describe it, and they also ask the questions in a manner that is methodologically consistent with the narrative research approach of hermeneutic phenomenology (van Manen, 2015). Additional validity verification was provided by the dissertation committee operating as peer reviewers. The questions effectively promoted discussion and exploration of the phenomena and facilitated the participant's storytelling.

Data Analysis Plan

A phenomenological approach lends itself to an abstract process of data interpretation. Descriptions of phenomenological data analysis generally focused on strategies or methods (Keen, 1975; Patton, 2015; van Manen, 2015) instead of specific concrete steps. For example, van Manen wrote that “Hermeneutic phenomenological research may be seen as a dynamic interplay among six research activities” (2015, p. 30). Keen (1975) explained, “unlike other methodologies, phenomenology cannot be reduced to a 'cookbook' set of instructions. It is more an approach, an attitude, an investigative posture with a certain set of goals” (Keen, 1975, p. 41). In spite of this, phenomenological researcher, Hycner (1985) created and promoted a clear set of concrete steps that the researcher could take to analyze data in a manner that was consistent with a phenomenological perspective and utilized a hermeneutic loop. Hycner (1985) explained that these steps could serve as a guide to the researcher and that, ultimately, the best “research method must arise out of trying to be responsive to the phenomenon” (p.280). The following steps served as a guide illuminating my process of data analysis, while also offering transparency on how this research was conducted. I revisited these steps during the data analysis process and I have shared them to facilitate repeatability.

Hycner’s (1985) steps to phenomenological analysis are listed below:

1. Transcription.
2. Phenomenological reduction.
3. Listening to the interview for a sense of the whole.
4. Delineating units of general meaning.

5. Delineating units of meaning relevant to the research question.
6. Training independent judges to verify the units of relevant meaning.
7. Eliminating redundancies.
8. Clustering units of relevant meaning.
9. Determining themes from clusters of meaning.
10. Writing a summary of each individual interview.
11. Return to the participants with the summary and themes: Conducting a second interview.
12. Modifying themes and summary.
13. Identifying general and unique themes for all the interviews.
14. Contextualization of themes.

Data analysis in phenomenological research is not intended to be a fixed linear approach but instead a series of loops where the researcher would visit and revisit the data to explore it from different perspectives through different strategies (Conroy, 2003; van Manen, 2015). This is demonstrated in the hermeneutic loop in which the parts of a specific interview are understood in relation to the whole and the whole in the context of the part (Cohen, Kahn, & Steeves, 2000). The steps by Hycner (1985) promote this back and forth interaction of looking at the whole (Step 3, “Listening to the interview for a sense of the whole”), looking at the part, (Step 5, “Delineating units of meaning relevant to the research question”), then looking at the whole again, (Step 9, “Determining themes from clusters of meaning”) and back to the part (Step 10 “Writing a summary of each individual interview”). Using the parts to understand the whole and the whole to

understand the parts will offer rich text based insight into the phenomenon (van Manen, 2015).

I used both a priori codes (diagnosis, resilience, and changed life) and emergent codes to initially organize my data. The predetermined list of a priori codes (diagnosis, resilience, and changed life) was derived from the research questions, the conceptual framework, and the interview guide. I had planned to assign each of the a priori codes a color and planned to use color coded markers to mark these on the printed paper transcripts. Instead, I initially organized all of my data visually through the use of the online visual presentation medium called Prezi. This was a medium I was already comfortable with and it prevented me from printing all of the transcripts onto paper. I re-listened to the audio interview while reading the transcript. As the data revealed new clusters of meanings, activities, or concepts they were assigned a new code. These emerging codes were developed as the data revealed new information. As a new code emerged I copied and pasted the participants' quotes from the transcript in Microsoft Word, into the Prezi display in a location that was most consistent with the statement content. I gave each participant a different bubble quote shape to illustrate the different sources. I wrote memos explaining the rationale behind the creation of a new codes in order to be transparent and keep record of my thought development during the research process. Codes contributed to the themes of the research as the codes may stand alone to form a theme or may be combined with other related codes to form a theme.

Themes, according to van Manen (2015) are "structures of experience." These experiential structures repeated in the interviews data were identified and explored

further. Per step 5, the structures that are relevant to the research question will be delineated from those not relevant to the research question. Van Manen (2015), described these as essential themes, and incidental themes. The essential themes, like the participants' descriptions of resilience, were those which "make a phenomenon what it is and without which the phenomenon could not be what it is" (p. 107). An incidental theme, like which treatment the participants selected, did not add to the central phenomenon and left the central phenomenon intact when removed. The themes were essential to the process as the themes offered structure to the narrative explanations of the phenomenon (van Manen, 2015).

Initially, I read the data to gain a sense of the whole and to identify essential themes with the use of Prezi. I identified codes and organized the data into themes. The visual medium of Prezi allowed me to drag and drop the bubble quotes of common meaning into a common area on the canvas and to cluster them around a theme. After posting all of the interview content onto the Prezi canvas, I went back to the original transcripts to re-code the interviews through the data analysis software Atlas.ti. Re-listening and re-coding gave me a chance to gain a sense of the whole again and pick up on details I had missed in the original coding. In the second coding with Atlas.ti, I tried to look at the data with a fresh perspective, focus on discovering significant statements, statements of meaning, textural descriptions of the phenomena, and structural descriptions of the phenomena.

I gained a sense of the whole by listening to the interview and reading the transcriptions. I read the interviews closely to identify units of meaning, engage in

phenomenological reduction, and cluster together items with common meaning. I participated in all of these activities initially through Prezi, and then engaged in them again through the use of Atlas.ti. The process of looking at the whole and then focusing on the details through the use of two sequential mediums was intentional to ensure that I was interacting with the data in a hermeneutic loop. After the second coding in Atlas.ti, I ran several reports that I compared back to the Prezi canvas to identify codes or themes I had initially missed. After identifying missed codes, I went back and added them to the Prezi canvas. As described above, my general approach was to listen and read the data as an overview, and then identify codes, essential, and incidental themes initially through Prezi and then through Atlas.ti. Effort was also made to discover, understand, and present the discrepant data as a part of this research.

Issues of Trustworthiness

Trustworthiness is a set of criteria for qualitative research that parallels the criteria required of conventional research: internal validity, external validity, reliability, and objectivity (Schwandt, Lincoln, & Guba, 2007). In their place, the parallel criteria for qualitative research are credibility, transferability, dependability, and confirmability (Schwandt, Lincoln, & Guba, 2007). The following will review the four criteria and how the accuracy of the data and the results will be assessed.

Credibility

To determine credibility, researchers will ask, *how confident can we be in the truth of these findings?* (Krefting, 1991; Shenton, 2004). As an analog to internal validity, credibility ensures that the findings are indeed an accurate reflection of the data collected

(Schwandt, Lincoln, & Guba, 2007). I engaged in the following strategies to ensure credibility; 1) researcher positionality, 2) prolonged engagement, 3) source triangulation, 4) peer independent review, and 5) member checks. Researcher positionality reflects my ability to embrace the research data as it is, but to also see it through the empathetic lens of one who has also experienced the phenomena. I engaged in prolonged engagement by building trust with the participants, spending ample time with them for the interview, offering a second interview to permit the participants to offer further explanations, and reviewing preliminary findings with them as a form of member checking. Spending time together interacting and observing helped identify and confirm salient issues to the phenomenon. I practiced source triangulation by cross-checking the consistency of the data from one participant to another. The dissertation committee served as peer reviewers to confirm the process and also served as a devil's advocate provoking thought and integrity to the process. I also identified the discrepant data and reflected its relation to the whole.

Transferability

To determine transferability, researchers will ask, *how well can the findings be applied to other people in other contexts?* (Krefting, 1991; Shenton, 2004). As an analog to external validity, transferability seeks the extent to which broader applications may be made from the findings. Insights from the lived experiences of prostate cancer survivors may offer insights into the experiences of other men or women with different cancers or diseases. I provided rich and thorough descriptions of the setting, the participants, their experiences, and the context so that the reader can take these into consideration when

trying to transfer the information to another group. Readers may find the results offer insights that may contribute towards understanding and helping other populations.

Dependability

To determine dependability, researchers will ask, *how consistent would the findings be if the same inquiry was repeated in a similar context?* (Krefting, 1991; Shenton, 2004). As an analog to reliability, dependability is concerned with the “stability, consistency, and equivalence of the study” (Krefting, 1991). Lincoln and Guba (1985) argued that credibility and dependability were closely interrelated and that strong credibility would yield strong dependability. To promote dependability, I documented a clear and detailed research process that will enable future researchers to repeat the work. Keeping an audit trail and inviting a peer review from the dissertation committee promoted a clearer process and an accurate product.

Confirmability

To determine confirmability, researchers will ask, *to what degree are the findings free of bias?* As an analog to objectivity, confirmability is the concern for neutrality and the influence of researcher bias. I will promote confirmability by acknowledging biases from the start of the research through the use of a Researcher Identity Memo (Maxwell 2005), recording personal reflections of my research experiences, and remaining open to redirection and feedback from my committee. The committee acted as peer reviewers who are aware of my biases and payed attention to ensure that my findings are not influenced by my biases.

Ethical Procedures

Prior to engaging in recruitment or data collection I sought permission from the Institutional Review Board. Participants were not be deceived nor coerced into participating in this study, it is entirely voluntary. I sought participants from a local prostate cancer support group in northeast Ohio. I visited a local prostate cancer support group with a regular attendance of 25-30 men, explained the research to them, and recruited their participation. I had never attended the group before nor met the attendees of this group.

Prior to the selection, I held a phone conference with interested participants to answer their questions, review the procedures, the purpose of the study and confirm their participation. After reviewing the pertinent information, if the prospect was still interested, I placed the prospect's name on a list of potential participants. After holding all of the phone conferences, the participants were selected from the list of potential participants. Both the participants and non-participants were informed via e-mail of their status. To avoid a dual relationship, conflict of interest, or power differential, I excluded any participant with whom I already had a social or work relationship.

The interviews were recorded using a laptop audio recording program that saved the recording into an audio .MP3 file format. MP3 is an audio compression designed to store audio files. Files were backed up to a password protected device that was stored in a secure location to protect the anonymity of the participants. The files were transferred securely to an online transcription service. To protect the data, all written notes, consent forms, demographic information, audio files, transcriptions, digital files, and the research

journal will be stored in a secure locked cabinet for 5 years after the study is concluded. I am the only person with access to these materials for that time.

Summary

This chapter reviewed the research design, methodology, and procedures for this study. A hermeneutic phenomenological design elucidated the lived experience of prostate cancer survivors. The researcher's experience with prostate cancer, bias surrounding prostate cancer, and research posture were also explored. Explanations consistent with qualitative data collection and analysis were also reviewed in enough detail to enable a future researcher to reproduce the study. Chapter four will provide an analysis of the data collected and the findings of this study.

Chapter 4: Results

Introduction

The purpose of this qualitative hermeneutic phenomenological research was to explore and describe the lived experiences of resilience of PC survivors. The results of this study will give voice to participants, offer a rich description of their everyday experiences, and offer insights into the meaning of resilience for these men as they coped with the adversity associated with PC. The central research questions were:

RQ1: What are the lived experiences regarding resilience for men who are survivors of PC?

RQ2: What does resilience mean to men who are survivors of PC?

RQ3: How do survivors of PC experience post-traumatic growth? This chapter will review the setting and background of the participants, as well as the data collection procedures for this study before exploring the central themes and discoveries of this research.

Setting and Demographics

The participants in this study were invited to participate through a presentation and distributed literature at a PC support group in northeast Ohio. On two different occasions, I offered a 5 minute presentation in which I introduced myself as a PC survivor, explained the purpose of the study, and distributed literature to recruit participants. All of the participants in the support group were voluntary attendees and may be more accustomed to listening to and talking with others about their PC

experiences than other men experiencing the disease. This should be taken into account when considering their narratives.

The seven men who participated in the study were on average 65 years old at the time of their PC diagnosis and 68 years old at the time of their interview. All of the men were White Caucasian, and six of the seven were married at the time of the interview. One of the participants was divorced and single. All men had the independence and resources to transport themselves to the group and to the interview meeting. None of the men lived in an assisted living or nursing home facility.

