

LEISURE IN THE LIVES OF OLDER MEN: COPING AND ADAPTATION
FOLLOWING PROSTATE CANCER DIAGNOSIS AND TREATMENT

By

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by

David Kingdon Howard

This dissertation is dedicated to my cousin Angelique “Angel” Adrienne Gunnell Tilby [1964–1998], and the many people who, like her (whether in the past, present, or future), encounter and face cancer and the challenges it presents to mind, body, and soul. And despite those challenges, or perhaps because of them, choose to continue to live with dignity, purpose, and tremendous courage.

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Abstract of Dissertation Presented to the Graduate School
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By

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On an annual basis, approximately 200,000 men within the United States are diagnosed with prostate cancer. In a variety of settings, health care professionals are called upon to assist men and their families who face decisions about prostate cancer treatment, and then afterward help them to cope with individual side effects. These side effects may be physical (e.g., incontinence, erectile dysfunction, hot flashes) and/or psychosocial (e.g., anxiety, embarrassment, self-image, withdrawal). Though literature exists describing aspects of men coping with physical side effects, less is known about efforts to adapt to psychosocial side effects. Furthermore, the dynamics associated with leisure or free time, voluntarily-chosen activity following diagnosis and treatment for prostate cancer has not been explored. Leisure is recognized as a crucial aspect of quality of life, especially for older adults.

Utilizing a qualitative research design with grounded theory methodology, interviews were conducted to explore older men's definitions of quality of life, their

perspective regarding leisure, and how the prostate cancer experience impacted their lives – in particular, leisure. Perceptions of quality of life included adherence to gendered roles and personal traits, significant relationships, health, and being active and productive. Events such as retirement were explored, along with “generativity” which focuses on older adults’ tendency and desire to transmit wisdom and knowledge to future generations. Leisure was illustrated as a phenomenon that included constructs of time, activity, participation, relationship contexts, and as an antithesis to work-place attitudes and behaviors. Motivational factors relative to leisure, meanings derived from leisure participation, and barriers that impede leisure involvement were identified.

It was found that men diagnosed and treated for prostate cancer were able to cope and adapt to individual circumstances, and they sought to keep free time, voluntarily-chosen activities as an important of their lifestyle. Men’s participation in leisure, recreation, sports, and hobbies, often with friends or family members was sometimes modified or altered due to the presence of treatment side effects. However, despite the presence of side effects, these activities still provided experiences that were enjoyable, helped establish and maintain significant relationships, and gave personal meaning to life.

CHAPTER 1 STATEMENT OF THE PROBLEM

The elderly are an increasingly large segment of society within the United States. In 2000, Americans 65-years-old or older totaled 35 million. This figure represents 12.4% of the population, or about one in every eight Americans. Since 1900, the percentage of Americans 65 years old or older has more than tripled. The number of older Americans has increased by 3.7 million, or 12% since 1990. In the year 2000, men reaching age 65 had an average life expectancy of 16.3 years. As of 2000, 16.4% of persons 65 years or older were minorities, with approximately half of them (8%) being African-American. By 2030, it is expected there will be about 70 million older persons, accounting for 20% of the total population (U.S. Administration on Aging, 1999).

Despite the sheer numbers of older men, which of itself warrants attention, successful aging is more than becoming a member of a certain age group. Aging and development throughout the human lifespan has been studied and explored as a multifaceted phenomenon including, but not limited to, fulfillment of social roles (Bowling, 1997; Whitbourne, 2001), aspects related to physical and psychological functioning (i.e., sexuality; (Schiavi, 1999), and meaning (Settersten, 2002)). Typically, as men grow older, amidst transition from work-place productivity to retirement and into a more of a leisure-lifestyle, decreases in functional ability occur and, not surprisingly, the chances of chronic illness or experiencing a disability increase, thus challenging the quality of life experienced (Seeman & Chen, 2002; Stuck et al., 1999). For example, the risk of being diagnosed with cancer increases with age. For men over the age of 40,

prostate cancer is the most frequently diagnosed type of solid organ cancer (American Cancer Society, 2003). For older men in particular, prostate cancer can be a serious threat to health and one's quality of life (Kelly & Dodd, 2001). More than 70% of all prostate cancer diagnoses occur in men over the age of 65. The probability of men aged 40 to 59 being diagnosed with prostate cancer is 1 in 45, and for men aged 60 to 79 it is 1 in 7. At any point in a man's life, from birth to death, the probability is 1 in 6 (American Cancer Society, 2003).

Located just below the bladder, the prostate is a walnut-sized gland that surrounds the urethra – the tube through which urine vacates the body. One purpose of the prostate gland is the production of semen, which aides the motility of sperm cells and protects them from the acidic environment of a woman's reproductive system. The prostate produces about 25% of the seminal fluid that combines with sperm during ejaculation. Alongside the prostate are nerves that facilitate penile erection. Adjacent to the prostate are sphincters that play an important role in control of urination (Bostwick, MacLennan, & Larson, 1999).

Carcinoma of the prostate, similar to cancers of other parts of the body, occurs when cells inside the prostate grow abnormally or out of control. Once detected, various treatments for prostate cancer are available (e.g., surgery, radiotherapy, hormone therapy). Each of these treatment alternatives, however, comes with certain risks and subsequent side effects that may impact quality of life (Kelly & Dodd, 2001).

Similar to other potentially serious illnesses, prostate cancer and treatment can pose a threat to the health and well-being of a man. It may create uncertainty and anxiety, and may necessitate adjustment for both the man and his family and friends (Kunkel, Bakker,

Myers, Oyesanmi, & Gomella, 2000). Though there is a great deal of literature concerning prostate cancer and post-treatment issues related to quality of life, the vast majority of studies have targeted aspects of physical functioning. Many studies have focused on incidence and impact of incontinence and erectile dysfunction (e.g., (Litwin et al., 1999; Pietrow, Parekh, Smith, Shyr, & Cookson, 2001). Less detailed information, however, is available about the nature and extent of the psychological, emotional, and social impact of prostate cancer during activities of daily living, including leisure behaviors.

Common side effects of cancer diagnosis and treatment include depression, uncertainty, grief, anxiety and stress, fatigue, diminished physical mobility and functioning, pain management, urinary incontinence, social isolation, diminished sexual functioning (erectile dysfunction), and added stress in relationships (Fransson, 2000; Kunkel et al., 2000; McPherson, Swenson, & Kjellberg, 2001). Because these side effects have not been explored in relation to how they impact leisure and one's chosen leisure lifestyle, healthcare professionals would benefit from having additional information about the role leisure plays in psychosocial adaptation and quality of life after prostate cancer. More knowledgeable professionals would be able to provide a broader range of effective services that meet the needs of the patient population, and empower men to successfully overcome challenges and resume important life activities. It is likely, however, that prostate cancer and its treatment negatively impact leisure attitudes and behaviors of older men. Despite the significant role that leisure choices and behaviors play in the life and development of older adults (J. Kelly, 1993; Douglas Kleiber, 1999; McGuire, Boyd,

& Tedrick, 1999), the role of leisure following prostate cancer and treatment, and the impact of the experience on leisure behavior has not been studied.

Because of the nature of the problem being investigated, qualitative methodology utilizing a grounded theory approach and sensitizing concepts was conducted (A Strauss & Corbin, 1998). This inductive strategy requires the researcher to be “close” to interview data, intensely and constantly reading transcripts until definitive concepts and theoretical insights emerge. While more specific information about this methodology and its procedures are found in the third chapter of this document, it is important to disclose some of the author’s background and biases for the sake of the reader who will access the findings of this study. These factors influenced the way this research was conducted and the way the data were interpreted. An undergraduate degree was earned by the author in recreation and leisure studies, with an emphasis in therapeutic recreation. This was followed by a masters degree in clinical social work. The author’s doctoral degree, and related course work, was completed in a multi-disciplinary rehabilitation science Ph.D. program, within the College of Public Health and Health Professions at the University of Florida. As a practitioner, the author has worked in mental health facilities with patients and clients of all ages, substance abuse treatment and prevention settings with adults and adolescents, and adult correctional institutions. Work in these settings was primarily as a certified recreation therapist, but, with a clinical social work background, additional responsibilities similar to that of a mental health counselor or therapist were often included.

The decision to conduct dissertation research on the topic of prostate cancer and leisure’s role in psychosocial adaptation stemmed from scholarly interests shaped from

experience in both academic and practice settings. These interests include: (a) to understand the leisure attitudes and behavior of people with disabilities (or who have potentially disabling conditions) and how disability impacts leisure, (b) to explore how the complexities of gender (e.g., attitudes and behaviors) affect the leisure behavior of people with illnesses or disability, and (c) to determine how illness or disability impacts issues related to sexuality when considering the dynamics of leisure and gender. The selection of men with prostate cancer as a study population allowed the exploration of several facets of these questions, as well as, furthered the scientific knowledge in an area of research that has been lacking. The following definitions of terms are provided to assist the reader in recognizing and understanding important concepts underlying the design and execution of this study.

Cancer – Disease characterized by cells that exhibit uncontrolled growth and division (Bostwick et al., 1999).

Disability – Any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being (World Health Organization, 1980).

Health – The state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (World Health Organization, 1948).

Leisure – Choices and behaviors within a combination of free time and expectation of preferred experience (Douglas Kleiber, 1999). Important constructs within leisure include freedom, lack of obligation (non-work time), the absence of worry, and a sense of opportunity and creative expression. *Recreation* and *play* are terms that embody traits, both similar and dissimilar as leisure, that include fun, spontaneity, social affiliation or

support, fulfillment, and growth (Godbey, 1999). Leisure may be considered as “the envelope containing the variety of experiences [and accompanying emotions] that occur during free time” (Kleiber, 1999, p. 4).

Psychosocial – Any and all psychological and social issues related to the individual’s response to physical disease and disability, decreased activity level, behavioral dysfunction, general health status (Renwick & Friefeld, 1996) and overall quality of life (Morrow, Chiarello, & Derogatis, 1978).

Quality of Life – Individual response to physical, mental, and social effects of illness that significantly influence the extent to which personal satisfaction with life circumstances can be achieved (Bowling, 1997).

CHAPTER 2 REVIEW OF RELATED LITERATURE

A wide variety of literature and resources can, and should, be discussed when examining issues related to men's health, aging, leisure, psychosocial adaptation to illness or disability, and the potential role leisure plays as it interacts with the experience of being diagnosed and treated for prostate cancer, and adaptation to inherent side-effects. The following is a discussion and summary of information taken from the scientific and academic literature pertinent to the questions being asked in this research study.

Men and Theories of Aging

A central aim for any discussion or study related to older men and how illness might disrupt their lives, is to first identify important components of normal aging, and theories that have brought understanding about issues important to men (Applegate, 1997). A theoretical model developed by Erikson (1959) and life stage theories proposed by Levinson, Darrow, Klein, Levinson, and McKee (1978) provided a foundation from which subsequent theories of aging emerged.

Erikson (1959) conceptualized human development as eight successive life stages dependent on the mastery of key developmental tasks and the resolution of associated psychological crises. *Middle adulthood* (35 to 55 or 65 years of age), the second to last developmental stage, consists of resolving crises related to being occupied with creative and meaningful work, and with issues surrounding the family. Herein, the significant challenge is *generativity versus self-absorption*, where generativity means to preserve one's culture and transmit values through the family, caring for others, and making

contributions to society. Opposite of this is self-absorption, or stagnation, that may result from fear of inactivity or failure to find a new purpose and satisfactory meaning of life. Erikson felt that much of life is spent preparing for middle adulthood. The final stage of *late adulthood* (55 or 65 until death), according to Erikson, involves a crisis of *integrity versus despair*. Integrity is the feeling when an older adult looks back on his life with happiness and contentment, feeling fulfilled with his contributions, accepting mistakes, and believing that his life had meaning. Despair, on the other hand, is experienced by those who are not able to look back and see purpose in their lives (Erikson, 1959).