Data Collection

Seven men emailed me expressing an interest in participating. I conducted a brief phone conversation with each prospect to review the purpose of the research, the nature of confidentiality, and their right to withdraw from the research at any time, as well as confirm their diagnosis was between 6 months and 5 years from the research date, answer their questions, and set up a location, date, and time that was convenient and comfortable for them. I e-mailed each of them an individual a copy of the informed consent form to give them a chance to read it in advance before the interview. I also brought a copy of the informed consent form to the interview to review and sign before the interview. Of the seven interviews, four were held at a local public library, two were held at a local coffee shop, and one was held at the participant's home on their front porch. Upon meeting with participants, I promptly thanked each of them by giving them their gift card, answered their questions, and proceeded to review and sign the informed consent form.

At this point, with their consent, I started recording the session with an Olympus Digital Voice Recorder (model number VN-721PC) and began the semistructured in-depth interviews with my first interview question. The interviews were on average 54 minutes in length, with the longest interview taking 86 minutes and the shortest interview taking 39 minutes. The only variation from my anticipated data collection procedures was that instead of using my laptop to audio record the interviews, I instead used the Olympus recorder which automatically saved the files into an .MP3 format.

Participants

In this section, I will briefly describe the PC survivors who participated in the interviews to discuss their experiences. I assigned each of the men a pseudonym to protect their identity. The names were assigned to the transcription in alphabetical order. The attendees in the group may be known to one another, so I have intentionally omitted personally identifiable information about them in the following descriptions. I focused on the background and perspective of each participant in this section.

Andy. Andy was diagnosed with PC at the age of 70 and was 75 years old at the time of his interview with me. Andy's diagnosis of an aggressive form of PC came as a surprise to him as he had generally lived a healthy life. He explained that he and his wife took a very realistic approach to the diagnosis and a positive outlook towards the treatment.

During his interview, he stressed how important conducting research and gaining knowledge about the disease and its treatment promoted his resilience. He and his spouse took the various treatment side effects into account as they decided on a specific

treatment. Andy eliminated treatment options based on the side effects of each treatment, “You have to find what you can’t live with,” he explained. He decided to undergo radiation treatment because he anticipated a more favorable side effect experience. He defined resilience as a positive mental attitude and credited his resilience with helping him overcome his feelings of depression due to the PC diagnosis. It was important for him to share with other men the realism of the PC experience and help them have a realistic perspective about the disease. He enjoyed helping other men and said: “this is a channel that I am an expert in.”

Bart. Bart discovered his diagnosis nearly 8 months prior to his interview, through a routine check-up at the age of 68 while preparing for his second knee replacement surgery. Bart’s two older brothers were diagnosed with PC 17 years earlier, so he knew it was a possibility that he may develop PC. He had monitored his PSA but the last numbers were trending downward so he was surprised to learn that the number had increased. The biopsy revealed cancer in all twelve biopsy cores. Between this and the fact that both of his brothers had had radical prostatectomies, Bart said it was an easy decision for him to also select a radical prostatectomy. After successful surgery, Bart and his doctors continue to monitor his post-surgery PSA score to determine the next course of action.

He explained that he learned about PC and its treatment by asking his brothers and other men who had experienced PC. Learning about PC helped him feel more confident. He accentuated the role of knowledge in his resilience experiences. He affirmed that the place in his body where he felt resilience the most was in his mind. He

preferred learning about PC by talking with others, and said he also enjoyed talking with other men to support them through their discovery and treatment. The advice he has shared with men who are newly diagnosed is to “Be as transparent as possible” and “Learn, learn, learn.”

Chuck. Chuck was diagnosed with prostate cancer at the age of 68 and was 72 years old at the time of his interview. A digital rectal exam (DRE) revealed a nodule that initiated a period of 8-9 years of monitoring his prostate gland through PSA scores and three biopsies. He was determined to undergo a radical prostatectomy, influenced to a large part by his professional medical training. Three months after the surgery he discovered that his PSA began to rise again and after discussing with his doctors, he opted to get radiation. After radiation, his PSA was undetectable and remained undetectable at the point of his interview.

He reported that supporting his spouse through her breast cancer experiences and chemotherapy treatment prepared him to cope with his own diagnosis and treatment. He gave his spouse credit for inspiring his resilience during his treatment recovery. His previous knee surgery taught him that physical exercise prior to the surgery contributed to a shorter recovery time. Prior to his radical prostatectomy, he placed himself on a regimented routine of performing Kegel exercises to cope with the possibility of incontinence. He explained that that form of preparation helped his recovery and helped him be more resilient. Chuck and his spouse enjoy the outdoors by traveling to other countries, hiking, and bird watching.

Dave. Dave was 60 years old when he learned he had prostate cancer and was 63 years old at the time of his interview. A DRE check by his family doctor revealed a lump on his prostate gland, which triggered a PSA check, and a biopsy. After receiving the official diagnosis, he opted to research his options and engage in an active surveillance response to cancer which included a PSA check every three months and a yearly biopsy. He jokingly expressed that he was “looking forward” to his fourth biopsy in six months. He reported that his decision to engage in active surveillance has been accompanied by second guessing and some anxiety over what treatment to finally pursue. He took comfort in knowing that his doctors were very patient and had his best interests at hand.

“The first three months after my diagnosis I thought it was a death sentence.” After a time discussing it with others, researching more about the treatment options, and attending a men’s support group, he slowly grew more and more comfortable coping with the disease. He teared up during his interview describing how several friends from his church came to his home and prayed with him. While the medical websites were initially more helpful to help him expand his knowledge base, he explained that he found more comfort and resilience by talking with caring compassionate people like his doctor or other prostate cancer survivors. On more than one occasion he reported that he enjoys nagging and bugging his friends to make sure they get a PSA check. Important themes in his coping were positive thinking and the compassion and care he experienced in his relationships with others. Dave stated: “There is nothing like that human factor.”

Eric. Eric described that his journey with prostate cancer began when his best friend of 35 years informed him he had terminal prostate cancer. Eric’s best friend passed

away 18 months after telling Eric about his disease. Eric's own routine medical check-up revealed his own PSA score was slightly elevated so the doctor monitored it more closely. This led to a biopsy revealing that 7 of 12 biopsy cores tested positive for cancer. This experience impressed upon him the urgency to treat the disease aggressively, which to him meant, having the gland removed through a radical prostatectomy. Four years after treatment, at the time of the interview, Eric continued to deal with incontinence issues, but his PSA remained undetected.

During his interview he explained that he was driven to live up to the legacy of his close friend who lived the last months of his life with dignity and faith. He used word pictures to illustrate his experiences;

- He explained that he developed resilience early in his life growing up in lower socioeconomic neighborhood dealing with gangs and fighting to survive, so fighting back against cancer was, "just part of my nature."
- He described resilience as the air inside the basketball that helps the basketball bounce back up when it is dropped.
- This experience with prostate cancer was like going from playing backyard baseball to standing in the hitters box watching a pitch in the major leagues come at you.
- Eric described that being diagnosed with prostate cancer was like driving down the highway at 60 mph and hitting a big pot hole, making adjustments, and continuing to move forward.

As a result of the diagnosis, he and his wife decided to retire at 65 to enjoy more retirement time together. He also credited his Christian faith and upbringing as being the most constructive to his resilience.

Frank. Frank was diagnosed with prostate cancer at the age of 71 based on his PSA scores. He kept detailed records of his PSA scores and approached the diagnosis from a very straightforward and pragmatic perspective. He read books about the disease to inform himself, focused on the facts about his actual condition, and sought the advice of professional researchers to determine treatment. He practiced active surveillance for five years before deciding to get a prostatectomy at the age of 76. His future longevity and the quality of his life were the deciding factors he reflected on in his decision to have a prostatectomy done.

...even though I felt I had a low-grade version at the point, that I had to make a decision on treatment, I had to decide between okay quality of life versus the effects of the treatment and you face a trade-off and I've often told people you never know whether you make the right decision or not until the day you die.

He described that learning more about the disease helped him feel more resilient. He explained how learning about the disease gave him a stronger perception of control, which motivated him to “make sure that it (the disease) didn't get out of control.” Learning about the disease gave him a stronger perception of control, which helped him feel more confident about his condition.

Gus. Gus learned of his elevated PSA at the age of 53 through an annual health fair screening at work. A follow-up screening a year later confirmed the earlier score

which led Gus to follow-up with a urologist and pursue additional PSA scores. The biopsy confirmed the presence of cancer when Gus was 55. Describing the moment when he learned his diagnosis, Gus said, “I became emotional you know I was like what am I going to do? What am I going to do? Am I going to die?” Gus did not know that prostate cancer was survivable, so the discovery was very upsetting. He credits his medical doctor for calming him down, “...he put his hands on my shoulders, he looked me right in the, he goes, ‘I’m telling you, you’re going to be fine. This happens all the time. You’re going to be fine.’” He opted to undergo a surgical procedure for removing the prostate gland called a prostatectomy.

Throughout his interview, Gus equated resilience with physical strength. He described his resilience as his ability to return to work, his ability to lift weights again, or his ability to engage in sexual intercourse. Physical accomplishments served as benchmarks that helped him feel more resilient. During the interview, he reflected on the progress he had made and said “It’s been a long time since I’ve had those thoughts like you know, ‘woe is me’ type thoughts...I guess that’s resiliency I guess as I’m saying it. I don’t even have those thoughts anymore.” He credited co-workers, his spouse, and his faith for promoting resilience into his life.

Data Analysis Process

The purpose of this qualitative, hermeneutic phenomenological research was to explore and describe the lived experiences of resilience of prostate cancer survivors. After conducting my interviews, I listened to the audio recording and took notes for a sense of the whole. After receiving the transcriptions, I read through each one closely

looking to identify units of meaning. I selectively highlighted items from the transcription that communicated significant statements, statements of meaning, textural descriptions of the phenomena, and structural descriptions of the phenomena from the participant experience and then created codes for each of these items.

I used the web-based online presentation tool, Prezi, as a visual medium to help me organize my data. Much like PowerPoint, Prezi offers the ability insert content and create an attractive visual presentation. I used images, shapes, quote bubbles, and colors to help organize the content. Prezi is distinct in that it offers the ability to zoom in and out of one large canvas where all of the presenters' content is displayed. This ability to zoom in on one piece of data and then zoom back out to view the entire collection of data is a unique feature that made this medium even more appropriate for qualitative data analysis where the researcher must understand the part in context of the whole (Cohen, Kahn, & Steeves, 2000). This feature supported the hermeneutic loop as I zoomed in on details, and then zoomed out to see the larger context of how the codes and comments fit into the bigger picture.

I copied the each of the coded interview quotes from Microsoft Word and pasted them onto the Prezi canvas. I assigned each participant a different quote bubble shape to distinguish the different voices and then grouped the quotes according to commonality and meaning. To explore meaning from the interviews, I organized my data on the canvas around a priori codes and themes while looking for emerging themes. The interview questions were organized around 3 structures of their cancer narrative; 1) their diagnosis experience, 2) their experience of resilience, and 3) any perceived sense of change in

themselves as a result of their cancer experiences. The participant responses were organized around these three structures which were my major themes and their responses coalesced around a number of commonalities which I identified as sub-themes with the use of a circle shapes on the canvas. The sub-theme circles contained their own supporting quotes with a title to identify the content. After entering all of the interview content onto the Prezi canvas I re-listened and carefully re-coded all of the interviews through the Atlas.ti software analysis program. This additional process illustrates how I engaged with the data in a hermeneutic loop as I listened again for a sense of the whole and tried to look for codes with a new perspective. After the second coding in Atlas.ti, I ran several reports from Atlas.ti that I compared back to the Prezi canvas to identify codes or themes I had initially missed. After identifying missed codes, I went back and added them to the Prezi canvas.

Figure 1 demonstrates a portion of the Prezi canvas. The key with the circle representing the sub-theme and the different quote bubbles for each participant. Figure 2, illustrates how I grouped similar quotes around the participant's diagnosis experiences. Under the sub-theme of experiences, I sub-grouped experiences surrounding the participants' cancer discovery including whether the participant's cancer discovery was due to a rise in PSA scores or a DRE check, if their family had a history of prostate cancer, their experiences with a biopsy, vivid moments, and whether the diagnosis was a surprise or anticipated. Some of the circles, although they represented different sub-themes, had areas of commonality and these were represented in the circles overlapping one another. For example, Bart described that he was anticipating the diagnosis of

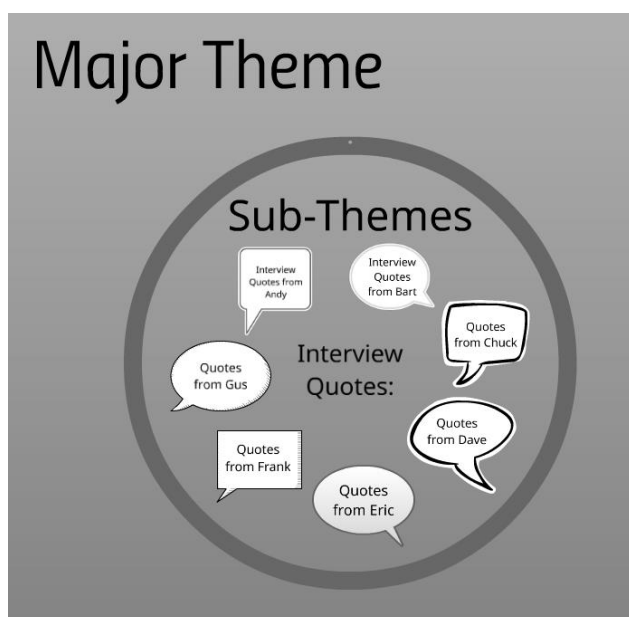


Figure 1. This key shows the large square as a major theme, circles for the subthemes and different quote bubbles for each participant.

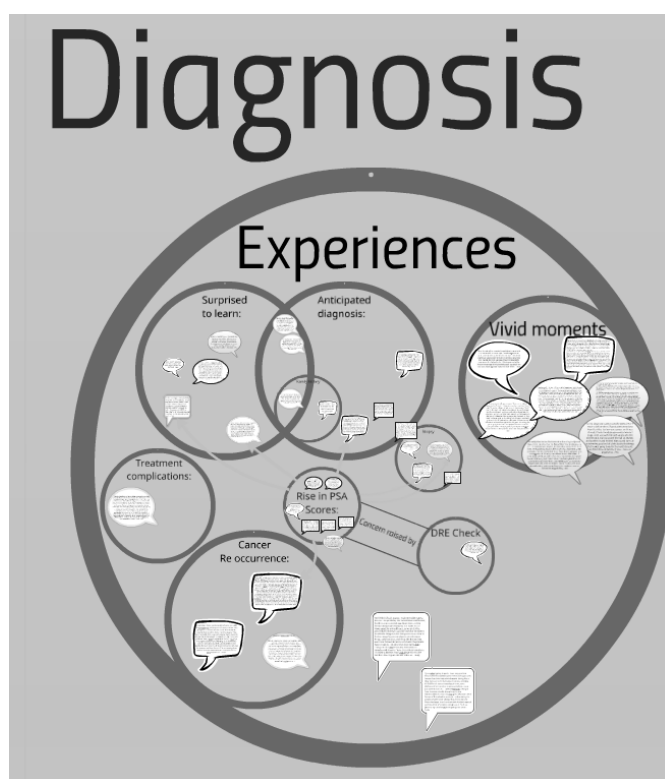


Figure 2. The major theme of Diagnosis with its subthemes.

prostate cancer and his statements qualified under the sub-theme of “anticipated diagnosis.” However, once he heard the diagnosis from the doctor, he reported “That was a big surprise.” This second statement qualified under the “Surprised to learn” sub-theme. By overlapping portions of both circles, like a Venn diagram, I created space for the intersection of very different responses and illustrated other responses that shared commonalities. While some of the sub-themes may have been anticipated, all of the sub-themes in the circles emerged directly from the interview content as I discovered commonalities between the various participants. Once I had organized all of the participant quotes onto the Prezi canvas, I listened to the audio interviews again to revisit a sense of the whole before coding the data into the Atlas.ti coding software.

Coding into Atlas.ti software was a process of re-reading each interview, highlighting content, and connecting it to a code. I used the same code structure as I had created with the Prezi but the coding on Atlas.ti was more thorough and it helped me catch and organize codes I had missed in the earlier process. This second pass also contributed to the creation of more sub-themes. The initial round of coding helped me to discover structure while the second round of coding helped me focus on details I had missed prior. This data analysis process remained consistent with my plan for inquiry in that it consistently followed a process of using the parts to understand the whole and the whole to understand the parts (van Manen, 2015). In the next section I will present the major themes with their sub-themes and their supporting quotes.

Major Themes and Sub-Themes

The interview questions were organized around 3 structures of their cancer narrative; 1) their diagnosis experience, 2) their experience of resilience, and 3) any perceived sense of change in themselves as a result of their cancer experiences. After collecting the data and analyzing it, these three structures seem to serve as good “containers” from which to conceptualize and present the data. These three will serve as my “Major Themes” and will be presented with their sub-themes and the supporting quotes.

Diagnosis

The diagnosis theme included content that was closely related to their cancer diagnosis. Their experiences surrounding their diagnosis, feelings about their diagnosis, treatment ambiguity, and their responses to the diagnosis created the four main sub-themes of this structure.

Experiences

The experience of receiving their cancer diagnosis was a moment that all of the interviewees remembered vividly. Four of the seven men reported they were surprised to receive the news:

- Andy: At the time, I’ve been very healthy my entire life and never really had any serious issues...health issues, so it was rather a surprise but because my doctor had kept an ongoing record of my PSAs, he noticed a jump and at the time then, like I said, I was surprised but it is what it is now what do we do next? That was my attitude at the time.

- Gus: I was almost like breathless I mean, and I remember just like questioning, “Are you sure? Are you sure?” And I remember my lip started quivering like I was on the verge of tears you know and that’s when he (the doctor) says, “You’re going to be fine.”
- Eric: It was like a bat hitting you. I mean just me. I just, you know just kind of it was on the forefront of my mind, probably more so than with a lot of people because of what had happened with Darryl but it was just, it was a big thing.
- Dave: “I’ll never forget that day they said, ‘Hey, you have cancer.’ Everything changed from that, from there.”

Three of the men who had anticipated the diagnosis were not quite as surprised:

- Bart: So my two older brothers both had prostate cancer. They got diagnosed 17 years ago so in the back of my mind I knew there was a risk but when my brothers were diagnosed, I read everything I could. I took supplements and did all the stuff I could. My number (PSA) actually dropped so I thought, “I’m good.” So I never expected to hear that it went up. Especially when I said, “At least I don’t have cancer,” and he (the doctor) looked at me and he got real quiet and I thought, “Uh-oh.” That was a big surprise but I guess in the back of my mind I wasn’t 100% shocked because of the family history.
- Chuck: I remember getting that...the diagnosis and it didn’t really shock me. You know, I mean I’ve known since I had read enough that one in four of us...you put four of us in a room, one of us is going to have it, statistically.

- Frank: I guess I had the feeling that I did have it based on the PSA and the way the PSA had bounced around. So I wasn't surprised at all ... when I found out that it came back positive.

Six of the seven men indicated the discovery of their diagnosis was triggered by a rise in PSA scores. One of the men reported that initial concern was raised from a DRE check. All of the men underwent biopsies as a follow-up to confirm their diagnosis.

It seemed like a normal ritual for the men to share the numerical statistics of their diagnosis. The terms and statistics seemed to give them a new language that they were comfortable disclosing with me as a fellow survivor. Eric stated:

I went to the doctor's for my annual physical and she said, "Your PSA is elevated a little bit. It went from a 2.8 or 2.9 to about a 3.1 or 3.2," and six months later it went from the 3.2 to a 3.7.

This led to a biopsy where Eric described the urologist found cancer in 7 out of the 12 cores. Frank stated: "they did my bloodwork and my PSA had jumped from 2 something to 3.94." The numbers seemed to be used to reflect their level of health or the treatment urgency. Numbers surrounding their PSA level, or the number of biopsy cores containing cancer were readily reported during the interview. Chuck reported that his cancer recurrence was discovered through follow-up monitoring of his PSA score after his prostatectomy. Bart explained that his brother had a recurrence of prostate cancer that was discovered through a rise in the PSA scores so he too was vigilant of his PSA scores in case the cancer came back.

Three of the gentlemen shared particularly vivid recollections of their experiences. Dave recalled tearfully how a week after his diagnosis, members of his church came to visit him, they placed their hands on him and prayed for him. Through tears he explained that this was one of the most meaningful experiences that he had had. Eric explained that 7-8 months prior to his own diagnosis, his best friend was diagnosed with prostate cancer that had already progressed to terminal stage.

My best friend from probably 35 years, walked up to the front door with his wife and said, "I just came from the doctor's and I've been diagnosed with terminal prostate cancer." ... He found out six months previously and went back for further testing and it had already metastasized around his spine and was inoperable. 18 months later he was gone. (During the last months of his life) I was with him and we got all of his stuff done at the house and finished up ditches, and put this in and finished that up and tore out a swimming pool and all of the bucket list things that he was going to do for the next 5-6 years, we did in those 6 months. It was, it was an experience.

Gus' appreciated his Doctor's support as he relayed his experience:

And I said, "So you're telling me I got cancer." And he goes, "Yeah." And I'm like well, shit. Okay, nobody wants to hear that word and then you know I became emotional you know I was like what am I going to do? What am I going to do? Am I going to die? And Dr. (omitted) was, he's like, he was so cool, he was like, "Hey look. You're going to be fine. Okay?" And he, you know, really grabbed me, not grabbed me, but he put his hands on my shoulders, he looked me right in

the, he goes, "I'm telling you, you're going to be fine. This happens all the time. You're going to be fine." "Okay. I guess, if you say so." So I didn't know at that time that prostate cancer was really survivable.

The vivid reflections reflect the intense emotions these men experienced in their discovery, but also the comfort they found in their medical doctor, or friends from the church. Next, I will review the men's reported emotional responses to the diagnosis in greater detail.

Feelings About the Diagnosis

The men's reports of their emotional experiences varied from pragmatic optimism to feeling it was a "death sentence." Three of the men, Andy, Chuck, and Frank described taking a pragmatic approach to their condition. Andy stated, "I was surprised, but it is what it is. Now what do we do next?" Chuck reported:

And I remember my wife asked me one evening right after I found out about it and she said, "Are you angry?" I said, "Well, I'd like to be but I don't know at whom." And so it never really, I didn't have a great deal of, I wasn't terrifically upset by the diagnosis to where I was angry or despondent or anything like that. My main thing was, "Let's get this thing taken care of." That was the approach I took to it. I never really grieved for my prostate or anything like that and I wasn't particularly angry at anyone about it because you know, the bumper sticker says it all, "Shit happens." That was just the way I looked at it.

Frank's response was similar in that he reported: "I think I just accepted it at face value and like I said, I didn't have any real fear of it. I didn't have depression because of that or anything like that."

The four other gentlemen, however, reported a common pattern in that they experienced an initial shock followed by different descriptions of what may be characterized as sadness or a grief response. Bart succinctly stated, "There was initial shock and then I guess kind of a disappointment." The other gentlemen offered more detail:

Eric: It was like a bat hitting you. I mean just, me. I just, you know just kind of, it was on the forefront of my mind, probably more so than with a lot of people because of what had happened with Pete but it was just, it was a big thing. ... but I broke down and cried and sat with her and talked. It was a pretty devastating revelation. It was tough.

Gus: You know at the time, at the doctor's office but I was almost like breathless I mean, and I remember just like questioning, "Are you sure? Are you sure?" And I remember my lip started quivering like I was on the verge of tears you know, and that's when he says, "You're going to be fine."

Dave: But, you know at first I thought it was a death sentence. You know when they say "cancer" that word changes everything because you hear a lot of people, they get it, it didn't happen to me but yeah it happened to me now. ... It was you know how it hit me. ... But it was just a wet blanket that had pulled over me that

haven't been able to completely take off yet. You know, it's always there. I don't think about it all the time but it's always there. It's the gorilla in the room.

Both, Bart and Eric used the words "roller coaster" to describe the emotional extremes they experienced in the process of coping with the diagnosis. Bart also reported experiencing a period of self-blame where he wondered if he had done something wrong to incur the diagnosis. Gus and Bart both reported feeling anxiety with "being laid up" from surgery. Chuck and Dave also reported they experienced a heightened sense of awareness of health concerns. Chuck said, "Yeah but you always look over your shoulder. You know I get an ache in my back or something in my pelvis, I go, 'Oh geeze.'" Dave, whose watchful waiting to monitor his cancer explained "I am always conscious of, you know, yeah there's something inside you that could kill you right now."