Levinson et al. (1978), like Erikson, believed men's lives evolve in a more or less orderly sequence of stable periods or "eras," that are emphasized by "transitional periods" from one era to the next -- a period that may last several years. According to Levinson, a man in the era of late adulthood was likely to be consumed by personal and social response to bodily decline, awareness of one's own mortality punctuated by medical wake up calls, the serious illness or death of loved ones, increasing movement to the periphery of professional and social status, and changing life philosophies (Levinson, Darrow, Klein, Levinson, & McKee, 1978). More recently, other theories emerged to help further capture and define the process and experience of aging. Many of these theories (e.g., role theory, activity theory, disengagement theory, and continuity theory), raise important questions pertaining to men, their health and quality of life, and the nature and utilization of leisure in their lives.

Role theory is based on the premise that aging brings about the potentially traumatic decline of familiar roles, particularly those vocational in nature, or exist within the family system, and roles that are embedded with well-defined behaviors and

expectations. Conflict and challenge occurs when it is perceived that one's role, and the identity that goes along with it, is diminished or extinguished. *Activity theory* holds that decreases in customary levels of activity, each laden with meaning, amounts to a diminished sense of well-being. *Disengagement theory* suggests that as age increases, men naturally become less involved with institutions of society, partially as a result of deteriorating strength; -- thereby resulting in fewer relationships with others and, again, personal challenge. *Continuity theory* allows for role loss, social disengagement, and a decline in activity participation while asserting that an individual's unique set of personality and behavioral traits, individual variation notwithstanding, helps the individual endure the test of time and provide a sense of continuity and predictability (Fry, 1992).

This type of theoretical underpinning provides a lens through which male experience can be better understood and interpreted, especially when threatened by a serious illness. In this way, a specific lens may be utilized as the context for male experience, thus enhancing theoretical sensitivity while allowing for multiple ideas within that context. It is interesting to note, however, that despite the large number of older men in American society, issues of elderly men have been notably absent from even mainstream men's studies (Thompson, 1994). This may be due, in part, to the fact that fewer men than women reach old age, lessening the priority given to men's issues. It is also possible that men's issues are obscured by the perception that older men are perceived as physically impaired, keeping a focus on illness rather than prevention, health promotion, or quality of life (Applegate, 1997).

Leisure and its Role in Older Men's Lives

Leisure is a component that many consider to be an important contributor to the quality of life of older men (Freysinger, 1999). Leisure is a complex phenomenon with dynamics that change based on one's life situation or health status. Regardless of a person's age, gender, economic situation, social status, or health condition, consistent and meaningful participation in leisure, recreation, and play provide opportunities for growth and development in all life domains – physical, intellectual, emotional, social, and spiritual (Godbey, 1999; McGuire et al., 1999). This is also true for individuals who are experiencing illness or who are facing the prospects of disability (Institute, 1989).

While many use the terms leisure, recreation, and play almost synonymously, important conceptual distinctions exist. *Leisure* can be considered simply as one's free-time when not at work, or while taking a break during the workday. Leisure may also be viewed as a set of activities or certain behaviors that an individual participates in -- some of which are done for the sake of diversion, some for relaxation, others for the purpose of gaining or strengthening interpersonal or familial relationships, and others for the sake of exercise and physical or emotional health. Other researchers who study leisure, however, view the topic not in terms of time or place, but as a set of activities. They see leisure, akin to subjective conceptualization of health, as a state of mind or a spiritual experience or place where one can escape from the stresses of daily living and contemplate the meaning of life. Self-awareness and renewed identity are also thought to be outcomes of many leisure activities, especially those that are internally motivated and based on perceived freedom (Godbey, 1999; R Mannell, Zuzanek, & Larson, 1988). *Recreation*, on the other hand, is more structured, often done with or in the presence of others, and is likely more physical in nature. Recreational activity often has tangible consequences,

such as winning a game, or achieving a high score. *Play* generally occurs during activities which are inherently carefree, spontaneous, or childlike (Ellis, 1973; Godbey, 1999).

It is helpful to realize that the participation in the same activity or experience by different people can be recreation for one, leisure for another, and play for yet another. Also, as one ages or the context changes, an activity can, for the same individual, be perceived as leisure at one point in time, recreation at another, and simply being playful at yet another (Dattilo, 1991; Goodale & Godbey, 1988). For example, as a teenager, a boy may learn to golf, and as he *plays* he simply likes the exercise, the enjoyment, and the chance to learn new skills. As a young or middle aged adult, golf may be more *recreational* as he competes against peers in weekend tournaments, or takes in a round as a break from his normal workplace routine. Once retired, golf perhaps has a different meaning – one that symbolizes a chance to get out-of-doors and into nature where he experiences *leisure* and the opportunity to be with good friends.

Many scholars believe freely chosen activities of recreation and leisure are paramount to quality of life, and that those activities become even more central in the lives of older individuals, especially those who have retired (J. Kelly, 1993; Tinsley, Colbs, Teaff, & Kaufman, 1987). Freysinger (1999) wrote that there is both continuity and change in leisure behavior across the human lifespan. Continuity exists when the same activity is engaged in because of familiarity, and the continual enjoyment it brings. Change may occur, however, due to altered roles, responsibilities, time, resources, opportunities, and interests. Change and continuity, however, apply not only to types of activity, but frequency of participation, as well as motivation, satisfaction, and meaning. Long (1987) specifically looked at continuity and leisure related to retirement for men,

and concluded that men who experienced the least changes associated with their leisure adapted best to their retirement.

Strain, Grabusic, Searle, and Dunn (2002) examined characteristics such as age, gender, education, health, marital status, self-rated health, and functional ability. They suggested continued education about leisure serves as a means of enhancing older adults' participation in desired activities and activity modification may compensate for diminished functional ability. Their study failed to demonstrate, however, a consistent pattern related to the continuation or ceasing of leisure activities; a finding perhaps due to individual differences and a wide variation in leisure interests and participation. Menec (2003) also stressed the importance of various activities in successful aging, and that different types of activities have different benefits. Activities that are productive and social in nature, including many distinctly leisure endeavors, result in better functioning and greater longevity. Whereas activities, including those of a more solitary nature, may have psychological benefits, provide a sense of continuity or engagement with life, and foster renewed meaning.

According to Sinick (1980), the attitude of men when faced with the prospect of retirement ranges from excitement to fear or dread. Many view retirement as an opportunity to spend more time doing things they are interested in, and thus take advantage of chances to be creative and productive. For others, however, growing older and facing retirement creates a sense of loss and emptiness. This is heightened when a man's identity is centrally tied to societal norms that place great value on workplace contributions. In such situations, a sense of powerlessness and despair may emerge. The prospect of diminished capacity and eventual death also add to the growing list of

concurrent stressors that are faced (Blum, 1990). And although older people may be more resilient to individual stressors, they tend to face more stressors simultaneously, such as comorbid conditions, loss of significant others, declining physical or mental abilities, and diminished income (Duffy & Iscoe, 1990). A diagnosis of cancer, further potentiates an abrupt realization of mortality, and motivates men to complete unfinished business, gives their life clarity, and helps them to prioritize the activities that carry the greatest meaning (McQuellon & Hurt, 1993). For others, though, the experience of being told they have cancer, and the decision of which treatment to use, if any, is a central part of a major crisis (Lewis, Gottesman, & Gutstein, 1979; Weisman & Worden, 1976). Efforts to scientifically understand leisure's role during times of illness such as cancer, or the impact of a cancer experience on leisure attitudes and behavior, are needed to be able to adequately address the holistic needs of the man with prostate cancer.

The Meaning of Leisure

A key attribute of the research design of this study is its intent to examine the meanings people ascribe to leisure. Settersten (2002) recently studied meaning in later life, and wrote that leisure, including volunteerism, is a source of meaning within the social domain for older individuals. Specifically looking at leisure, Watkins (2000) explored three research questions related to this topic. The areas investigated were: (a) how individuals gain knowledge about leisure and form a meaning of leisure, (b) how different individuals form different meanings of leisure (even if the experience or activity is essentially the same), and (c) how individuals change their meanings of leisure over time or place.

These questions are based on the assumption that the meaning of leisure results from knowledge gained through experience, and that individuals have the capacity to

learn different leisure meanings and modify existing ones. Watkins' (2000) examination led to the description of four traditional paradigms used to study leisure meaning: (a) behaviorism, (b) cognitivism, (c) individual constructivism, and (d) social constructivism. *Behaviorism* is described as the idea that people gain knowledge about an event through the use of their senses. By associating the stimulus associated with an event with a particular behavioral response, the behavior becomes habitual, and meaning is inferred. *Cognitivism* applies to knowledge obtained from within the mind that is used to help make sense of phenomena – knowledge that otherwise might be unstructured, or without meaning. *Individual constructivism* suggests that “knowledge is not passively acquired from the outside world or implanted as a priori representation in the mind but is constructed by the mind’s ability to actively explore and develop its own meaningful accounts” (pp. 97-98). This paradigm is based on many of the tenets of symbolic interpretation, and allows for differences in meaning, depending on variations of a person’s conceptual abilities and their changing needs. *Social constructivism* is described as obtaining knowledge or meaning as a result of participation in social practices that are subject to structuring influences of historical processes and sociocultural beliefs. A fifth paradigm, *experientialism*, is presented by the author as viewing knowledge “as an experience of the relationship formed between an individual and some aspect of his or her world” (p. 102), and implicitly involves the person’s awareness of him or herself as an individual (Watkins, 2000). The meanings men place upon their leisure, and the construction of those meanings as it relates to their prostate cancer experience, is of central interest to this study.

Prostate Cancer Etiology and its Threat to Health

Prostate cancer is a very commonly diagnosed type of cancer in men, second only to skin cancers. In the United States in 2003, an estimated 220,000 men will be newly diagnosed with prostate cancer, and approximately 28,900 men will die as a result of this disease. Within the U.S., Florida ranks second behind California for the number of men (15,800) who are expected to be diagnosed with prostate cancer this year (American Cancer Society, 2003). The sheer numbers of older American men who have been diagnosed with prostate cancer, or are likely to be diagnosed in the future, demonstrates the need to understand issues related to the general health and well-being of older men (Kinsella, 2000). Individually, men who are diagnosed with prostate cancer must learn to cope with the disease and subsequent treatment that will likely impact physical and psychological well-being (Kunkel et al., 2000). The incidence of prostate cancer has generated greater attention than ever before within our society. In 2000, U.S. News and World Report featured a cover story about prostate cancer, in which it was stated that “prostate cancer is an inglorious disease, rife with indignities that cut to the core of male sexuality and self-esteem” (Brink, 2000, p. 66), and that men with prostate cancer today are “part of a generation of men in their 40s and 50s who are forced to understand the male body and its betrayal in a way never required of their fathers”(p. 66) . For many, it is a threat to overall quality of life, and it challenges their vocational, familial, and leisure lifestyle (Freidenbergs & Kaplan, 1999).