Ambiguity in Treatment Protocol

Upon discovering their diagnosis, all of the men reported they felt compelled to gather more information about it by speaking with other survivors, by searching online, getting second opinions, or interviewing other medical professionals. Five of the men specifically reported that they gathered more information because they experienced frustration with the ambiguity in treatment protocol.

Gus stated:

So, I had mine the first week in January, my diagnosis, and they just happened to have the (support group) meeting the second week. Raised my hand, I said, "You know, I just was diagnosed like 4 days ago. The doctor said I've got options. I've

got...I can have radiation. I can have seed therapy. I can have surgery.” I said, “I don’t know what to do.” I said, “I’m a factory worker. The doctor tells me I have three options. I...you know, ‘You’re the doctor, tell me what’s the best. I don’t know. You tell me.’ And he wouldn’t. He said, ‘No it’s up to you.’ I don’t know.”

Frank reported:

There’s a lot of information out there and it’s very difficult because even at the point of trying to decide on a procedure to follow to try to make sure that it didn’t go into a metastatic phase, even talking to like the Prostate Cancer Foundation, they were very on the fence just like I was about whether I should or shouldn’t do something at that particular point in time and if I did do something, exactly what it should be.

Andy stated:

when I found out how many procedures were available to me, we interviewed the surgeon and the radiologist and my oncologist and urologist and all those just to get an idea and realized none of them were very positive about their particular approach to it

Dave stated:

You know the doctor initially gave me some information about it and gave me some, you know, leaflets that he had xeroxed and that he gave to every patient that was diagnosed. A lot of those have websites and where to go for more information. So you know, of course, the first three months, I was online. I was getting this information, and you know staying up until 11, 12 o’clock at night

just kind of pouring through data and people's life stories and the newest cures for it.

The emergence of this sub-theme was a unique surprise as the frustration or challenges caused by the decision-making process seemed to be very significant for the men.

Response to the Diagnosis

Deal with it. Among four men the phrase "Deal with it" was mentioned 24 times. It was most often mentioned in the context of how they responded to the diagnosis. Chuck recalled his initial response to the diagnosis and said: "The initial one, (pause) when I was told I had cancer, (pause) my most was, gotta deal with it." This phrase was also often used in terms of how the men have coped with other adversity, and how they advised other men to cope with their cancer diagnosis. Stated most often by Chuck (18 times), he seemed to use it in context of facing or coping with a difficulty or threat, instead of avoiding it.

Treatment Decisions. The men pursued different treatments based on their research, personal preferences, and their current condition. Table 1 identifies the initial treatment pursued by each participant and if follow-up treatment was needed, what they pursued. All of the men who underwent a prostatectomy experienced the more modern laparoscopic version of that surgery. None of the men had undergone brachytherapy or hormone forms of treatment.

Table 1

Participant Treatment Decisions

Participant Pseudonym	Initial Treatment	Follow-up Treatment:
Andy	radiation	None needed
Bart	prostatectomy	Treatment needed, monitoring to determine
Chuck	prostatectomy	external beam radiation
Dave	active surveillance	Yet to be determined
Eric	prostatectomy	None needed
Frank	active surveillance	Prostatectomy
Gus	prostatectomy	None needed

In summary, the diagnosis experience was life changing for the seven participants. They reported varying emotional responses, distinct experiences to their diagnosis, and different treatment decisions. While three approached their diagnosis with pragmatism, four others reported experiences of shock, sadness, dread, anxiety, emotional extremes, and heightened awareness of illness. All of them reported they felt the need for more information and majority reported some frustration with the ambiguity in the treatment protocol. Eric offered this rich description of his diagnosis experience:

I think the diagnosis was like driving down the road 70 miles an hour and all of a sudden there's a chuck hole in the middle of the road that's two feet deep and 18

inches or two feet across and you hit it and it KAWBAM! You, for a little while have that, “Oh my gosh. What was that?” I think that the diagnosis was that pot hole and when you drive 50 feet down the road you kind of, “Well, the tires are okay. Everything’s pretty much alright. I’m ready to move on.”

Resilience

The participant statements were coalesced around various sub-themes. As demonstrated in figure 3, the sub-themes that emerged were; the discovery of resilience, source of resilience, description of resilience, the uniqueness of this experience of resilience, meaning making, experiences that promoted and discouraged resilience, and activities that demonstrated resilience.

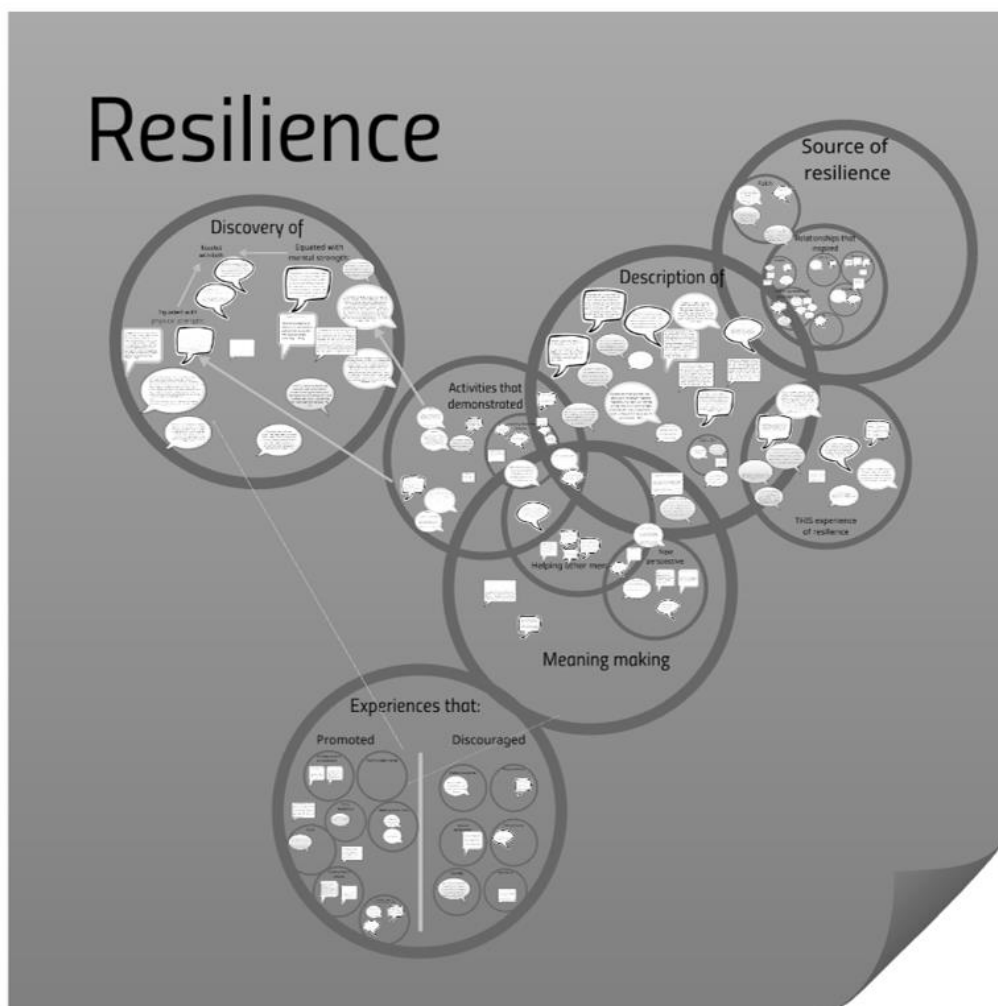


Figure 3. The major theme of Resilience and its subthemes.

Discovery of Resilience

To learn about their experiences with resilience I inquired how they discovered their own resilience. The inquiry drew out responses revealing that some men associated resilience with mental strength while others equated resilience with physical strength. The grouping of common responses to this inquiry helped me see other statements where the participants seemed to generally associate resilience with either mental or physical strength, while a few participants indicated both.

Resilience associated with mental strength. This association was characterized in Bart's statement: "Knowledge is power." Complimented by the need to learn more to determine treatment, some of the men reported that the more they learned about the disease and its treatments the more confident they felt to respond to it. The following statements by Dave reflect this:

Luis: Would it be fair to say that learning and studying contributed to your resilience, contributed to your bouncing back?

Dave: Yeah. Oh yeah. I think it was, that gave me you know that confidence to keep going and to keep addressing it. I'm not ignoring it you know it's there. I'm still not out of the woods but I'm still, I feel comfortable now in terms of knowledge and preparedness for that but part of that knowledge is helping other people learn what I learned because knowledge is everything.

Frank stated:

I don't know that I had a particular moment at which I realized I was resilient to this thing. But I do think that reading the materials about it helped me a great deal in developing resilience to the thing,

Dave seemed to reaffirm this connection between resilience and mental strength when he said: "I kept keeping on. I never quit. I never closed the door on learning new things."

Bart explained that knowledge was like a tool that he armed himself with:

I started reading all I could on the internet, books, going to the support group because that was only like a month after my surgery I started there so I thought, "I've got to arm myself with all this stuff and just do the best I can."

Other men associated mental strength with resilience by giving examples of faith, positive thinking, decision making, and a thick skin to keep oneself from taking things personally.

Resilience associated with physical strength. Chuck related his discovery of resilience to having had his knee replaced a year earlier. In order to prepare for the surgery his wife had hired him a physical trainer to exercise and train him for a year prior to the surgery. The exercises were critical to his successful and speedy recovery so he said “You know if you are prepared, you can do it. I think that’s a form of resilience.” Andy reported that he associated resilience with physical health because he had essentially lived a healthy life: “I’d never had any serious issues, so that too, so I had that kind of confidence that this is going to be handled and cured.” Initially, Gus reported that “There was no discovery” of resilience and that he had not thought about it from that perspective. Gus explained that he associated resilience with how he felt physically because he worked as a factory worker most of his life. He evaluated his recovery on his physical strength, his ability to lift weights, and his ability to engage in sexual intercourse with his wife.

Resilience Described

The men had various descriptions of resilience but six themes emerged from the interviews. They described resilience as knowledge, an attitude, a fight, an ability, coping, and as an energy. I used their own words as the headings and descriptors for each of these themes below.

“Knowledge is power.” Chuck reported that upon hearing his diagnosis he initially panicked because he believed prostate cancer was terminal. He explained, however, that once he understood more about the cancer, his condition, and the treatments he felt much more confident to cope with it. As mentioned earlier, many of the men reported that resilience was associated with mental strength because of the impact that learning and knowledge had in their recovery. Frank attributed learning to the development of his resilience when he said, “reading the materials about it helped me a great deal in developing resilience to the thing.” Frank further explained “I did work closely with the doctors and so forth to try to understand the disease and make sure that it didn’t get out of control.” The presence of the disease seemed to contribute to a perceived loss of control in his life. I followed up by asking:

Luis: Yeah. And would, how does educating yourself about the disease contribute to your feeling more in control?

Frank: Well, I think that understanding, having an understanding of what the disease and what other people have experienced with it; how they’ve treated it; and what the different treatments might do; and how they might, you know...how successful and what their effects would be; one versus another.

For Frank, the disease threat created a perceived loss in control, but learning about it seemed to offer a greater perception of control. Frank went on to explain: “I think that resilience comes from having a positive understanding and a positive attitude about the disease. In other words, that you...that I do understand it.”

Bart explained that knowledge helped him to understand the disease and to cope with it as well: “Because once I had the knowledge, what this was all about and was able to share this with other people I just felt, you know, that gave me strength to deal with it myself.” Dave reported that knowledge was so valuable to his recovery that he focuses on educating other survivors to help them cope. Dave said: “I feel comfortable now in terms of knowledge and preparedness for that, but part of that knowledge is helping other people learn what I learned because *knowledge is everything*.” Knowledge about the disease, the status of their disease, and the treatment options offered them insight into their actual condition, equipped them with choices over their treatment, and eventually contributed to their own recovery. In this context, several of the men promoted resilience as knowledge, because that knowledge gave them “power.”

“Positive attitude.” When asked how they experienced resilience, three of the men reported they experienced resilience as a positive attitude. Andy stated: “Well to keep a positive attitude. That’s, I feel, the literal definition of resilience: physical, emotional resilience.” He further explained that being surrounded by family helped him to feel good and keep a positive attitude. Eric expressed two vivid ideas illustrating how a positive attitude related to his resilience. In the first he seemed to describe the positive thinking as a choice of resilience:

The biggest factor was in my mind; my thinking pattern. That’s where I felt the most resilient was what I decided to let affect me and what I decided not to let affect me and my mind controlled pretty much where I went and what I did. I just kind of didn’t, didn’t dwell on or think about the bad sides and just moved to the

positives. So I would say probably my mind was the biggest factor or the biggest place I felt a resilience.

In the second statement, Eric seemed to indicate that resilience is promoted by positive thinking:

I would say probably like a bounce back. In other words, like a basketball. Its resilience is if you drop it from three feet, is it going to rebound to 2 feet 9 inches or is it going to rebound to 2 feet 6 inches or 1 foot? I think the resilience is depending on that basketball, its return, and the return that it has depends on what's in it and so I try to keep in me the things that make me like the ball has the air, I try to keep in me positive attitudes and positive outlooks so that my air is full and that when I hit the ground I bounce back good. I just think that resilience is something that you control by what's inside.

In the first statement, Eric promoted that positive thinking came from resilience, and in the other he promoted that resilience came from positive thinking. While initially these may seem like contradictory ideas, they may instead be complimentary ideas reflecting his experience of how these two constructs may mutually reinforce one another in his life. Bart explained resilience by saying "It's just a very positive outlook." The three men seemed to present this thinking as a choice to think positively in spite of the challenges ahead. None of them reported an avoidance of their reality or a denial of their circumstances but instead a choice to focus on positive outcomes in spite of the threat to their health.

“I want to fight it.” On several occasions the men explained that their resilience was a “battle,” a “fight,” or a refusal to be defeated. Bart stated: “I’m not giving into this. I want to fight it and do all I can to deal with it and just live a full life as much as possible.” Eric elaborated by contrasting two of the treatment options, watchful waiting vs the prostatectomy:

When they told me what was, what my options were, I decided then that waiting, I wasn’t going to do that. I was just going to have it done and then it would be done. And I had no thoughts about it being life threatening or terminal when I realized that I was going to have the prostate taken out. I think my resilience started right there and making that decision instead of waiting and seeing what was happening and seeing, but I think it started right away. I just decided that I wasn’t going to let it beat me.

Eric used sports language comparing cancer to being “behind in a game, you’ve got to be resilient and come back.” In Eric’s language the choice of watchful waiting to him may have been like playing prevent defense as opposed to surgical treatment which was playing more aggressively to win. Eric referred to his cancer condition as a “battle” that demanded his response: “It was a necessity that you had to do this. You just had to come back. And that’s how I looked at it and how I felt.” Frank his response through a quote that inspired him:

I had a boss one time and he lost his wife at a fairly young age to cancer and he had given me a quote from Rose Kennedy of her resilience and her statement was: “I will not be overcome by events.” And I’ve never forgotten that quote for one

reason or another and I've often used it to...in a moment of...where I need some resilience. Okay, you know, you have to face these things and don't be overcome by the event.

Frank's response reflected a posture reflecting a refusal to be defeated, or an unwillingness to surrender, and a will to fight for their lives.

“Ability to bounce back.” Several of the men referred to resilience in terms of it being an ability or a capacity. Gus stated: “the whole theme of this was the ability to bounce back to normal, being resilient and bouncing back. You can either mope around; feel sorry for yourself or you can get on with life and appreciate life.” Eric agreed as he reported he learned a lot about his own ability to endure:

You learn what you're capable of doing and what you can face. It's just, and you are able to do more than you think you can if you just realize that and come to grips with it but you are able to do more than you just think you can initially.

Bart explained this by saying: “I just think it helped me see what I could face and what I could go through.” When faced with the threat of cancer he initially thought of giving up but then responded:

“Well, no. I can deal with this. I can make the best of it.” If I wasn't that way, I wouldn't tell anybody. I think just by telling people it reinforces my resilience to go on and do what I can.

His words, “I can deal with this,” seemed to reflect possession of confidence, ability, and capacity to address the threat experienced from cancer. All of the men affirmed how they experienced resilience as an ability by reporting a greater confidence in their capacity to

endure future hardships as a result of their experiences with prostate cancer. This will be explored under the major theme “Changes in self.”

“Coming to terms.” Gus and Chuck used language suggesting they also saw resilience as coping with a new reality.

Well I would describe resilience, coming to terms. Coming to terms with the new normal I guess. Physically, especially for guys that are our age, which, we’re young. Physically you’re going to bounce back in a relatively, I’ll say very short order; weeks. Mentally, in terms of incontinence and maybe sexuality is, you know, just being able to (pause) this is the new normal. Deal with it. It could be worse.

Chuck went on to explain that the inability to get or sustain an erection during sexual intercourse had affected him. While he had believed that sexual intercourse had to peak in orgasm to be successful, he explained that he and his wife have adapted to enjoy sexual intimacy with, or without, the “happy ending.” He stated: “so resiliency was I guess me coming to grips with that. It’s okay...okay with that.” In this language, resiliency was described as coping or adapting to a new reality. Chuck explained it by saying, “the ability to gather the facts...I mean to hear something, gather the facts, and then deal with it.” In this context, “deal with it” refers to a coping response triggered by new information.

“Energy.” Dave was the only participant in this study to describe resilience with this language but his explanation was compelling. When asked what he felt as he experienced resilience, he responded:

I felt empowered. I felt energized. I deal with people every day and I used to be in the people business. I used to be in sales. I got my success from talking to people and you know I made a sale that energized me, that kept me going. That, I don't know, it turns light bulbs on, opens door you know, there and that, resiliency if I'm able to feed it and keep it strong, I want to take steps to keep it energized. Sometimes you know you get problems or you know there's something wrong with your car you don't think about it when problems come up but if I can go back and kind of rekindle success stories to keep that resiliency. I get that from going to Wednesdays and the support group. I want to keep that light alive there.

When Dave discovered his resilience he reported he felt "a new source of energy." This description was significant because Richardson (2002) proposed that resilience was an energy source within all individuals promoting development and self-actualization.

Source of resilience

While it was not uncommon for the men to indicate they experienced multiple sources of resilience, all of the men reported that a significant source of their resilience came from another person; parents, spouse, siblings, friends, doctor, or another PC survivor. Three of the men also indicated that their faith and spirituality was a significant source of resilience for them.

Relationships that inspired. Five of the men combined to report that a spouse or a parent had been a significant source of resilience for them. Chuck reported that having previously watched and supported his spouse through breast cancer, inspired him through

his experiences. Eric explained that his spouse helped him the most through her support.

Andy also explained:

Being around positive people: my parents, my wife. We've been married 32 years and still happily married. That helps a lot. Just having positive feedback with life's decisions: education and work and all that so it's just a culmination of many things.

Five of the seven men reported that another prostate cancer survivor had been a significant source of resilience for them. Eric's best friend Pete discovered his cancer after it had spread and his disease was terminal. Eric reported:

Seeing Pete go through his experience, and he was a good Christian too; strong Christian and seeing him face it all the way through, knowing from the start that it was terminal and to see his steadfastness and his dedication and his attendance and daily, I mean, every week to church just as regularly as could be, no wavering in his faith, nothing, and to see that kind of, (pause) was an inspiration that if he can do that, then I can beat this too. It was just, it was, he was a big motivator.

Dave did not attribute the source of resilience to one person but used meaningful language to explain how speaking to other men who had also experienced what he experienced inspired him:

You're talking to humans, that kind of trounces all of the book studies and white paper studies because there is nothing like hearing a story from a guy that is going through what I am, and shakes my hand, puts his arm around me. That's big, you know that's big right there. (very emotional here.) So there's two different, it's

apples, oranges. I still get benefit from all that but there's nothing like that human factor, patient guy, doctor, look you in the eye, "It's going to be okay. We did this but you can do this and this." You can do it. That human, that x-factor you would call it there.

Among the men they also reported that their prostate cancer support group, their doctor, siblings, and friends were also sources of resilience.

Faith. Three of the men also reported their faith was a significant source of resilience. Bart stated: "Well God first of all. I'm a very spiritual person so just though my prayer and meditation, my connection with Him, that gives me the main strength. It really does." Eric reported that his Christian experience "was the biggest stabilizer I had." Dave tearfully explained that his faith and the people at his church were a source of peace and strength for him. In general, experiences of spirituality were referred to in supportive terms by the men though they were not always in connection to organized religion.

Experiences that promoted or discouraged resilience.

I asked the men what activities promoted or discouraged resilience. Among their responses of what promoted their resilience, they stated healthy upbringing, experiencing options in treatment, early hardships in life, faith, helping other men, positive health results, and confidence to explore health issues. The men reported that the experiences that discouraged their resilience were multiple surgeries, physical illness, side effects to treatment, erectile dysfunctions, family, and feeling helpless.

Activities that demonstrated resilience. While interviewing the men, I listened for examples of resiliency behavior. I identified the following activities as demonstrating resiliency;

- practicing patience with incontinence,
- planning future surgeries,
- thinking positively,
- learning about the disease,
- helping other men,
- telling one's story,
- attending a support group,
- advocating for one's self,
- practicing self-care, and
- preparing for surgery by doing Kegel exercises.

Meaning making. Some men found meaning to their experiences when they helped other men. Andy reported:

That helped with the resiliency too. I felt like I was doing something positive by helping some other people and I've gotten feedback because of that so that was one of the experiences that had been very helpful to my feeling of well-being, feeling good about myself.

Chuck also spoke of helping other men and told of a time when he drove a friend of his to get his first radiation treatments after the reoccurrence of the disease. Chuck had a

medical background and experience in his own treatments and he used these to calm his “terrified” friend.

Several men reported that after recovering from the disease or helping others they experienced themselves with a new perspective. Bart reported feeling impacted by the first time he thought of himself as a cancer survivor:

Once you have cancer you’re considered a cancer survivor and that really stuck with me. I’d never thought of myself being a cancer survivor you know? I thought, “Yeah, I guess that is the term that people would use with me.” I do have cancer in some form or anything. I’ve had cancer, got some cells left in me so I’m a cancer survivor so deal with it.

Gus reported he felt touched when he went to a “Relay for Life” walk. He saw a luminary dedicated to him and walked among other survivors. He stated: “I’m a survivor.”

Andy reported he was an “expert” as he felt more equipped to help others as a result of the new found knowledge. He said: “This is a channel that I’m an expert on, I guess you would say, because I’ve been there. Had my results been very negative in that I probably wouldn’t be doing this you know?” Dave reported feeling the responsibility to advocate for early screening among his friends. He told a story of an older friend who was “squeamish” about the rectal exam and argued that the threat of prostate cancer was overblown. Dave said:

So I think a little bit of his machoism coming up there. “Hey, I can do it my way.” That kind of concerns me but, so I’m an advocate of that and that was one of the reasons why I want to tell my story to you.

Dave saw himself as an advocate and also had framed his experiences as “chapters” that are contributing to the story of his life. He said: “Yeah, that’s a story to tell. That’s an important story. I think I’ll always keep telling it.” As a result of their prostate cancer experiences many of these men saw themselves in a new perspective, with a new role, and a story to share with others.

The major theme of resilience contained the men’s discovery, their description of resilience, their identified source of resilience, experiences that promoted and discouraged resilience, as well as any meaning made from their experiences. The following major theme reviews the changes men reported to have experienced as a result of their experiences.

Changes in Self

The third major theme reviews the changes that men reported from their experiences with prostate cancer and resilience. This included, but was not limited to, an inquiry into areas of post-traumatic growth. Demonstrated in figure 4, the sub-themes that emerged were that men reported experiencing changes in their priorities, in their physical body, and in their philosophy / spirituality. This major theme also included the reported gains the men experienced and the advice they would offer to other men.