Risk Factors and Cancer Screening

While it is not known what causes prostate cancer, certain risk factors have been shown to be associated with the development of the disease (Chan, Stampfer, & Giovannucci, 1997). A risk factor is any characteristic or behavior that increases a

person's chance of acquiring a disease. While some risk factors can be accounted for and modified through behavioral changes, others are uncontrollable. Risk factors that cannot be changed include age, race, nationality, and family history. Examples of risk factors that can be modified include diet, tobacco and alcohol use, weight, and physical activity. Race is an important consideration since, for reasons not fully known, prostate cancer is more prevalent among African-American men than Caucasian men (Hoffman et al., 2001). Nationality is also a factor, as prostate cancer is most common in North America and northwestern Europe than in other parts of the world. It is also known that men with close family members who have had prostate cancer (i.e., fathers or uncles) are at a greater risk. A high-fat diet, body composition, weight, and regular physical activity are also variables that have been studied as to their relationship to prostate cancer risk (I. Lee, Sasso, H., & Paffenbarger, R., 2001; Society, 2002). It is important to note, however, that as with other parts of the body, the prostate may undergo changes due to normal aging, or the effects of non-cancerous disease. For example, benign prostatic hyperplasia (BPH) is a condition wherein the prostate enlarges very often due to hormonal changes associated with aging. Though rarely a threat to health, BPH can result in pressure on the urethra and difficulties in urination (Bostwick et al., 1999).

Screening is important for all men, but especially for those at risk for the development of prostate cancer. And while digital rectal exams are a routine procedure for older men, the use of methods such as testing for levels of prostate-specific antigens (PSA) and biopsies of prostatic tissue allow for earlier detection of prostate cancer. For men who are diagnosed early, there is time for a thorough gathering of information and consideration of treatment alternatives (Nash & Melezinek, 2000). However, some

controversy exists surrounding the use of PSA tests. Some consider the PSA test to be the best marker for cancer, while others view it with caution as it detects cancers that are so minute some feel they should not be treated (Ganz & Litwin, 2001); thus adding to the anxiety and uncertainty that can exist while making decisions about treatment options. For many, it may be a question of prolonged life with the potential of diminished quality of life, versus the possible significant risks associated with not actively pursuing treatment, but thus avoiding side-effects which can be stressful.

Treatment for Prostate Cancer and Potential Side Effects

Prescribed treatment for prostate cancer depends upon the age of the man, the stage of the cancer, and other medical conditions that are present. Surgery and radiotherapy are commonly performed in an attempt to cure the patient of the cancer. Radical prostatectomy is the surgical removal of the prostate gland. Procedurally, there are different ways of performing the surgery (i.e., retropubic or perineal methods), depending on various factors such as whether efforts to preserve nerves will be made to preserve erectile function. Cryosurgery aims to kill cancer cells through freezing prostatic tissue. Radiotherapy delivers controlled doses of irradiation to the cancerous tumor and surrounding tissue. Hormonal therapy is commonly recommended to thwart the development of cancerous tissues, and chemotherapy is often a prescribed alternative for metastatic disease when the cancer has spread beyond the prostate to nearby lymph nodes or pelvic bones (W. Kelly & Dodd, 2001). For men with low-grade or early-stage tumors, or who are much older, expectant therapy or “watchful waiting” may be recommended. This consists of careful observation without any active treatment (Ko & Bubley, 2001). As is seen in Table 1 below, each of these treatment alternatives, despite their respective advantages, is known to have potential side effects (Talcott et al., 1998).

Table 1 - Advantages and Potential Side Effects of Prostate Cancer Treatments

Treatment	Advantage	Potential Side Effects
Radical Prostatectomy	Removal of the prostate gland and accompanying cancer using a single procedure intended to cure the disease.	Erectile dysfunction and urinary incontinence are common. Pain and fatigue are also frequently experienced after surgery, but is typically brief. Psychosocial side effects will vary for each individual, but may include anxiety, identity crisis, uncertainty, depression, and isolation
Cryosurgery	Use of cooling probes that cause the death of prostatic tissue through freezing. This is a newer procedure and its efficacy is still being fully investigated.	Physical side effects may include urinary retention, perineal pain, erectile dysfunction, and rectal fistulas. Psychosocial side effects will vary for each individual, but may include those mentioned for radical prostatectomy.
Radiation therapy	Delivery of precise doses of irradiation to the cancerous tumor intended to cure the disease.	Erectile dysfunction, urinary incontinence, and bowel problems. Psychosocial side effects will vary for each individual, but may include those mentioned for radical prostatectomy.
Hormone therapy	Typically involves taking a pill, therefore less invasive than surgery or radiotherapy. If side effects become too severe, treatment can be discontinued and symptoms may subside.	Depends upon the specific treatment used, but may include water retention, hot flashes, breast growth and tenderness, and nausea. Psychosocial side effects will vary for each individual, but may include those mentioned for radical prostatectomy.
Expectant therapy	No treatment is administered, thus no side effects other than those caused by the cancer itself.	Psychosocial side effects will vary for each individual, yet knowing that one has cancer and no treatment is occurring can cause increased anxiety and uncertainty for patients and family members.
Information for this table obtained from Curtis and Juhnke (2003) and Kelly and Dodd (2001).		

Psychosocial Adaptation, Coping, and Health

Studies that focus on physical side effects are numerous, and generally fall in the category of examining health-related quality of life (Wei et al., 2002). While a great deal of literature exists pertaining to the effect of prostate cancer on physical aspects such as

urinary incontinence and erectile dysfunction (Eton & Lepore, 2002), fewer studies have focused on aspects of psychological, social, or emotional well-being of older men with prostate cancer. The term *psychosocial* has been defined as psychological and social issues related to the response to physical disease and disability, decreased activity level, behavioral dysfunction, general health status, and overall quality of life (Morrow et al., 1978). The relative paucity of research about the psychosocial aspects of prostate cancer, and the limited number of interventions in this area, has resulted in a definite gap in scientific literature. More information on this topic will help health care professionals better consult with and meet the needs of men with prostate cancer, including their needs beyond merely the physical domain.

Weber (2003) reviewed the literature between 1970 and 2002, and found that over 12,000 manuscripts had been written related to prostate cancer treatment. Of those, however, only 8% included keywords embodying psychosocial issues as descriptors of the research. Even more concerning is that only five known studies have reported the results of intervention research that sought to improve the psychosocial well-being of men with prostate cancer (e.g., (Johnson, 1996; Kim, Roscoe, & Morrow, 2002; Weber, 2002) (Johnson, 1996; Kim et al., 2002)). An aim of this research study was to add to the knowledge base about leisure's role within the context of psychosocial adaptation, and thereby enhance the efficacy of potential interventions for this population.

A diagnosis of cancer is likely to bring with it certain levels of anxiety and uncertainty, numerous questions, and a need for information and answers. Anxiety stems from fear and concern about loss of bodily functions, pain, treatment alternatives and their potential side effects, possible loss of independence and social isolation, financial

concerns, and issues related to returning to work or future involvement in civic functions or volunteerism. Uncertainty about the future, and worries about family and loved ones and if or how relationships may change, are common (Freidenbergs & Kaplan, 1999). Fear and concern about the possible loss of bodily functions (e.g., potency), pain, side effects of treatment, negative body image or sense of self, and potential loss of control or independence can be significant. Worries about how others will perceive him and his situation (concurrent with possible incontinence) may lead to social isolation and, if financial concerns exist, the situation may indeed prove troublesome (American Cancer Society, 2002). The need for certain types of information required to make decisions related to treatment will vary because of the unique educational needs and background of each individual (Visser & van Andel, 2003; Wong et al., 2000).

Individual issues related to the diagnosis and treatment of individuals with prostate cancer may include depression, grief, anxiety and stress, hopelessness, fatigue and diminished physical mobility, pain management, social isolation, impaired relationships, decreased participation in free-time activities that previously were enjoyable and provided a sense of satisfaction, and diminished sexual function (Freidenbergs & Kaplan, 1999; Livneh & Antonak, 1997). Each of these issues deserves continued study, in addition to the relationship they have with one another. For example, Gil and Gilbar (2001) studied and found a link between depression and hopelessness among cancer patients. Another study reported an association between diminished physical functioning and depression (Kurtz, Kurtz, Stommel, Given, & Given, 2001). In today's health care community, approaches that are holistic in nature and take into account the entire person

and the constellation of issues that may be present is a preferred method of service delivery (Short & Talley, 1999).

All of these factors, when viewed in relation to the unique background, personality, and life experience of the man involved, may impact psychological and social well-being, vocational opportunities (present and future), as well as pursuit of leisure and recreational activities significant to one's quality of life (Livneh & Antonak, 1997). The process of adjustment and adaptation to prostate cancer and its effects helps an individual maintain their desired quality of life. As a concept, quality of life continues to be an important focus of scholars, researchers, and practitioners within rehabilitation sciences (Renwick & Friefeld, 1996); and many feel quality of life should be the primary outcome of rehabilitation (Bishop & Feist-Price, 2001; Livneh, 1988). Quality of life, however, is a concept that many feel is a combination of economic, social, emotional, familial, and health-related factors -- factors that continue to theoretically and methodologically challenge scholars and practitioners who study these type of questions (Hunt, 1997).

Men with prostate cancer likely face the need to cope and adapt to the physical, emotional, and psychological challenges present in each unique situation. Weisman and Worden (1976) labeled the diagnosis of cancer and the subsequent 100 days as an "existential plight." Metaphorically, the term *plight* is used to describe the varying concerns a person may have that affect his life. For example, a person is likely to consider the coping strategies that are available and decide if he has the necessary resolve to carry them out to a satisfying conclusion. The experience of dealing with cancer may also include coming face-to-face with one's vulnerability, and each of these concepts -- vulnerability, coping, and resolve -- will, according to the authors, collectively predict the

nature of an individual's mood disturbance following cancer diagnosis (Weisman & Worden, 1976).

An understanding of typical ways that people cope or grieve is helpful to this discussion. Kubler-Ross (1969) is noted for her work in promoting understanding of what occurs when individuals are faced with the prospect of their own mortality or possible death. She suggests that coping and grieving happens in stages of: (a) denial, (b) anger, (c) bargaining, (d) depression, and (e) acceptance. *Denial* occurs when an individual is unable to admit to themselves that serious consequence (i.e., loss of function or even death) is possible. *Anger* is manifest when the pain or fear of loss is expressed and projected onto others. *Bargaining* is an effort at overcoming the serious illness or possible death by negotiating, perhaps with doctors or a higher power, for longer life; and *depression* may coincide with a full realization of potential mortality or disabling conditions. *Acceptance* occurs when grieving transcends into acknowledgment and preparation for what the future may bring. A man who has been diagnosed with cancer may experience any or all of these stages.

Smart (2000) proposed a slightly different model – one that uses phases instead of stages to describe what happens psychologically and emotionally when people attempt to adapt to situations. Smart theorized that it was possible that people might experience stages of: (a) shock; (b) disbelief or denial; (c) depression or mourning; (d) psychological regression to an earlier, more favorable, or “normal” time of life; (e) personal questioning and/or anger; and (f) integration and growth. For the man with prostate cancer, he (or his family members) may experience any or all of these phases, in no set or pre-determined order, and spend varying amounts of time and energy within the different phases.

Regardless of which model is used, it is very likely that men diagnosed with prostate cancer, along with their family and friends, will experience some change in their lives and relationships (e.g., (Beatty, 1978).

In addition to the challenges men face when diagnosed with and treated for prostate cancer, one must recognize that wives, partners, and family members are also likely to be affected by the disease. Wives especially are known to carry a unique burden in assisting their husbands to monitor and care for health-related conditions (Davison, Degner, & Morgan, 1995; Norcross, Ramirez, & Palinkas, 1996). Prostate cancer and treatment are likely to impact normal day-to-day activities, involving work, leisure, and family activities or obligations (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). For all those involved, health-related problems and caregiver burden has its own set of physical, emotional, and psychosocial problems. It is not easy for many to separate work from leisure or vice versa (Sanford, 2002), and family issues may be central to either or both (Snir & Harpaz, 2002).