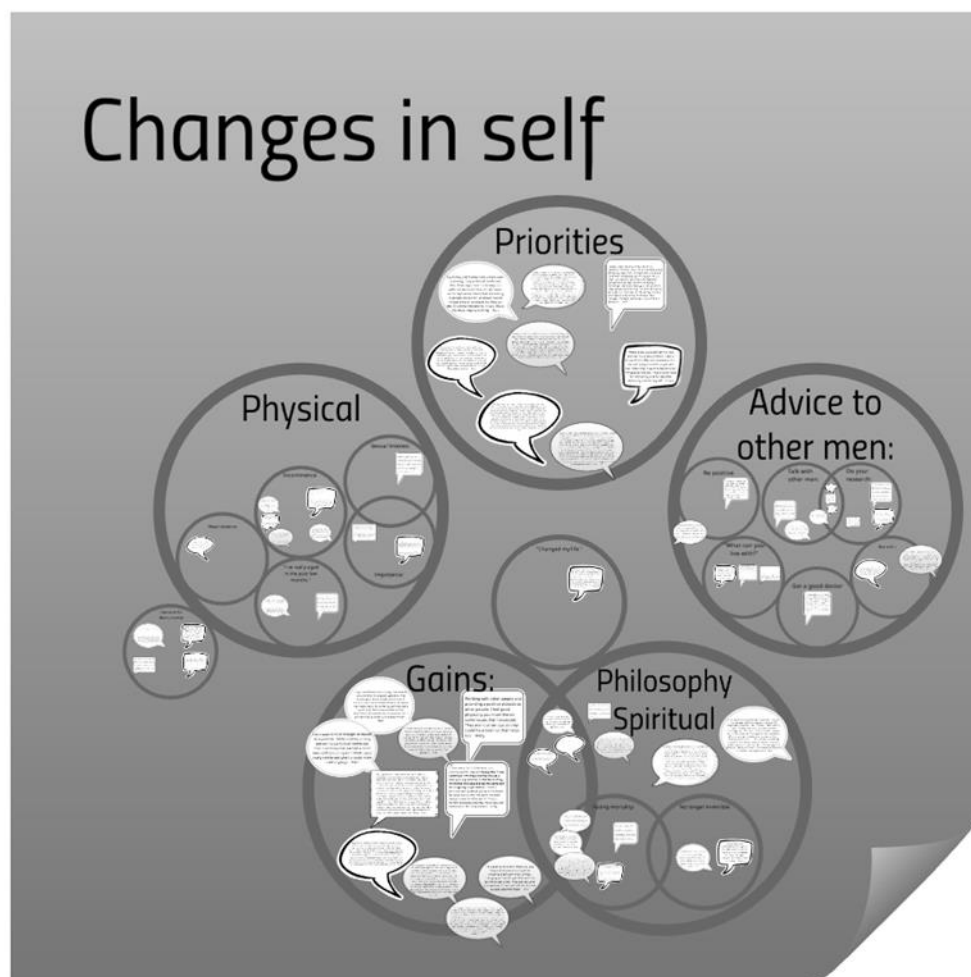


Figure 4. Major theme Changes in self and its subthemes.

Priorities

Several of the men reported that as a result of cancer, they see life differently.

Dave stated: "Life as it is, it's in a different, we're looking at it differently now." Six of the seven men reported some change in priorities. The reported changes may have been as small as healthier eating (Andy) or more significant as the decision to retire from full time employment in order to spend more time with family (Eric). Bart reported: "My family and friends have always been a priority, it's just kind of reinforced that: how important it is to keep up with my family and friends." Eric and his wife both determined

to retire at the age of 65 as a result of his experience with prostate cancer. He explained his decision:

So we would have kept working until 67-68 possibly 70 but we just decided that we don't know how much time you've got. You never know so we took the retirement and never looked back and it was a good thing.

Eric reported that he spends more time with his family and devotes himself to hobbies he really enjoys. Dave and Chuck also reported taking better advantage of their retirement to travel and spend more time with family.

Physical change

All of the seven men complained of experiencing a change in their physical bodies as a result of their cancer treatment. Andy reported a loss in sexual drive. Chuck, Frank, and Gus complained of impotence. Bart, Chuck, and Eric complained of incontinence. Andy and Bart agreed they feel older and have slowed down the pace and the number of activities they engage in. Dave complained of feeling restricted from donating blood. Lastly, Bart, Chuck, and Frank expressed they have experienced anxiety or a concern for the reoccurrence of cancer.

Philosophy / Spirituality

The men's responses demonstrated that some reinforced their spirituality, some reflected on their mortality, and some lost a sense of invincibility. Gus discussed his experiences reflecting alone in the woods, observing nature. He reported that he was taking more time to slow down and notice nature. "You just see things you know. It is very, it's my church." Eric reported that as a result of his experiences: "It's reinforced the

fact that I probably made the right decision back when I was 12. That was my Christian experience, was the right direction to go. It's reinforced that I think." Dave and Bart reported they see themselves as stronger men. Dave stated: "Just as a stronger man. More at peace with myself, you know. I accepted myself." Bart also said: "I think it's just made me stronger to realize, I am what I am, and things are as they are, and you face them and go with it."

Loss of invincibility. Chuck captured the essence of this experience when he stated: "I guess the major philosophical change has just been a realization that there are chronic diseases that even I can get. I thought I was pretty damn invincible." Andy, Bart, Chuck, and Dave reported they had lived healthy lives and that this was the first serious threat to their health. Dave stated, "you're a guy, you think live forever and you feel pretty healthy but that took me down some notches." This loss and the threat to their health may have also helped several of the men to face their mortality.

Face mortality. Five of the men expressed that their experiences had encouraged them to face their own mortality. Chuck described that in facing cancer and his mortality, he experienced a "maturing process" that reaffirmed the importance of facing the disease instead of avoiding it. Andy stated "I'm lucky to be alive because I was at a point where I wasn't going to be alive in my life." Gus stated: "life is precious. You get a wake-up call; it scares the crap out of you. There but for the grace of God go I, you know." Bart interprets for the deaf at Alcoholics Anonymous meetings and he expressed how he views his mortality: "One day at a time, because you don't know what could happen tomorrow. So take it one day at a time and live it as best, as much as you can."

Gains

All of the men expressed some element of gratitude in their experiences. Andy described he was grateful that he no longer has to worry about prostate cancer and looks forward to going to the doctor. Dave and Frank both expressed confidence in the advances in the field of medicine and share an optimism for future generations. Bart, Dave, and Eric described feeling more confident in themselves to handle future challenges. Eric said:

I think my resilience made me more determined not to let anything bother me; not let anything be undoable; and to not take anything off the table that I was doing before. I just kind of made sure, I guess the resilience is, made me keep plugging and just keep pushing that bubble to where I am today.

Advice to other men

All of the men interviewed spoke highly of their experiences attending a support group so it was no surprise that six of the men recommended talking with other men to learn more. Bart said:

I never saw myself going to a support group. Over the years I'd hear of people going to support groups or you know different things like that. "Oh those aren't for me." I realized there's a lot of benefit from getting with other people and sharing experiences.

Bart also explained that "Doctors don't tell you everything." So speaking with other survivors one could pick up nuanced experiences and insights that the doctor might not know to share. Chuck's advice was: "Talk to people. Seek out advice. Stay the hell off

the internet. Talk to people that have had, you know, access to support groups.” Related to this was the advice to “do your research” from Andy. This was echoed by similar comments from Chuck, Dave, and Frank. Talking with other men and do your research were the two most common pieces of advice.

Three of the gentlemen advised that men explore the “trade-off” between “quality of life versus the effects of treatment.” Chuck asked “What do you want to live with?”

Andy explained:

make a list of some of the things you can’t accept as a result of this. Just can’t live with this. Not meaning that you can’t, it’s just that you’d be very uncomfortable to live with this. ED could be one of them. To me, it just wasn’t at the top of the list. Incontinence was at the top of the list no matter what type of incontinence but there’s so many different levels of it that some could just be an inconvenience and some could be debilitating.

Their rationale was that some men could live with ED and may select a certain treatment because of that. Other men may not want that side effect and may opt for a different treatment as a result of that. In addition, the men’s advice was to be positive, deal with it, and get a good doctor. Clearly, the cancer experiences changed the lives of all the men. Many of them saw a change in their priorities, their physical bodies, and in their philosophy / spirituality. Many of them also experienced gains from their experiences and have advice to offer men experiencing similar circumstances.

Discrepant Data

Much of the discrepant data was integrated into this chapter's explanations of the major themes and sub-themes to illustrate the diversity of experiences reported by the men. For example, the men each sought different forms of treatment and some required follow-up treatment. While the information was relevant to their experience, it did not add to the central meanings gleaned as a whole. I included information about their treatments however in the form of a table. Only Eric described his emotional experiences as a "rollercoaster," but his words illustrated the volatility of the emotional experiences that the various men also reported so his quote was used earlier as such. Dave was the only participant under an Active Surveillance protocol at the time of the interview and he reported experiencing uncertainty about his decision.

One sub-theme that was not reported, as it did not seem to contribute significantly to the central meaning of the experience, was the disclosure of the disease to relatives or family members. Five of the men reported that the disclosure was not a difficult experience while two men reported that it was difficult experience. While the five men reported it was not difficult to disclose, two of them explained that they delayed disclosure to family and friends until they had a better understanding of their disease and the treatment. This was seen as discrepant data as there seemed to be an abundance of data on the men's experiences, the men reported different experiences, and it was not an essential theme.

Evidence of Trustworthiness

Credibility

To be confident in the truth of these findings I utilized; 1) researcher positionality, 2) prolonged engagement, 3) source triangulation, 4) peer independent review, and 5) member checks. In my positionality I embraced the data as presented and tried to reflect it as such to the reader offering context where applicable and at times presenting conflicting experiences among the men. I strove to maintain an empathetic neutrality to the data disclosed and ensured that themes were thoroughly supported by the quotes. Prolonged engagement took the form of ample time for the interviews and ongoing interaction with the men. On average, each interview lasted 54 minutes. Since the interviews, I have also reached out to the men on 4 occasions via e-mail to thank them for their participation, to offer the opportunity for them to contribute more clarifying information, to ask them to review their transcript (and their participant profile), and to review a draft of the results chapter. I triangulated the data by comparing the members' quotes to cross check for consistency. After identifying specific codes and themes, I re-read and re-listened to the entire interview to maintain a sense of the whole and ensure that the quotes were used in proper context and were accurately represented. My dissertation committee served as peer reviewers by offering feedback and confirming my approach. Finally, as stated earlier, my participants were invited to review the transcripts and the findings to offer feedback.

Transferability

The findings were placed in context of their setting, the participants, and their experiences and as such were not generalized to a larger population. While insights gleaned from the lived experiences of prostate cancer survivors may suggest insights into the experiences of other men or women with different cancers or diseases, I made no generalizations, suggestions, or applications of such transferability. The reader should consider the setting, participants, and experiences before generalizing the findings. The themes of resilience, the experiences of these survivors, and post-traumatic growth reported by the participants in this study may offer insights for counselors and caregivers offering support to other men.

Dependability

A clear and detailed research process was provided and adhered to so that if the same inquiry was repeated in a similar context it would yield consistent results. I have maintained a detailed audit trail and included my committee in the peer review process. This process included using a professional transcription service to protect me from making mistakes in transcription, reading the transcriptions while listening to the audio tape to ensure transcriptionist accuracy, and the use of the Prezi presentation website, and Atlas.ti software to identify and confirm the codes and themes.

Confirmability

To protect the research from being influenced by bias, I completed a Researcher Identity Memo (Maxwell, 2005), and offered a thorough review of possible areas of researcher bias in chapter 3. I strove to adhere to concepts of empathetic neutrality

(Patton, 1990), critical subjectivity (Reason, 1988), and openness (Gadamer, 1975).

These concepts promoted a sense of respect for the research process and the integrity of the data while permitting the researcher to include their own experiences as a source of data. My own experiences contributed significantly to the wording of my interview questions and to the a-priori structures; *diagnosis*, *resilience*, and *changes in self*. These structures offered broad categories that organized the participant responses but the sub-themes clearly emerged from the participant responses. My committee reviewers was also aware of my experiences and biases and they offered feedback throughout the research process.

Summary

The study's research questions sought to explore the participants lived experiences with prostate cancer, the meaning of resilience to them, and their experiences with post-traumatic growth after prostate cancer. Three core themes; *diagnosis*, *resilience*, and *changes in self* provided an organizing framework for their responses. Overall, all of the men perceived prostate cancer as a threat (to their health, lifestyle, or mortality) that required a response from them. Some saw resilience as a physical response, but most agreed that at the core, resilience was a mental response. Finally, all of the men reported gaining some form post-traumatic growth as a result of their experiences. The narratives of their experiences and descriptions of resilience offered rich insights into their responses to prostate cancer. In spite of their hardships, all of participants in this study demonstrated a sense of gratitude for their experiences, their new found insights, and the gains they derived. In chapter 5, I will discuss the

implications of the study results, suggest applications, and identify areas for further research.

Chapter 5: Summary and Conclusions

This chapter presents concluding perspectives on men's lived experiences with PC, resilience, and post-traumatic growth that were derived from this study. I will summarize key findings and describe how these confirm, disconfirm, or extend the knowledge of men's experiences with PC as described in Chapter 2. I will analyze and interpret the findings in context of resilience and post traumatic growth theories. Next, I will make recommendations for further research and address the implications of this research for positive social change. Finally, I will address my own experiences and how my understanding and biases were affected by this research.

In this study, I sought to reveal the lived experiences of PC survivors and explore the phenomena of resilience and post-traumatic growth through the lens of PC survivorship. Their narratives offered rich and insightful perspectives surrounding their cancer diagnosis response. I learned how resilience helped these men cope through adversity and the personal growth they identified as a result. Their experiences and insights offered unique perspectives on their experiences with PC, resilience, and post-traumatic growth.

Key Findings

The codes were organized around themes and two levels of subthemes to create three levels of data. The data coalesced around three major themes (level 1), diagnosis, resilience, and changes in self, with 16 related subthemes (level 2), followed by 14 additional related subthemes (level 3). Table 2 illustrates the themes, their related

subthemes and the theme level. I will review the key findings surrounding each of the major themes.

Table 2

Summary of themes and two levels of subthemes

Major Themes (level 1)	Sub Themes (level 2)	Sub themes (level 3)
Diagnosis	Experiences	
	Feelings about	
	Ambiguity in treatment protocol	
	Response to the diagnosis:	"Deal with it" Treatment Decisions
Resilience	Discovery of	
	Resilience associated with:	Mental Strength
		Physical Strength
	Resilience described as	"Knowledge is power"
		"Positive attitude"
		"I want to fight it"
		"Ability to bounce back"
		"Coming to terms"
	Sources of resilience	"Energy"
		Relationships Faith
Experiences that promoted or discouraged resilience		
Activities that demonstrated their resilience		
Meaning making		
Changes in self	Priorities	
	Physical Change	
	Philosophy / spirituality	Loss of invincibility
		Facing mortality
	Gains	
Advice to other men		

Diagnosis

The diagnosis theme was a collection of the men's experiences, feelings, and responses to their cancer discovery. Their experiences included the medical procedures they endured to get screened and identify the disease, as well as a collection of vivid moments that seemed to reflect the intensity of their experiences. All men indicated that they did not forget their moment of discovery and several of the men disclosed the moments in vivid detail, reflecting just how important the moment was.

All of the men also expressed a need to collect more information about the diagnosis and their treatment options. The men reported they spent hours online reading, interviewed doctors, talked with friends and family members, sought second opinions, read books, contacted nonprofit organizations, and attended support groups to learn about PC and seek advice. Even though PC is very prevalent, all men reported the need to learn more about it and its treatment. For example, Gus' immediate reaction in the doctor's office was fear and panic when he learned he had PC, as he thought he was facing death. According to Gus, the doctor grabbed both of his arms, looked him in the eyes, and told him, "You are not going to die from this." This began Gus' process of learning more about the disease and his options for treatment. Lack of knowledge about the disease among all participants is consistent with what is known about masculine norms that discourage communication and education. Traditional masculine stoic norms discourage open disclosure, communication, and help-seeking behavior among men (Courtenay, 2009; Saltonstall, 1993). Men's cancers also remain underrepresented in the media (Gough, 2006) and under researched in comparison to breast cancer research (NCI,

2016b). Lack of representation in the media and the lack of research reinforce the social norm that men should not educate themselves about their own health. This lack of education may leave men more vulnerable when they discover the presence of cancer in their bodies. To make matters worse, the men also reported that once they learned about the disease, the treatment protocols for PC were ambiguous.

Five of the men reported they gathered more information because they experienced frustration with the ambiguity in terms of treatment protocol. Upon discovery of the disease, doctors traditionally offer the patients options for treating the disease. The four most common options are radical prostatectomy, radiation therapy, hormone treatment, and active surveillance. While the options offer men more control in their medical treatment, each of the treatments have different side effects. Participants reported they selected treatment based on the side effect they did not want to have. As Andy stated: “You have to find out what you can’t live with.” The decision making process was also influenced by the threat of a cancer tumor growing inside of them. This threat created a sense of urgency for the men to quickly sift through the information about the disease and the treatment options. Four of the men reported that in light of the confusion, the voluminous amounts of information, and the growing threat, their preferred response was to remove the tumor. In the context of a cultural norm where men hesitate to inform themselves about medical issues, this experience of frustration and ambiguity at a time when they are experiencing their health being threatened is a significant obstacle that I have not seen reported in the current literature.

Resilience

The participants' statements describing their experience with resilience seemed to coalesce around the following statements:

- “Knowledge is power.”
- “Positive Attitude.”
- “Fight it.”
- “The ability to bounce back.”
- “Coming to terms.”
- “Energy.”

As explained in Chapter 2, the literature describes resilience as a trait, process, outcome, and mechanism. Due to the varying definitions of resilience in the literature, I felt that a synthesized definition would allow for a fuller range of reported experiences and offer room for the participants of this study to explain their experience with resilience in language that remains true to that experience. For the purposes of this research, resilience was conceptualized as the traits, processes, or forces returning individuals towards previous levels of psychological functioning after a traumatic event.

The participant descriptions seem to align with these three categories set forth in the definition. When represented as a trait, the literature suggested that resilience is a cluster of characteristics assisting the individual to adapt to the post-traumatic experience (Connor & Davidson, 2003). In this context, the statements “Positive Attitude” and “The ability to bounce back” seem to relate to the identified resilience traits of optimism, commitment, and hardiness (Earvolino-Ramirez, 2007; Fletcher & Sarkar, 2013;

Herrman et al., 2011). Eric's description of resilience as the air inside of a basketball that helps the ball bounce back up is also consistent with the conceptualization of resilience as a trait. When conceived as a process, the literature stressed the beneficial impact of relationships, the stress process, and the selection of and development of coping strategies (Earvolino-Ramirez, 2007; Fletcher & Sarkar, 2013; Herrman et al., 2011). The statements most related to process and coping strategies seem to be "Knowledge is power" and "Coming to terms." Researching and attaining knowledge seemed to be a process that helped them understand their condition and treatment options and also offered a sense of perceived control over their lives. "Coming to terms" was a process of accepting their current condition and realigning their thoughts and decisions accordingly. Lastly, the resilience descriptions of "Fight it," and "Energy" relate to Richardson's (2002) resilience theory which states the resilience is a "force within everyone that drives them" (p. 313). The men's statements reflected a refusal to concede defeat and a drive to overcome the cancer threat. The men's statements and their themes are consistent with definitions for resilience found in literature.

Post-Traumatic Growth

Calhoun (1995) conceptualized post-traumatic growth as "perceived changes in self; developing closer relationships; changing life philosophy/increased existential awareness; changed priorities and enhanced spiritual beliefs" (p. 5). The changes reported by the men as a result of their diagnosis and cancer experience were grouped into the major theme "Changes in self" with the sub themes; 1) Priorities, 2) Gains, 3) Philosophy / Spiritual, 4) Physical changes, and 5) Advice to other men. Of these 5 sub themes, the

first 3 seem to closely fit Calhoun's description. The priorities theme largely reflected the men's decisions to place more value on close relationships, their health, and on looking at life from a different perspective. When asked what gain they had derived from their experiences, all of the men expressed some element of gratitude in their experiences and some described feeling more confident in their ability to handle other challenges. The men's responses to changes in their philosophy and spirituality demonstrated that some felt reinforced their spirituality, some reflected on their mortality, and some lost a sense of invincibility. These three sub themes are consistent with descriptions of post-traumatic growth found in the literature. Lastly all of the men reported having advice or insight to help other prostate cancer survivors through their ordeal. Andy explained his willingness to help others, "This is a channel that I'm an expert on, I guess you would say, because I've been there." This may be loosely associated with post-traumatic growth because several of the men explained they discovered a new role for themselves in helping others.

Unsupported Bias

The construct of masculinity was at the forefront of the topics covered in chapter 3, but there seemed to be minimal discussion of this construct in the interviews. In chapter 3, I presented the literature on the social impact of a prostate cancer diagnosis, the perceived loss in masculinity after a prostate cancer diagnosis, and the most predominant definitions of masculinity in current literature, anticipating this may be a significant discussion point among the men. My rationale was that the prostate cancer diagnosis would cause a disruption in sexual functioning and a perceived loss of their masculinity. I found that while all of the men complained of experiencing a disruption in

their sexual practices, only one, Gus, expressed that it affected how he viewed his masculinity. Gus reported, “But you know, the resiliency is coming back from that funk. Not the man I used to be and now intimacy doesn’t always have to have the happy ending you know.” In this and other statements, Gus seemed to connect his resiliency with the ability to engage in sexual intercourse. His statement reflects a loss in perceived masculinity as a result of the inability to engage in sexual intercourse or to achieve an orgasm with sexual intercourse. He was the only participant to report a relationship between sexual activity and perceived masculinity.

There may be a few reasons why this construct did not emerge as a significant finding in this study. The first reason, I suspect, was that I did not directly ask for this information. My research questions asked about their experiences and how they were affected by them, but I did not directly ask questions about their masculinity as I sought to focus on their experiences and on resilience. I trusted that if the phenomena was significant for the men, it would emerge through open ended questioning. The second reason why this may not have emerged was the age of the participants. The average age of the participants at the time of the interviews was 68. Gus, the participant who stated he was “Not the man I used to be” was 56 at the time of the interview. Older participants may have already seen a decline in sexual activity due to age and may have already accepted that as part of getting older. Frank seemed to confirm this when he stated that he was “fortunate” to have had to deal with “sexual aspect” of prostate cancer at his age (76 years old at the time of his prostatectomy) and not at a younger age. “I think that would have been tremendously different situation. I think like 180 degrees different situation. I

think that would have been just a much, much tougher situation than what I faced.” My personal experiences of coping with prostate cancer at the age of 43 may also reflect my bias anticipating that the loss of sexual activity would be as significant of an issue for other men as it was for me. Hopefully, this demonstrates that I strove to let the data emerge and speak for itself without infusing my own bias into the research. The last reason I believe this construct did not emerge as a significant finding was that all of the participants were recruited from and were active participants in a support group for prostate cancer. In this support group, the perceived loss of masculinity may have been a normalized experience among men, reducing the stigma and shame associate with it. Through the group, the men may have also learned to identify with other markers of masculinity other than sexual activity.

Limitations of the Study

The study was limited to interviews with male prostate cancer survivors who attended a prostate cancer support group and were willing to discuss their experiences for this research. The transcribed interview data was subject to member checks and the interpretation of that data was reviewed by the committee and was offered to the research participants for review. Due to the smaller sample size and the nature of the data collected, the findings of this study many not be applied universally to all cancer survivors nor all prostate cancer survivors. Efforts were made to provide rich and thorough descriptions of the setting, the participants, their experiences, and the context so that the reader can take this into consideration when trying to transfer the information to another group. Great care was taken to identify my own biases and open myself up to

accountability with my research committee to ensure that I could be a neutral yet active part of the research process.

Recommendations

My recommendations were written for caregivers supporting the prostate cancer survivor, for prostate cancer survivors, and for researchers engaged in future research. The findings offer caregivers the opportunity to gain empathy and insight into the prostate cancer experience. Based on the information shared by the men caregivers may consider

- providing immediate access to informative medical literature on prostate cancer;
- clarifying the treatment options, their advantages, and disadvantages to help men make more informed choices;
- making a mentor who has been through similar experiences available to serve as a guide to other men;
- offering a list of local support groups and mental health providers who are sensitive to the issues facing cancer survivors;
- promoting and supporting more community awareness and media coverage of prostate cancer and its treatment to normalize the experience for men.

All of the men in the group reported that they had positive experiences attending a PC support group and sharing their experiences with other men. Men experiencing PC may consider the value of finding a trusted mentor or group of men who have been

through the disease. Other men can normalize the experiences, provide support, and offer valuable information.