When told they have prostate cancer, older men may experience depressive symptoms, guilt, denial, anger, and threats to body image and self-esteem that are distinctly specific to issues of gender and masculinity (Livneh & Antonak, 1997). Men are often characterized as unwilling, or unable, to ask for or seek help when experiencing a problem. Likewise, men are believed to deal with illness and disease differently than women. The sexes differ not only with regard to their reproductive organs and physical bodies (Witzemann & Pardue, 2001), but also in the way they think, feel, and behave when confronted with situations that may illicit the need to seek help (Addis & Mahalik, 2003). Environmental, cultural, and psychosocial factors also play a prominent role in

masculinity, and some researchers have reported that certain symptoms of male depression (e.g., low impulse control, alcohol misuse, aggressive behavior) are gender specific (Kiss & Meryn, 2001). Porter, Marco, Schwartz, and Neale (2000) reported that men faced with illness cope in ways that are problem-focused, rather than emotion-focused. Moynihan (2002) theorized similar gendered responses, concluding that while a woman's adjustment to cancer is conceptualized to be within herself, a man's adjustment to cancer occurs outside the person in the context of an information-gathering solution. Consideration of these and other salient issues are necessary to adequately understand, investigate, and plan interventions for the promotion of health and quality of life for men with prostate cancer.

World Health Organization and the ICF Model

From a global perspective, the World Health Organization (WHO) seeks to attain the highest standard of health for every human being. The WHO (1948) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. This conceptualization has been used as a foundation for the construction of theory and practice, as well as for financial reimbursement to health providers. The latest WHO model describes the relationship between a person's health condition, their level of activity and participation, and the influence of other personal and environmental factors. Labeled the *International Classification of Functioning, Disability and Health* (ICF) model (World Health Organization, 2001), this conceptualization is a blend of medical and social factors into a multi-faceted, non-directional biopsychosocial model (Bickenbach, Chatterji, Badley, & Ustun, 1999). This model may be helpful as a guide to frame the health condition of men with prostate cancer and their ability to perform expected activities and participate in normal roles. As a necessary component of

health, the ICF conceptualization places more importance on the opportunity and abilities of a person to participate in and engage in activities as a necessary component of health, than in the existence or absence of a disabling condition. Thus, simply having prostate cancer or receiving a certain type of treatment does not automatically imply that a man will have a disability or disabling condition that subjectively lowers his health or quality of life.

Health is not, then, purely determined by body functions or level of impairment. In the ICF model, the term *activity* refers to being able to execute and complete tasks. *Participation* implies being able to complete tasks or duties as part of being involved in life situations. Within the conceptualization of activity and participation, *activity limitations* are difficulties or problems experienced by a person when attempting to perform an activity, and *participation restrictions* are challenges experienced by a person when seeking to be involved in actual life situations. Other issues are paramount to this conceptualization of health. *Environmental factors* are aspects of the physical, social, and attitudinal environment within which people live. *Personal factors*, though not explicitly defined in the ICF due to the large cultural and social disparities that exist, encompass variables such as gender, race, age, lifestyle, fitness, upbringing, coping styles, education, vocation, psychological assets, and overall behavior styles or character (World Health Organization, 2001). Any of these factors, including anxiety, uncertainty, threats to masculinity, or altered role identity, can impact the health condition of a man with prostate cancer.

Positive leisure involvement results not only in the maintenance or enhancement of physical health, but psychological, emotional, social, and spiritual health as well

(Godbey, 1999). The WHO, within their ICF conceptualization, lists “recreation and leisure” as a category within the activity and participation domain, and recognizes that recreation and leisure are important avenues of functioning in relation to the individual’s health condition and environmental factors (World Health Organization, 2001).

Coping and Leisure

For individuals coping with the daily stresses of life, leisure has been identified as having a significant role. Iwasaki and Mannell (2000) reported several important aspects of leisure that worked to counter or ameliorate the effects of stress. According to these authors, leisure: (a) is a coping mechanism, (b) promotes autonomy, (c) facilitates friendship and companionship, and (d) enhances mood. More specifically, leisure is believed to promote coping strategies (e.g., escape-oriented activities designed to keep people’s minds and bodies busy), develop and reflect personality characteristics, help create and maintain people’s friendships, provide discretionary and enjoyable shared experience as a form of social support, and promote positive mood while reducing negative thoughts.

Settlage et al. (1988) theorized that having a serious illness (such as prostate cancer) may act as a catalyst for new development and a renewed exploration and discovery of self. Serving as a process-oriented model of adult development, decline or loss of physical function, relationships, and resources are seen as possible traumatic experiences that may then be a primary stimulus for development. Important elements of the model include: (a) tension and conflict, (b) resolution, and (c) changes in self-representation. Within this conceptualization, an individual (e.g., a man diagnosed with or treated for prostate cancer) may perceive aspects of the experience as a challenge, and desire or feel the need to acquire new skills, adapt and find new ways of managing

feelings, and may acquire new attitudes and values. Challenges of coping with prostate cancer may result in a person moving from being uncertain to the individual being goal-oriented. This may include a transition that might be complicated by psychological and emotional *tension* that may spill over into relationships with others. For some, this transition is natural and easy, but for others, it may be a time of intrapersonal or interpersonal *conflict*, when the desire for change evokes fear and anxiety about unknown consequences (Settlage et al., 1988). These early stages are likely to invoke strategies of psychosocial adaptation, and may involve or impact leisure attitudes or behaviors.

In the later stages of this conceptualization, *resolution* may occur, involving either mastery of new skills and the integration of new ways of coping and adapting, or a sense of failure or despair if self-appraisal is less than positive. The outcome from the resolution stage may be frequently re-assessed as time passes and the cancer experience gets further away. This process, regardless of the outcome, culminates in a *change in self-representation*, and one's views and recollection of the meanings ascribed to the original challenge are altered. Theoretically, outcomes include new functions (psychological, emotional, social, physical, or spiritual), refined pre-existing abilities, reorganized cognitive and emotional structures, and a higher, or better, level of functioning (Settlage et al., 1988). Within the context of coping, adaptation (resolution), and possible changes in one's self, leisure is thought to likely impact a person's appraisal of the meaning of life and one's priorities. Leisure can either be positively or negatively impacted by this appraisal (D Kleiber, Brock, Lee, & Dattilo, 1995).

Specific to men's issues, (S. Hutchinson & Kleiber, 2000) studied the role of leisure and recreation and found that notions of masculinity were impacted by one's

disability status. This research examined magazine portrayals of men's recovery from spinal cord injury (SCI), and considered the possible influence of these portrayals on their adjustment following being injured. They found that a theme of "heroic masculinity" was identified in the portrayals, and, that, according to the authors, such a limited representation may actually limit men's appraisal or understanding of successful adjustment.

Other researchers have generated theories related to the concept of development and growth following illness or onset of disability. Though many intra- and interpersonal factors may exist, having prostate cancer and undergoing treatment may be seen as a crisis, or, retrospectively, as a critical event in a man's life, thereby becoming a "turning point" wherein he comes to realize he is not the same person he was before (A. Strauss, 1997). *Posttraumatic growth* (Tedeschi & Calhoun, 1995; Tedeschi, Park, & Calhoun, 1998) is a phenomenon experienced when people develop beyond their previous level of adaptation, when they acquire greater psychological functioning or life awareness. Often based in existential psychology, which seeks to give meaning to life's events or circumstances, opportunities are thought to exist for growth as a result of trauma and suffering. This conceptualization of posttraumatic growth is based upon, and related to, past work on *resiliency* (Harvey, 1996), personality characteristics manifested as a *hardiness* (Florian, Mikulincer, & Taubman, 1995), and *stress inoculation* (Meichenbaum, 1985), stress management training (Pierce, 1995), and *sense of coherence* (Schaubroeck & Ganster, 1991). Specific to prostate cancer, Curtis and Juhnke (2003) reported that a healthy sense of coherence, defined as a dynamic feeling of confidence, is critical for older men with the illness. The authors report that the most important

component of the sense of coherence is meaning, which is defined as “the degree to which one uses life events to learn more about oneself and others” (p.164). A person with a high sense of meaning will “remain open to the many lessons a cancer diagnosis can teach” (p.164).

According to Tedeschi et al. (1998), several types of posttraumatic growth may be seen. First, changes in perception of self may be observed as (a) viewing oneself not as a victim, but a survivor; (b) enhanced self-reliance; and (c) heightened awareness of vulnerability or sense of mortality. Second, changes in interpersonal relationships may include (a) an increased self-disclosure and emotional expression and (b) greater compassion or empathy for others. Finally, changes in philosophy toward life may involve (a) a reassessment of priorities and appreciation of life, (b) a heightened sense of meaning, (c) possible spiritual development, and (d) an accumulation of wisdom. Regarding research design, Tedeschi and Calhoun (1995) suggest that qualitative methods, such as interviewing, are “ideally suited for the qualitative assessment of posttraumatic growth” (p. 34).

Leisure has been theorized as activity that is inherently self-protective and restorative (D. Kleiber, Hutchinson, & Williams, 2002). During negative life events, leisure has been conceptualized to: (a) serve as a distraction, (b) act as a catalyst generating optimism about the future, and (c) preserve of a sense of self. Hutchinson, Kleiber, Loy, and Datillo (2002) later tested this theory within a qualitative study of sixteen individuals who had suffered a traumatic injury or had experienced the onset of a chronic illness. In this study, leisure was found to serve several important functions. First, leisure provided a psychological “time out,” allowing escape from the physical confines

of the body or a person's problems and helping to keep one's mind off of the illness or related challenges. Second, leisure acted as a catalyst to sustain or bolster coping efforts. Third, leisure fostered a sense of purpose and competence that provides strength for more difficult aspects of living. Fourth, leisure served as a mechanism for keeping busy and providing structure, especially for those not employed. Finally, leisure provided a context within which belonging and acceptance comes as a result of shared leisure interests, not just shared disability status. Herzog, Franks, Markus, and Holmberg (1998) also studied the positive effect of activities on well-being, and found that leisure activities, defined in their research as "activities performed for their own sake, rather than for their consequences" (p. 180), were observed to provide a sense of competence and self.

Research Questions

The nature and function of leisure for men following prostate cancer diagnosis and treatment is unknown. As more men are diagnosed and treated, exploration of leisure's role can provide important information. This is especially important in men who are diagnosed earlier in their lives due to an increase of the time potentially impacted by the physical and psychosocial effects of the disease.

The three research questions for this study are:

- What are the key psychosocial variables and conditions that impact the process of coping and adjustment related to leisure following prostate cancer diagnosis or treatment?
- What function does leisure play in the lives of men with prostate cancer, and how does the experience with prostate cancer interact with leisure attitudes, choices, and behaviors?
- What role does leisure play in potential changes or personal development of men who are survivors of prostate cancer?

Answers to these questions will build knowledge and understanding about critical issues salient to patients and health care providers. Ultimately, it is hoped that this information will lead to new and improved interventions that will more fully meet the needs of older men.

CHAPTER 3 METHODOLOGY

Overview

Once diagnosed with prostate cancer, most men adapt to the fact that they have a potentially serious illness – one that may pose a threat to their life, health, and perception of quality of life (R. Lee & Penson, 2002). This chapter provides a description of the research methods employed in the present study. It focuses on topics of research design, the selection of participants, the interview process and data collection, analysis of the data, standards for the quality of conclusions, methodological variability, and ethical considerations. An overview of the demographics of study participants, along with a brief description of the pilot study conducted as part of this research, is also included.

Research Design

The primary objective of this research is to examine quality of life factors among men who have been diagnosed with and treated for prostate cancer. How men adapt, what they use as coping strategies, and their actual lived experience (including aspects related to leisure) are questions that can be addressed through qualitative inquiry (Strauss & Corbin, 1998). The present study is designed to determine (a) the key psychosocial variables and conditions that impact the process of coping and adjustment related to leisure following prostate cancer diagnosis or treatment, (b) the function leisure plays in the lives of men with prostate cancer and how the experience with prostate cancer interacts with leisure attitudes, choices, and behaviors, and (c) the role leisure plays in potential changes or personal development of men who are survivors of prostate cancer.

The grounded theory approach, including researcher-as-instrument and sensitizing concepts, are explained in the next sections.

The Grounded Theory Approach

Qualitative methodology is more than a set of procedures. It provides a way of thinking about and viewing the world in a unique and deeply personal way. Strauss and Corbin (1998) describe the *grounded theory approach* as a “general methodology for developing theory that is grounded in data systematically gathered and analyzed. Theory evolves during actual research, and it does this through continuous interplay between analysis and data collection” (A Strauss & Corbin, 1998, p. 158). This approach stands in sharp contrast to quantitative methodologies that too often oversimplify the complex nature of real-world experiences had by human beings (Patton, 1990).

The grounded theory approach is based on over-arching principles of pragmatism and symbolic interactionism. *Pragmatism*, a philosophical doctrine espoused by Charles S. Peirce (1839-1914), states that the meaning and the truth of any idea are functions of its practical outcome. Peirce posited his idea of pragmatism as a theory of meaning, and believed there is an intrinsic connection between action (behaviors) and meaning (Ketner, 1995). *Symbolic Interactionism* is an orientation of social psychology, based primarily on social behaviorism and the writings of George Herbert Mead (1863-1931). Symbolic Interactionism focuses on the symbolic nature of human interaction, forms of communication (linguistic and gestural), and how language is used to form mind, self, and society (Blumer, 1969). Procedurally, grounded theory is “designed to develop a well integrated set of concepts that provide a thorough theoretical explanation of social phenomena ... [that] should explain as well as describe” (Corbin & Strauss, 1990, p. 5). A thorough explanation of social phenomenon is generated when a researcher

can present and validate a theory that is pragmatic, and embodies the meaning(s) associated with human interaction and communication.

Little is known about the role of leisure and its relationship within the psychosocial adaptation of men and the prostate cancer experience. Therefore, use of the grounded theory method as a qualitative approach is an appropriate and effective strategy to identify and understand important, but heretofore unidentified, issues of these men related to leisure. Two additional principles, change and determinism, are key to the development of grounded theory. The principle of *change* pertains to the fact that phenomena are never seen as uniform or static, and are thought to change continually in response to evolving conditions. The process of documenting change is central to this methodology. *Determinism* is the control people have over their destinies, and is manifested in the way they respond to the conditions they face. Using a grounded theory approach allows the researcher not only to uncover relevant conditions and processes (i.e., salient issues related to the cancer experience, such as social support or the use of leisure to mentally get away from one's problems), but to determine how individuals respond to changing conditions and the apparent consequences of their choices or behavior (Corbin & Strauss, 1990).

Qualitative methodology using the grounded theory approach relies heavily on the abilities of the researcher. Skills a grounded theorist should seek to obtain and improve include: (a) the ability to step back and critically analyze situations, (b) the ability to recognize potential bias, (c) the ability to think abstractly, (d) the ability to be open to productive criticism, (e) an awareness of and sensitivity to the words and actions of those being studied, and (f) a sense of purpose and dedication to the process by which

meaningful results emerge (A Strauss & Corbin, 1998). These characteristics are elaborated on more fully in later sections of this chapter.

Researcher as Instrument

Many, if not all, forms of qualitative inquiry rely heavily on the researcher (or research team) acting as the primary instrument for data collection and interpretation. As part of the research design, I served as the “instrument” by which data was collected. This framework of researcher-as-instrument provided several advantages specific to this research situation (Lincoln & Guba, 1985). Some of these advantages include: (a) responsiveness, (b) adaptability, (c) holistic emphasis, and (d) opportunities for clarification and summarization. Within the framework of researcher-as-instrument, *responsiveness* implies that the researcher is able to sense and react to personal and environmental cues that may exist. *Adaptability* means that the researcher can collect information about multiple factors at multiple levels, simultaneously. Having a *holistic emphasis* means that the researcher sees and appreciates the world that surrounds participants, and existing phenomenon and context are examined holistically as separate, yet inter-related activities. Finally, *opportunities for clarification and summarization* infer that the researcher has the “unique capability of summarizing data on the spot and feed[s] them back to a respondent for clarification, correction, and amplification” (p. 194).

Researchers need to be aware of their own frames of interpretation and that a researcher should be aware of our perspectives and experiences within a unique cultural background (Caroleo, 2002). Given this reminder, I felt it important to state that neither I, nor anyone in my immediate family, has had to deal with the ramifications of a cancer diagnosis and treatment. I did have, however, an extended family member (a cousin,

Angel) who passed away several years ago after an extended struggle with a rare form of cancer. Extraordinary efforts were made to extend her life, and I was always impressed by the courage she and her husband displayed. Angel was even able to have a child and see her daughter grow up to the age of five before Angel's body ultimately succumbed to her disease. At the end, there was nothing medicine could do except to ease the pain. I remember sitting by her bedside one evening, just hours before she passed, shocked and amazed at the devastation that cancer can cause.

That experience with Angel, along with experiences I have had within other professional settings, has fostered in me a greater appreciation for life and health, and has kindled a determination to help others overcome physical, psychological, spiritual, or emotional challenges. This type of personal experience, coupled with experience and interest in understanding more about the impact of disability or disabling conditions on people and their leisure lifestyles, made doing this research about men with prostate cancer more satisfying – both personally and academically.

Sensitizing Concepts

A sensitizing concept is a “construct that is derived from the research participants’ perspective, uses their language or expression, and that sensitizes the researcher to possible lines of inquiry” (van den Hoonaard, 1997, p. 28). This concept not only applies to what is derived directly from interviewees’ articulation of events, but also suggests meanings that people attach to the world and events around them, thereby guiding the researcher’s inquiry. Sensitizing concepts suggest directions for explanation and description, and alert the researcher to potentially fruitful avenues of further exploration. In other words, a sensitizing concept is a starting point from which to think about an issue or experience that allows the researcher to become more knowledgeable or sensitized to a

particular aspect or category of data about which little is known or that was unexpected. Use of such a framework recognizes that the world experienced by others is real, ever changing, and full of passion and meaning (Reinharz, 1993).

Further, sensitizing concepts empower the researcher to consciously move toward a neutral ground where the ideas of society and the individual meet with those of the scientist, keeping the language of the participant in order to maintain empirical roots. The use of sensitizing concepts also enables the researcher to “frame the studied activity as a social process” (van den Hoonaard, 1997, p. 28). The researcher can thereby construct an analytical framework, which then acts as a “gateway” to a new avenue of inquiry and theory. For example, within the present research, I was struck by the often frequent and powerful comments several men made about the role of religion and spirituality in their lives. This theme or line of inquiry thus remained part of the interview process throughout the study – with some men supporting and others discounting the role of spirituality in their experience with cancer.

When seeking sensitizing concepts in conjunction with the use of the constant comparison method (fully described later), generalization or the transfer of findings to other social settings or situations can occur (e.g., for persons with other types of illnesses or threats to health) with greater confidence. As a researcher, having theoretical sensitivity refers to “the attribute of having insight, the ability to give meaning to data, the capacity to understand, and capability to separate the pertinent from that which isn’t” (Strauss & Corbin, 1990, p. 42). It is important to note that sensitizing concepts evolve with the analysis of data, rather than from ideas that existed before the collection of information (van den Hoonaard, 1997)

Developing Grounded Theory

As described earlier, the “strongest case for the use of grounded theory is in investigations of relatively uncharted water, or to gain a fresh perspective in a familiar situation” (Stern, 1995, p. 30). In order to obtain a satisfactory outcome, specific procedures for grounded theory have been established. First, the data collection and data analysis processes are interrelated. This means that analysis occurs from the very outset of data collection, after the very first interview. This analysis is used to assimilate all seemingly relevant issues into the next interview. Second, concepts are seen as the basic unit of analysis. As themes develop, they are identified and labeled. Third, concepts that relate to a similar theme, called phenomena, are identified. These are grouped to form categories that are at a higher or more abstract level than the concepts they are made from (Corbin & Strauss, 1990).

As an example, the decision-making process used by a person to determine what he or she does with free time on a Friday night, and the reasons given for why he or she finds a particular free time activity personally satisfying, are separate concepts. The first concept is the basis of motivation and the other is a reflection or recollection of past experiences, personal needs, and desired outcome. But together, these concepts both relate to use of free time and are symbolic of leisure behavior, or may be set within the category of leisure motivations. During further analysis, leisure may be conceptualized as what a person does (based on the activities participated in) or how he feels afterward (subjective state of wellness). Within the realm of older men’s life experience, leisure choices may be hypothesized to serve as an indicator of the emotional state manifest in a man’s thought processes and subsequent behavior. Likewise, grounded theory may serve

to prove or dispel the notion that men engage in leisure differently than before diagnosed with prostate cancer.

Constant Comparison

The use of constant comparison is a very important analytical tool that sets grounded theory apart from other forms of qualitative research. Constant comparison means that as incidents are noted, they are compared against other incidents for similarities and differences. For example, the psychological and behavioral reaction of one man after being told he has prostate cancer is contrasted against the reactions of others. Some may react with shock and denial and put off the task of gathering information necessary to make an informed decision about treatment. Others may see their diagnosis as simply yet another obstacle to be overcome, and immediately jump into an information-gathering mode and decide quickly on a treatment strategy.

Making constant comparisons also helps the researcher avoid personal bias as one challenges concepts with new data. This assists the researcher to achieve greater precision and consistency in terms of grouping similar phenomena together. Patterns of behavior are identified, and the constant comparison results in theory that describes processes or stages of a certain phenomena. Hypotheses about the relationships among categories are created, developed, and verified as often as possible during the research process (Corbin & Strauss, 1990). Using constant comparison, representativeness of concepts, not people, is a crucial aspect of grounded theory as people's actions or attitudes allow the conceptualization of theory regarding behavior.

Another principle of interviewing and grounded theory includes the writing of self-reflexive and theoretical memos. These are systematic running accounts of what is being seen or heard and help the researcher keep track of categories, themes, and hypotheses

that evolve throughout the research process. These memos are not just a log of ideas, but are crucial in the formulation and revision of theory, in addition to tracking and being able to understand the researcher's personal reaction and feelings to what he or she experiences (Caroleo, 2002).

Peer Debriefing

Given the nature of this research project, a peer-debriefing model was used, wherein committee members provided supervision to ensure that the qualitative techniques being used were adequate, and that employed methodology addressed the important issues and questions being studied. Collaboration such as this helped guard against bias, and often led to new insight about the phenomenon being described, thereby enhancing validity, or "theoretical sensitivity" (Corbin & Strauss, 1990, p. 11).

Since psychosocial adaptation to prostate cancer and the role of leisure has not been fully explored, it was believed a qualitative grounded theory approach would result in the identification of primary phenomena, related categories, and the creation of substantive theory. Theory is labeled *substantive* when it is developed from a specific area of inquiry, which over time may lead to further analysis and revision of existing, more formalized theories (Glaser & Strauss, 1967).

Selection of Participants

Grounded theory incorporates sampling based on theoretical assumptions. This means that selection of participants is not a matter of reaching a certain number of participants for statistical significance, but of understanding the concepts, dimensions, and variations that emerge during investigation of a certain condition. The terms *purposeful sampling* and *theoretical sampling* are often used interchangeably (Lincoln & Guba, 1985).

Purposeful and Theoretical Sampling

Patton (1990) stated that the power of purposeful sampling results from the selection and in-depth study of individuals who have been identified as having had the experiences that are of central importance to the research. Strauss and Corbin (1998) defined theoretical sampling as “sampling on the basis of emerging concepts, with the aim being to explore the dimensional range or varied conditions along which the properties of concepts vary” (p. 73). In an earlier text, Strauss and Corbin (1990) stated the aim of theoretical sampling was to “sample events, incidents, and so forth, that are indicative of categories, their properties, and dimensions, so that you can develop and conceptually relate them” (p. 177).

Due to the rich nature of the stories of the fourteen older men with prostate cancer who were participants in this present study, the actual sample size should not be considered small. In theoretical sampling, the actual number of cases studied is relatively unimportant. What is important is the ability of the researcher to extract the potential of each participant’s story case to assist in developing theoretical insights pertaining to the area of social life being explored. Theoretical sampling was employed to ensure that men with a wide variety of experiences (i.e., based primarily on the type of treatment received, age, retirement status, and marital status) were interviewed. This sampling method is based on the idea that known, suspected, or reported conditions (e.g., side effects associated with prostate cancer, uncertainty over treatment options, or possible isolation due to incontinence) are used to identify and select topics or areas for further review (A Strauss & Corbin, 1998).

A snowball sampling technique was incorporated into the study design protocol. Snowball sampling involves asking participants already interviewed for information

needed to locate other individuals within the same population (Babbie, 1997). Screening of men referred using this method, consistent with theoretical sampling, was done to interview men who were believed could add critical insight about identified categories and themes. For example, theoretical sampling led to interviews of several Black men toward the end of the study as an attempt to capture aspects of racial and cultural differences that might exist. The final participant selected was interviewed primarily because of his involvement with Man-to-Man groups (described below) and more conceptual density was thought to be needed to understand the dynamics involved within that setting.

Ethical Considerations

Approval to conduct this research study was obtained from the Institutional Review Board (IRB-02: UF Campus/Non-Medical) at the University of Florida. Potential participants were allowed to contribute after the study had been explained to them, and they were made aware that involvement was strictly voluntary. It was also stated that their participation would not affect any health care they were receiving at the time, nor would it impact their relationship with the Man-to-Man group.

Informed Consent

Before being interviewed, each potential participant was given a consent form that described: (a) the purpose of the study, (b) what participants were being asked to do, (c) the expected time required, (d) potential risks and benefits, (e) confidentiality and compensation information (there was no monetary compensation provided), and (f) statements re-affirming that participation was voluntary and that the participant could withdraw at any time or refuse to answer any question without consequence. Each potential participant was given time to thoroughly read the consent form, and the

opportunity to ask questions or address concerns was provided. Terminology within the consent form was geared so that it would be understandable.

Potential Risks and Benefits

There were no anticipated risks associated with participation in this study. Potential benefits were listed for the participant as the possibility of receiving some psychological or emotional benefit from talking about difficult issues associated with prostate cancer and treatment, in addition to gaining insight into how they have adapted and what the role of leisure is in their lives. Participants were told they could request a copy of the final results once the study was completed.

Confidentiality

Each participant was given the assurance that confidentiality would be maintained throughout the study, and that his name would not be associated with any information he provided. Each participant was given a code number, and code names were assigned and used within all transcripts and reports. Names used to represent study participants within this manuscript are pseudonyms. Pseudonyms were assigned chronologically and alphabetically. For example, 'Alan' was the first man interviewed, 'Brian' the second. The audiotaped interviews and printed transcripts were kept in a locked file cabinet, accessible only to the researcher and supervisory committee members. These tapes were then magnetically erased at the completion of the study.

The Setting

Potential participants for this study were recruited through *Man-to-Man* discussion groups in two cities in the southeastern United States. These monthly groups, which are sponsored by the American Cancer Society, are designed to help men cope with prostate cancer through community-based education, and often have guest speakers and

opportunities for participants to discuss information about their condition, treatment experiences, side effects, coping, and other relevant topics. The present study was explained to the facilitator of each Man-to-Man group, and permission was obtained to attend and distribute introductory flyers (see Appendix A) at a meeting. Typically, the researcher was able to attend the meeting and give an overview of the study, and group members were encouraged to ask questions if further clarification was needed.

Those who indicated their interest in participating (either to the researcher, if present, or to the group facilitator) were contacted later by phone and provided with a full explanation of the research study. The sole eligibility criteria for men in this study was that the man had been diagnosed with or treated for prostate cancer within the past five years. Men were excluded if they were feeling too ill or fatigued to physically cope with the interview process. Once eligibility was ascertained and the man verbally consented to participate, a face-to-face interview was arranged for a mutually agreeable time and location. In most instances, this occurred at the participant's home.

Pilot Study

To ascertain the appropriateness and effectiveness of this methodology to answer research questions and explore issues related to older men and prostate cancer, inclusive of psychosocial adaptation and leisure topics, a pilot study was conducted. This pilot study consisted of interviewing, transcribing, and analyzing data from six men recruited from local Man-to-Man discussion groups. These six men were carefully selected based on the determination that, as a group, their ages, cultural backgrounds, and treatment experiences constituted a diverse range of anticipated topics.

Information obtained from the pilot study assisted in the formation of the semi-structured interview guide used for the remainder of dissertation research study. This

pilot data helped identify initial categories as part of initial coding. Several of the men within this pilot study were interviewed a second time to provide both the participant and researcher an opportunity to address topics brought up by later pilot-study participants in an effort to compare experiences and further develop the semi-structured interview guide. Data and interpretations from this pilot study were shared with supervisory committee members as part of the peer debriefing process. Pilot study findings were also presented at a regional cancer conference to solicit feedback as to whether or not lines of inquiry were sufficient to capture the full experience of men with prostate cancer (Howard, 2003).

This pilot study was valuable in that it provided the researcher with the ability to determine the effectiveness of the interview protocol, in addition to being able to judge how clear and appropriate the interview questions were, along with practical aspects of the interview process. The protocol established during this pilot study was replicated in the dissertation study, and data from the pilot study was incorporated into the larger dissertation study.

Interview Process and Data Collection

Participants were interviewed at a location of their choosing, as long as it provided a semi-private atmosphere and access to amenities. Having restrooms nearby was important since a common side-effect of prostate cancer treatment is incontinence. A consent form (see Appendix B) was provided and reviewed thoroughly with the participant before obtaining their signature. A copy of the consent form was given to each participant for their records. A semi-structured interview guide (see Appendix C) was developed from the data obtained from the pilot study, existing literature on men's quality of life following prostate cancer diagnosis and treatment, and experiences of the

researcher. Questions for the interview guide were designed to enhance the development of evolving theory (A Strauss & Corbin, 1998). The following questions or lines of inquiry were established for this research:

1. Tell me a little about your life before having prostate cancer. Where were you born and raised? Education? Vocation? Significant relationships?
2. What does quality of life mean to you?
3. What does being a man, or the term masculinity, mean to you?
4. How do you define the term leisure? What does leisure mean to you?
5. Share with me your experience of having been diagnosed with and treated for prostate cancer.
6. What impact did cancer have on your quality of life and/or leisure, and vice versa?
7. How has your perception of yourself been affected by having had prostate cancer?

The items in the interview guide, and the order in which they were presented, were intended to encourage the participant to openly describe his experiences with prostate cancer and the personal meaning attributed to those experiences. Active participation by both the researcher and participant proved necessary to facilitate an open dialogue and sharing of experience. The interview guide, however, was only intended to steer the discussion, as the interview was presented as an opportunity for the participant to “tell his story” and elaborate on his experience in his own words (Strauss & Corbin, 1998).

Probes underlying each primary question of the semi-structured interview were created to supplement the information elicited from each participant by encouraging greater introspection and a deeper level of meaning and interpretation. Possible probes were used during interviews. For example, after asking, “What does the term leisure mean to you?” follow-up questions such as, “What types of leisure or recreation activities have you enjoyed throughout your life?” or “What made those activities enjoyable or

personally satisfying?” or “What changes in your leisure, if any, did you experience as a result of being diagnosed or treated for prostate cancer?” were asked. The use of these probes (see Appendix C), along with “pumps” (verbal “uh-huh” or “okay,” visual gestures), phrases such as, “So you mean that...?” or “Share with me more what that was like...” and/or the intentional use of silence, were used as appropriate. Interviews lasted, on average, about 70 minutes, and were audio-taped using a Panasonic micro-cassette recorder. An additional recorder of the same brand was used as backup, in case of equipment failure (which, on one occasion, did occur). Immediately following the interview, personal notes and reflections on theoretical and methodological issues were recorded, and these notes served as the basis for later journal entries that elaborated on ideas that were discussed in the interview, identified concepts that emerged, and included suggestions for further elaboration and comparison to interviews both past and future.

Because these interviews were semi-structured, yet open for men to tell their stories in their own words, some variation of participant responses was both expected and experienced. This allowed the researcher to identify and probe more deeply around points of specific interest to develop conceptual density and thick description. *Conceptual density* refers to the data’s explanatory power (Patton, 2002) and is sought to produce findings that are both understandable and meaningful. *Thick description* generates empathetic and experiential understanding by including a lot of detail and many direct quotations. This allows a better understanding of all the possible meanings within the data (Denzin & Lincoln, 1994).

Interviews were transcribed verbatim by the researcher. The decision to end recruitment of participants was based on saturation of existing categories, meaning

phenomena were thoroughly explored and conceptual density obtained (Corbin & Strauss, 1990). Saturation of a category is described as occurring when “no new information seems to emerge during coding, that is, when no new properties, dimensions, conditions, actions/interactions, or consequences are seen in the data” (Strauss & Corbin, 1998, p. 136). According to Lincoln and Guba (1985), “redundancy of information” (saturation) typically appears with a sample size of twelve. In this research, fourteen information-rich cases were obtained. Redundancy of information was found early in the sampling, and themes within men’s stories were more easily recognized for their many similarities, rather than for dissimilarities.

Other sources for data collection and/or verification existed. Strauss and Corbin (1990) suggested that “letters, biographies, diaries, reports, videotapes, newspapers, and a variety of other materials . . . be used as primary data” (p. 55). These sources of information can be used to cross-check and supplement interviews. For example, similarities and differences between the data and emerging themes from this study were compared against information or reports within “documentary evidence.” Numerous accounts of individuals being diagnosed and treated for prostate cancer are available in electronic and print media. Many books are available providing medical advice and autobiographical information. Video presentations, such as *No Big Deal!*, describe men’s experience with prostate cancer, and several celebrities have appeared on TV and in videos discussing issues related to prostate cancer.

Furthermore, invitations to give presentations for the local meetings of the American Cancer Society afforded me opportunities to network with other educators, community advocates, and most importantly, additional men with prostate cancer.

Occasional attendance at Man-to-Man meetings gave me further opportunities to hear men tell their stories in a setting where many feel welcome to open up, share concerns, and are supported in their challenges.

Coinciding with my immersion into the data, employment as a research assistant on a federally-funded project studying the efficacy of dyadic social support allowed nearly daily contact with men who had prostate cancer. Though my contact with them was structured and often restrained due to adherence to a different research protocol, issues and topics germane to my own research efforts were plentiful. These additional sources of information and experiences occurred parallel to my own research study, and may be considered as *triangulation*, a term used to describe the verification and validation of qualitative analysis through combined multiple data sources (Patton, 1990).

The Participants

Table 2 summarizes the demographic data of the participants in this study. A total of fourteen men (N=14) were interviewed for the study. The ages of these men ranged from 54 to 87, with a mean age of 70.3 years. Most of the men in the study received varied treatment combinations for their prostate cancer. Five men had undergone a radical prostatectomy (surgical removal of the prostate) as the primary method of treatment. Two of these men later had radiation, and one of these two also received brachytherapy (implantation of tiny radio-active pellets within the prostate or area of the prostate capsule). Eight participants received radiation therapy, with four of these men also receiving brachytherapy. Of the fourteen participants, four men reported having received hormones (typically in the form of injections such as Lupron) to reduce the size of the prostate or to curtail testosterone, upon which prostate cancer feeds. One man had

adopted the expectant therapy or “watchful waiting” approach, but stated that he was anticipating beginning hormone treatments to lower his PSA scores.

The mean number of years that had passed from the time of initial diagnosis of prostate cancer to the time of his interview was 4.1. Nine men had been diagnosed and treated within the past four years, with two of those nine having undergone treatment procedures (one radiation, one surgery) within six months of being interviewed. Five of the men had been diagnosed at least six years before being interviewed (longest survival was eight years).

Nine of the men who participated in the study were White. Four were Black, and one was Hispanic. Two of the Black men were born outside the United States, but reported living the vast majority of the lives within this country. Eleven of the men were married, while one was widowed, one was single and had never married, and one was separated and in the midst of divorce proceedings. With the exception of the single man, all reported being fathers. Excluding this single man with no children, and one participant who reported having ten children, the average number of children for the remaining twelve men was 2.5. As for education, four men reported receiving graduate degrees, three were college graduates, five had attended some college or completed a technical program, one was a high school graduate, and the remaining man had a partial high school education.

Eleven participants indicated they were retired, one was working part-time, and two were employed full-time at the time of the interview. Of those who were retired (for whom data was available), the average age of retirement was 62.0. An average of 10.7 years had passed since retirement. Reported vocations for these participants included the

fields of education (3), ecclesiastical (3), sales/marketing (2), personnel management (2), economics (1), telecommunications (1), electrical engineering (1), and building maintenance (1). When asked how they viewed themselves in terms of socioeconomic status, two reported being below-average, six as average, and six stated seeing themselves as above-average.

Table 2 - Frequency Distributions of Selected Demographic Variables

	n	%
<u>Age</u> (mean = 70.3)		
50 – 59	1	7.1%
60 – 69	7	50.0%
70 – 79	4	28.6%
80 – 89	2	14.3%
<u>Marital Status</u>		
Married	11	78.6%
Single, never married	1	7.1%
Widowed	1	7.1%
Separated	1	7.1%
<u>Race</u>		
White	9	64.3%
Black	4	28.6%
Hispanic	1	7.1%
<u>Work Status</u>		
Retired	11	78.6%
Employed full-time	2	14.3%
Employed part-time	1	7.1%
<u>Education Level</u>		
Partial high school education	1	7.1%
High school graduate	1	7.1%
Some college/technical school	5	35.7%
College graduate	3	21.4%
Earned graduate degree	4	28.6%
<u>Primary Treatment</u>		
Radical prostatectomy	5	35.7%
Radiation	8	57.1%
Watchful waiting	1	7.1%
<u>Time Since Diagnosis</u> (mean = 4.1 years)		
0 – 1 year	2	14.3%
2 – 3 years	3	21.4%
4 – 5 years	4	28.6%
6 – 7 years	4	28.6%
8 – 9 years	1	7.1%

Since 1994 (the earliest year that a man in this present study had been diagnosed with prostate cancer), numerous historical events, whether they be political, social, or technological, have occurred that potentially impacted the lives of men in this study. World events such as the tragedy of September 11th, the war against Iraq, and heightened concerns about terrorism, affect people in different ways. Living in Florida often means dealing with natural disasters, or the threat of them (e.g., Hurricane Andrew in 1992, Hurricane Floyd in 1999). These types of events may impact the lives of men, their perspectives of themselves and the world around them, and their attitudes toward life in general. Significant to daily life, advances in media technology (e.g., the Internet), and medical technology (e.g., pharmaceutical and treatment technologies) have greatly influenced people's awareness and access to information and services, thus potentially impacting their lifestyles.

Within the realm of leisure, the rise in availability of fitness centers and sports events, such as the national football championship of the Florida Gators in 1996 or the death of race car driver Dale Earnhart in 2001, are examples of events that potentially impacted the lives of residents living this area. Factors such as the climate of north central Florida with its hot and humid summers, occasional shark attacks at Florida beaches (with more or less media coverage), and the University of Florida and its large student population from August through April, can impact what, when, and where people do leisure in their daily lives. Depending on the time of year that a particular participant was interviewed, his perception of leisure may have been affected by these factors. Within this present study, these variables were not specifically asked about, and, given the nature of the research design of the present study, they are not controlled for.

However, it is important for the reader to realize that just as I, within the role of researcher-as-instrument, feel compelled to disclose significant aspects of myself and my experiences as a reflection of my life perspective and potential biases, the participants have also had events occur within their environment that have potentially affected their perspective and attitudes.

Analysis of the Data

A qualitative computer software program (QSR NVivo) was used to manage, code, and systematically analyze the data. Specific procedures used during analysis included three basic types of coding: open, axial, and selective. *Open coding* resulted in the formation of categories based on discrete units (e.g., paragraphs, sentences, words), with each unit being given a label that represents the phenomenon being observed. For example, words such as “therapeutic,” “restful,” and “enjoy” were used by Brian (see note below) when describing having played the piano. Each word carries with it its own conceptual relevance and meaning.

In open coding, events, actions, and interactions that are described by participants are identified and compared with events, actions, and interactions of others to: (a) develop a comprehensive list of initial themes or categories, and (b) determine similarities and differences. The properties of these events, actions, or interactions were examined in terms of both duration (long or short) and manner (type and intensity) of the experience (Strauss & Corbin, 1998). Each transcript was reviewed at least two times in order to identify key words and phrases indicative of meaningful experiences for men with prostate cancer. Transcripts were examined for similarities and differences, themes and patterns, and additional concepts emerged and were identified. This type of analysis was done following each interview and became the basis for further theoretical sampling.

The analysis stimulated questions that guided the researcher's work as additional participants were interviewed (Corbin & Strauss, 1990; Creswell, 1998).

Axial coding consisted of exploring the interrelationship between and within categories. In this phase of analysis, a coding paradigm or "theoretical model," that visually illustrated the interrelationship between categories of information was created. Using the terms mentioned above regarding Brian and his past experience of playing the piano, these smaller units can be set within a larger concept, such as leisure satisfaction. A comparison of this category, or sub-categories, with other comments he made about leisure activity, or what other men said about leisure, helps to increase our understanding about even larger phenomenon. For example, questions can be asked in terms of other leisure or social contexts, or in looking at other activities that he said he participated in (e.g., using the computer), and whether or not he or other men used the same descriptive words: "therapeutic," "restful," or "enjoy" as descriptors. Analysis can also be done to see if these same words are used by other men when describing leisure activity, or if these descriptor words convey a decidedly different meaning or intensity. In grounded theory, this is sometimes referred to as a *conditional matrix* (Creswell, 1998). Axial coding is also a process where the researcher continues to alternately collect and analyze data to eliminate or fill in gaps in the developing theory (Corbin & Strauss, 1990).

The final phase of analysis, termed *selective coding*, culminated in the identification of a principal theme that integrated all other categories from the earlier steps in the process (Creswell, 1998). Corbin and Strauss (1990) defined this phase as "the process by which all categories are unified around a 'core' category" (p. 14). Strauss and Corbin (1990) stated that selective coding is the process of "selecting the core

category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development” (p. 116). The term “supra-concept,” often used in discussing sensitizing concepts, applies to concepts that encompass a wider body of empirical data (van den Hoonaard, 1997), much like the process engaged in when conducting selective coding around a central theme or phenomenon.

Strauss (1987) provided the following criteria for choosing a central category:

1. All other categories can be related to it.
2. Themes from the central category must appear frequently in the data.
3. Explanation used in describing the relationship between categories is logical and consistent. There is no forcing of the data.
4. The name or phrase used to describe the central category should be sufficiently abstract so as to allow further research, and lead to development of more general theory.
5. The central category is analytically refined and integrated, thus supporting theory to grow in depth and explanatory power.
6. Concepts within the central category are able to explain and account for variation, as well as the main point made by the data (p. 36).

Selection of a central category was done when enough coding had taken place so that the researcher realized a clear perception of a specific category or conceptual phenomena that integrated the entire analytical process (Corbin & Strauss, 1990). Thereby, the emerging theoretical framework captured the essential message of the research in such a way that individual concepts, along with their meanings and relationships with other concepts, are interwoven into an “explanatory theory that closely approximates the reality that it represents” (Corbin & Strauss, 1990, p. 57).

As illustration, the men interviewed in this study could all be classified as survivors, and several identified themselves as such. Each provided examples or thoughts symbolic of having moved past the cancer episode, and having moved on with life. Many shared, each with subtle or not-so-subtle indications of having been changed or having developed or having personal characteristics strengthened, in part, due to adaptation experienced as part of dealing with cancer.

Standards for the Quality of Conclusions

This study, like all other qualitative inquiries, took place in the real world. The study itself, as well as results of this study, can have consequences in people's lives. For both quantitative and qualitative researchers, the issue of "trustworthiness" and the quality of data is crucial. To produce and report findings from this present study that are worthwhile, "standards for the quality of conclusions" were identified before beginning data collection (Miles & Huberman, 1994). These standards include: (a) objectivity and confirmability; (b) reliability, dependability, and auditability; (c) internal validity, credibility, and authenticity; (d) external validity, transferability, and fittingness; and (e) utilization, application, and action orientation.

Objectivity/confirmability acknowledges inevitable researcher biases and promotes self-awareness to enhance neutrality and freedom so that conclusions rely upon those being interviewed and conditions of the inquiry, not the inquirer. Efforts were made to establish and maintain a record of the study's methods and procedures, and competing hypotheses or conclusions were thoroughly considered. Key to this process were repeated meetings with committee members (most often individually or in dyads) who, acting in the capacity of peer-debriefers, raised and discussed questions about the creation and formation of conceptual categories and the meaning given to interpretation of

relationships between and within concepts. Likewise, negative evidence or rival explanations were listed. As categories were generated, a process referred to as “verification mode” was engaged in to challenge my hypotheses by actively seeking (constant comparison) for negative instances of the phenomenon or other plausible explanations (Miles & Huberman, 1994). Here again, the use of peer debriefers facilitated this process.

Objectivity, though oft-times elusive, was sought as I attempted to check for personal biases on a regular basis. Though I became invested both in the individuals and in my study of them, I constantly reminded myself to stay open to the possibility of different findings or possibilities. Part of this involved being self-reflexive, and I adhered to recording personal reactions to the process in a journal, as well as my feelings about interpretations of participants’ experiences.

Reliability/dependability/auditability infers that the process of this study will be consistent and stable across time. Data were collected across a wide range of situations, conditions, and participants as suggested by the research questions, literature review, and constant comparison and analysis. The use of qualitative software helped in checking the accuracy of coding data and was made available for auditing by supervisory committee members (Miles & Huberman, 1994).

Internal validity/credibility/authenticity were determined by asking questions such as, “Do the findings make sense?” “Are the results credible to the people being studied?” and “Do the findings represent an ‘authentic portrait’ of what is being explored?” Descriptions of accounts were written in ways that were rich and meaningful to the reader, in addition to being comprehensive, yet respectful, of the context in which they

occurred. Data presented were linked to categories of pre-existing or emerging theory, and conflicting areas were identified.

External validity/transferability/fittingness refers to knowing whether the conclusions drawn by the present study have any larger significance, and if they are transferable to other contexts or are generalizable to other settings or populations. Lincoln and Guba (1985) described the concept of transferability as one where the researcher “can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion” (p. 316). To ensure external validity, transferability, and fittingness, efforts were made to sample a theoretically diverse group of participants. For example, greater understanding of how older men adapt and make different choices with their leisure time may be applicable to older men facing similar challenges following other illnesses or threats to health. The final chapter of this document provides suggestions for additional settings where findings could be tested further and how replication can occur effectively.

Principles underlying *utilization/application/action orientation* serve to promote and stimulate working hypotheses, and do so at an appropriate level of usable knowledge that is “intellectually and physically accessible to potential users” (Miles & Huberman, 1994, p. 280). Findings are presented to have a motivational effect that will lead to specific action (e.g., further research or the development of interventions) by the researcher or others which may help to address identified challenges faced by men with prostate cancer (Lincoln, 1990). Adherence to these standards helped guide the qualitative analysis and enhanced the probability of a meaningful outcome for this present research (Miles & Huberman, 1994).

Methodological Variability

Two incidents occurred during data collection that are particularly note-worthy. Each embodied, for a brief time in the interview process, moments of reflection on the methodological procedures outlined in the research protocol. The first involved a man who, during the early stages of the interview, expressed his belief that he was a transgendered person. The term *transgendered* is defined as “exhibiting the appearance and behavioral characteristics of the opposite sex” (Merriam-Webster, 2003). The second instance occurred when two men, who had been scheduled for interviews at different times, showed up on the same day, at the same time and location, asking to be interviewed together.

Issues of sexual identity were not an identified focus of the present study, although sexuality was certainly expected to emerge since the semi-structured interview guide included questions related to masculinity, and erectile dysfunction is a common side effect of prostate cancer treatment. Harold’s disclosure of himself as a transgendered man, had this been quantitative study, would have caused him to be classified as an *outlier*, defined as “an unusual, atypical, data point – one that stands out from the rest of the data” (Pedhazur & Schmelkin, 1991, p. 398).

When Harold shared this perception of himself, one proven to be significant as he shared experiences of his past and present life situation, it caused me moments of questioning whether his interview should be conducted, or thereafter analyzed, any differently than the rest. It was decided, during the interview process and later during analysis, that data collected from him should be included since issues of sexual identity (along with issues of sexual orientation) are independent of the experience of being diagnosed and treated for prostate cancer. Within our society, there are numerous

individuals outside the context of those who consider themselves heterosexual males.

This instance served to illustrate the fact that the unique challenges and life experiences encountered by transgendered men, or bi-sexual or homosexual men, are real and deserve the attention of research and the health care community.

The second instance of methodological variability involved Leroy and Martin. My experience of interviewing these two men brought with it numerous questions, and was an invaluable learning experience. As mentioned earlier, Leroy and Martin, who lived within the same town and had been recruited from the same Man-to-Man meeting, had been scheduled for interviews at different times. However, Martin, whose appointment was scheduled for a later time, showed up at the home of Leroy on the day and time of Leroy's scheduled interview. Perplexed, I tried to ask if meeting separately would be possible, but from their response it was readily apparent that they both desired to be present. Sixteen years separated the ages of these men, with Leroy being older, and it was mentioned that Leroy's now deceased wife had been Martin's first-grade teacher. It may also be important to note that these men were Black, had lived in the South their entire lives, and Leroy had earlier shared an experience of having his college years cut short when an uncle and a friend of his uncle's were lynched. Leroy stated that his father mortgaged his home to bring the body of his brother home. Leroy said that several of his father's other brothers also returned home due to this incident.

Interviewing two men at the same time undoubtedly influenced the dynamics of the experience, and the openness with which each shared information. It is impossible to speculate on how the experience would have been different had they been interviewed

separately, and how that impacted the nature of the data that were collected. Near the end of the interview, however, they revealed why they chose to be together when interviewed.

At one point in our discussion, Martin was sharing his experience with the local Man-to-Man group. Leroy interrupted Martin, saying, “Let me make a confession to him.” Martin said, “Alright,” and we shared a laugh, I being curious about what Leroy was going to say. He stated:

Okay. You called me, and told me who you are, and what you wanted to come for. And I thought about it, and just yesterday it occurred to me, ‘You receive a call, from a man you don't even know. And, you don't have time to ask for doctors if they know him. Don't you think you've been a little hasty in telling him to come to your house?’ [brief, mutual laughter, and I commented, “...and opening your door to me”]

So, I called [Martin], and [Martin] said...[I interjected, “Who got the same call...”] Well, you mind if I come up to your house and we'll see him together? [Shared laughter, spoke to Martin] I had to make that confession to him. You know, there is a lot of carrying on out there. [I then stated, “Yeah, I am a stranger, or at least I was awhile ago.”] Martin then made his own “confession” to me, stating “When you told me, and said, 'I'll come over to your house,' I said to myself, I said now, I don't know . . . [laughing] I said, I'll meet you at the hospital. And then [Leroy] called, and I said, I'll come over to your place.]

Clarke (2000) wrote about the complexities of what he termed “sociological interview methodology,” including racial considerations such as the one I encountered – with myself being White, and the interviewees being Black. Clarke (2000) concluded that through experiences foreign and unfamiliar to the interviewer, the interview material can

become even more enriching and valuable. For this to occur, however, it required me to revisit my own biases and assumptions, thus allowing for a clearer interpretation of potential meanings (Strauss & Corbin, 1998). In essence, to meet and talk with a man who had actually lived through an experience of a family member being lynched, and that both were apprehensive about me coming to their home was a new experience. I had to ask myself, 'Do I know, or just assume that Leroy's paternal uncle was killed by White men; and was their apprehension about me coming to their homes due, in some part, to cultural or racial differences?' Regardless of the answer to these questions, this situation brought with it some real feelings that I previously had not experienced through the simple reading of literature.

Summary

The use of a qualitative research design, incorporating the procedures described herein, was anticipated to provide additional information and knowledge about men's psychosocial adaptation following prostate cancer and treatment. Prior to writing the findings of this study, a final theoretical framework was established. This existed in the form of journal entries, participant quotations and transcript excerpts, and visual diagrams of categories and their linkages – all having been cross-checked against the data. Communication between myself and committee members as peer debriefers helped discover potential discrepancies or biases I may have made in the analysis or in the way themes were constructed. The final manuscript was then written by weaving together the concepts and pertinent themes with actual participant quotes, along with my own interpretations.

CHAPTER 4 INTRODUCTION TO FINDINGS

Men diagnosed with prostate cancer and treated for the disease reported facing situations replete with decisions that most acknowledged could impact their well-being and quality of life. Treatments were decided upon and received, side effects were experienced and men described efforts made to carry on with their lives. Many acknowledged having been required to dramatically change their way of living – that their experience with prostate cancer impacted attitudes and behaviors. Some, however, spoke about life going on pretty much as it had before. These men varied in terms of age, race, education level, vocational preference, age at diagnosis, treatment(s) selected and side effects encountered. How men adapted since diagnosis and treatment for prostate cancer in order to satisfactorily live their lives also varied. Some men undoubtedly, as findings suggest, argued they never lost this foothold on life.

Numerous personal, interpersonal, and environmental factors – the number and nature of which exceeds the scope of this analysis – have influenced, and continue to influence, these men’s journeys through life. It is important to note that the interview process and the questions that were asked imposed a certain amount of linearity upon the description of their accounts. However, these men’s lives represent a dynamic journey and process without any sort of pre-fabrication. As will be seen, these men’s lives and their efforts to meet life’s challenges and achieve personal goals continue.

Before beginning interviews as part of this study, research questions were formulated to serve as the foundation of its design. A review of those questions will help

the reader revisit the origin of this study before an exploration and discussion of what was discovered. The three research questions were identified as:

- What are the key psychosocial variables and conditions that impact the process of coping and adjustment related to leisure following prostate cancer diagnosis or treatment?
- What function does leisure play in the lives of men with prostate cancer, and how does the experience with prostate cancer interact with leisure attitudes, choices, and behaviors? and
- What role does leisure play in potential changes or personal development of men who are survivors of prostate cancer?

These questions led to the design of the study, which, as described in Chapter 3, was to conduct semi-structured interviews and analyze transcribed data, using techniques of constant comparison. The aim was to then develop grounded theory (ideas about “what is going on here?” stemming from comparison of participant comments) that will help in better understanding the impact of prostate cancer and its treatment on the quality of life and leisure experience of older men.

Men in this study shared attitudes, opinions, and behaviors consistent with the experience of coping and adaptation in the wake of being treated for prostate cancer. While attitudes, opinions, and behaviors varied among men, all were consistent with an individual seeking to make the best of a situation in the best way he knew how at the time. While these findings are specific to the men within this study and, based on the nature of the research, cannot be automatically generalized to any larger population, the knowledge and information stemming from this research may be carefully applied and contrasted to other men facing similar experiences. Figure 1 below provides an overview of the major conditions, phenomenon, properties, and dimensions identified as part of the processes engaged in by men.

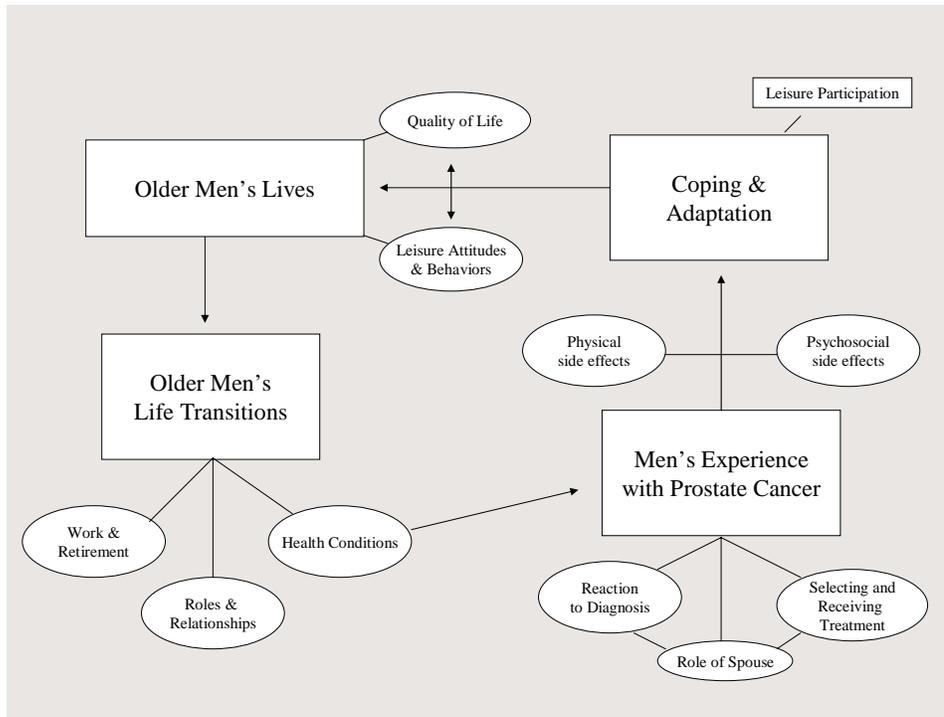


Figure 1 – Quality of Life, Leisure, and Coping and Adaptation following Prostate Cancer Treatment

Narrative description of this model follows, beginning at the top left of the graphic and moving in a counter-clockwise fashion. Primary themes such as quality of life and leisure attitudes and behaviors are shown as components of older men's lives. Work and retirement, roles and relationships, and health conditions are shown as conditions exemplary of older men's life transitions. Likewise, as men's experience with prostate cancer is an obvious focal point of this study, reaction to diagnosis and selecting and receiving treatment are salient sub-themes that interact with data supportive of the spouse's role for those men with a partner. Stemming from men's experience with prostate cancer are categories of physical side effects and psychosocial side effects. Coping and adaptation are shown to occur in response to those side effects, with leisure participation viewed as a condition indicative of effective or ineffective coping or adaptation. The results of coping and adaptation are then shown in relation to ever-

evolving perceptions of quality of life and one's leisure attitudes and behaviors as life progresses.

According to Strauss and Corbin (1998), the term *condition* means “sets of events or happenings that create the situations, issues, and problems pertaining to a phenomenon and, to a certain extent, explain why and how