This study raised questions and areas that deserve further exploration. I will present areas for further exploration in the form of inquiries and potential research questions below:

1. What are the lived experiences of prostate cancer survivors under the age of 55 and how are their experiences different from those of older prostate cancer survivors? The participants of this study were of the following ages at the time of their diagnosis; 68, 70, 68, 60, 64, 71, and 55. Only Gus, the youngest at 55 years old identified that the change in sexual activity after treatment affected how he perceived himself as a man. Men's age at the time of the diagnosis may be an interesting variable that may affect their experience of the diagnosis, treatment decision, and response to the cancer.
2. How are the lived experiences of resilience similar to, or different from the resilience descriptions of survivors with other cancers? This inquiry focuses more on the resilience response that, in this case, was limited to men coping with prostate cancer. How would women experiencing breast cancer experience or describe resilience? How would men and women coping with (for example) colon, liver, or pancreatic cancer describe resilience? What might be the commonalities or the differences in these descriptions that may help cancer caregivers better help their survivors?

3. What are the measurable benefits of attending a prostate cancer support group?
How are the lived experiences of those individuals who do not attend a support group different from those who do attend a support group?
4. How is the men's reported perceived ambiguity in prostate cancer treatment reflective of a larger phenomenon? If the reported ambiguity is experienced by other men, it is possible this may be a barrier to effective treatment. It may be valuable to explore how the perceived ambiguity is affected by;
 - a. the natural outcome of offering several treatment options (as opposed to one treatment),
 - b. the communication from the medical doctor advising treatment,
 - c. the men's lack of education on men's health issues.

Additional research in these areas may give a clearer picture of the experience of prostate cancer survivors, may offer a clearer picture of the resilience that bolsters cancer survivors, may remove barriers to treatment, and may offer insight to caregivers.

Implications

The implications of this research are explained in terms of the implications for the medical field of urology, mental health field, the counseling field, and the field of counselor educators. I will also review the social change implications of this research.

Medical Field of Urology

Five of the seven participants reported they felt the need to gather more information because they experienced frustration with the ambiguity in treatment protocol. The participants reported they were offered treatment options but felt ill

equipped to make decisions about their treatment. Consequently, they sought out information to gain a better understanding of what PC was, of the treatment methods, treatment success rates, and treatment side effects. This is a phenomena that is not identified in the literature and deserves further research. Medical doctors may want to consider taking more time to review the options available to men and offering reliable reading materials, websites, and resources to help men make informed decisions.

Mental Health Field

In the broadest sense, this research provides insight to the mental health field of the possible emotional experiences of men diagnosed with prostate cancer. According to the American Cancer Society (2017), the United States has an estimated 2.9 million men who have at one time been diagnosed with prostate cancer that are still alive and will have 161,360 new cases of PC in 2017. This large and growing constituent of men, many of whom may have also experienced depression as a result of their cancer experiences (Sharpley, Bitsika, & Christie, 2013) may benefit from professional treatment that is sensitive to their needs. The participants interviewed in this study associated their diagnosis with feelings of shock, grief, fear, confusion, anger, self-blame, anxiety, and heightened emotional instability. The mental health field may benefit from an improved understanding of:

- The cancer threat experienced by men with PC.
- The anguish brought by decision making for men with PC.
- The value of medical information to men with PC.
- The role support groups have played in helping men.

- The role resilience played to help depressed men cope with their diagnosis.
- The long term physical side effects afflicting men after treatment of PC.

Counseling Field

In contrast to other mental health traditions that have focused on the medical model of diagnosis and treatment, the field of counseling has historically focused on wellness, development across the life span, mindfulness, meaningfulness, as well as the treatment of mental disorders (Gladding, 2018). A salutogenic model promotes health by focusing on factors that support human health and well-being. With this background, the field of counseling may be uniquely positioned to promote resilience and post-traumatic growth as a salutogenic model of wellness.

Counselors would benefit from awareness of the experiences of PC survivors to help them understand and anticipate how men may be affected by a prostate cancer diagnosis. Awareness of the diagnosis experiences may help counselors understand the anguish and hardship that men may experience learning their diagnosis and determining the treatment choice. Understanding the effects of the cancer disease and the long term effects of treatment will prepare the counselor to anticipate the issues men may face on their own and in a partner relationship. Counselors may also promote resilience by exploring with the client how they may participate in similar activities that promoted and demonstrated resilience in the men in this study. For example, all of the participants reported that they benefited from learning about the disease, attending the support group, sharing their story, helping other men, and practicing self-care. The experiences and stories of the participants in this research may also be shared with clients to normalize

their experience with cancer. Revealing how other men found meaning and experienced post-traumatic growth may also be an inspiration to clients experiencing PC.

A counseling practice or agency may consider promoting the services of a male counselor who is familiar with PC issues as men with PC may initially feel more comfortable speaking with a male counselor. Counselors are uniquely positioned to offer effective support to men because of their training in listening and rapport building skills. Counselor or agency participation in (and support of) events to raise awareness of prostate cancer may demonstrate to the community that the counselor and agency are sensitive to the subject. Counselors will want to be aware of support groups and additional resources in their communities to recommend to their clients.

Counselor Educators

Counselor educators can enhance the training of counseling students by informing them of the experiences and the impact of a prostate cancer diagnosis. Additional qualitative studies that give voice to PC survivors may raise awareness and bring more attention to the cancer experience. The field would benefit from more research into the interaction between resilience and depression in men with PC diagnosis. Counselor educators may also reinforce the historical roots of the field of counseling by promoting a salutogenic model of wellness through constructs like resilience and post-traumatic growth.

Social change implications

Prostate cancer is as prevalent and deadly to men as breast cancer is to women (American Cancer Society, 2017). However, prostate cancer research receives less than

half of the research dollars that breast cancer receives (NCI, 2016b). Prostate cancer survivors reported higher scores of perceived stigma, self-blame, anger, and depressed affect over their diagnosis than women with breast cancer (Else-Quest, LoConte, Schiller, & Hyde, 2009). Men are exposed to less media coverage of prostate cancer compared to the current media coverage of breast cancer (Gough, 2006). With less media presence and less research, men may have less access to support and information about PC than women have about breast cancer. The lack of communication, interaction, and information contribute to a social norm that promotes ignorance, silence, and isolation.

By reducing the stigma of prostate cancer, promoting early screening, and normalizing the experiences that men endure, we may encourage more awareness, education, and support among men. More research into the experiences of PC survivors may raise awareness in the general public, benefit caregivers interested in better supporting survivors, and benefit the survivors themselves. Giving voice to the experiences of these men takes a step towards reducing the ignorance, silence, and isolation that men experience.

Conclusion

The purpose of this hermeneutic phenomenological qualitative study was to reveal the lived experiences of prostate cancer survivors and explore the ascribed meanings held by the participants. The results of this study intended to elucidate the phenomena in the fullness, essence, and meaning intended by the participants, while giving voice to prostate cancer survivors' challenges and offering insight into how these men found meaning and adapted constructively to their adversity.

Seven PC survivors participated in-depth semi-structured interviews revealing their experiences, insights, and gains from the PC experience. Three core themes; *diagnosis, resilience, and changes in self* provided an organizing framework for their responses. Overall, all of the men perceived prostate cancer as a threat (to their health, lifestyle, or mortality) that triggered feelings of shock, grief, disappointment, self-blame, aggravation, anxiety, fear of death, and heightened emotional instability. Some of the participants described resilience as a physical response, but most agreed that at the core, resilience was a mental response. Their descriptions of resilience coalesced around the following themes; “Knowledge is power,” “Positive attitude,” “I want to fight it,” “Ability to bounce back,” “Coming to terms,” and “Energy.” Finally, all of the men reported gaining some form post-traumatic growth as a result of their experiences. The descriptions of their post-traumatic growth included changes in priorities, new-found role helping other men, more confidence in themselves, and renewed perspectives about themselves. In spite of their hardships, all of participants in this study demonstrated a sense of gratitude for their experiences, their new found insights, and the gains they derived. The narratives of their experiences and descriptions of resilience offered rich insights that will hopefully aid caregivers and other PC survivors responding to prostate cancer.

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Appendix A: Researcher Identity Memo

- 1) What prior experiences have you had that are relevant to your topic or setting? What assumptions about your topic or setting have resulted from these experiences? What goals have emerged from these, or have otherwise become important for your research? How have these experiences, assumptions and goals shaped your decision to choose this topic, and the way you are approaching this subject?
- 2) What potential advantage do you think the goals, benefits, and experiences that you have described have for your study? What potential disadvantage do you think these may create for you, and how might you deal with these?

(Maxwell, 2005, p.28)

In 2012, at the age of 43, I was diagnosed with prostate cancer and underwent a robotic-assisted radical prostatectomy. This was the first major illness and medical procedure I had ever experienced so the experience was shocking and overwhelming. I had decided to get screened regularly starting at the age of 40 as my paternal grandfather had been diagnosed with prostate cancer, and his two sons (my Father, and Uncle) were also diagnosed with prostate cancer. Although my cancer was discovered at an early stage, I decided to pursue surgery in an effort to “get cancer out of me” as soon as possible. My urologist patiently answered all of my questions, performed the procedure, and has continued to provide aftercare support, monitoring side effects as well as bloodwork for recurrence of cancer. At the time of the cancer disruption, I was a husband and father to 5 children still living at home and my feelings of shock had been accompanied by confusion, fear, and uncertainty. I spent time in reflection and prayer seeking to find order, meaning, and benefit out of the experience. I found order, meaning, and benefit by turning the situation into an opportunity to help others while teaching my kids how to deal with adversity. I believed that “God allowed this to create an opportunity to help others,” so I explored avenues for constructive social change. Conducting a social awareness campaign at our local high school during a high school football game became an effective opportunity to raise awareness among the general public, bring other survivors together, and raise money towards a good cause (Lacourt, 2014). Since the initial event, I have conducted additional awareness events and have facilitated a monthly prostate cancer support group.

As a direct result of my experiences, I carry presuppositions that I need to be aware of as a researcher. I will list some of these beliefs below:

- *Positive bias towards the use of spirituality for coping.*
- *Positive bias towards the medical field and its medical treatment of prostate cancer.*
- *Positive bias towards and empathy for prostate cancer survivors.*
- *A belief that because I share common experiences with other prostate cancer survivors we may also share in similar feelings, values, and beliefs.*

As a researcher, it is imperative that I am aware of these biases to protect the data and my research from being skewed by my own perceptions and to ensure that the

experiences of my participants are truly represented. My research may benefit from these experiences and beliefs as I am a passionate person and I will direct that passion to complete this work and will take great care to give voice to other survivors. A disadvantage may be that in my passion and bias I may push or drive a question or an issue to promote an issue in my research that may be important to me. I will work closely with my dissertation committee to open myself up to accountability.

Appendix B: Recruitment Letter

Are you a prostate cancer survivor?

Participants needed for a study that explores the resiliency and post-traumatic growth of prostate cancer survivors.



You qualify to participate if you:

- ❖ Are a survivor of prostate cancer in between 6 months and 5 years after initial diagnosis.

What is the time commitment?

- ❖ Complete a brief questionnaire (5 minutes).
- ❖ Participate in one interview (45-90 minutes).
- ❖ Some maybe invited to participate in an optional follow up interview (45 minutes).

Why participate?

- ❖ Your contributions give voice to the challenges experienced by prostate cancer survivors.
- ❖ Your contributions may help future prostate cancer survivors and their caregivers.
- ❖ You may learn more about yourself.

For more information, or to participate in the study:

Please contact the researcher, Luis E. Lacourt.

Cell: 330-605-XXXX

E-mail: luis.lacourt@waldenu.edu



The results of this study will be included in a dissertation for a PhD in Counselor Education and Supervision from Walden University

Appendix C: Demographic Questionnaire

The online questionnaire was created with the assistance of Google Forms. It was made available to the participants through the online link:

<https://goo.gl/forms/fmZNZiISbNjwhtrk1>

Screening Survey

Thank you for agreeing to participate in my research project. Walden University has asked that I take a number of precautionary steps to ensure your safety and protect the integrity of the research. One of those steps is to have you complete this Screening Survey. Please remember that all information disclosed at any point in the process will be kept strictly confidential.

First name: _____

Last name: _____

E-mail address: _____

Phone number: _____

Please confirm that you were indeed diagnosed with prostate cancer: (Yes or No)

Please indicate the date when you were initially diagnosed with prostate cancer:

I am willing to discuss my experiences surrounding my prostate cancer diagnosis, treatment, and recovery: (Yes or No)

Age at diagnosis: _____

Age now: _____

Appendix D: Prezi Canvas

Link to Prezi Canvas:

http://prezi.com/hfizpgoyttrz/?utm_campaign=share&utm_medium=copy&rc=ex0share

Screenshot:

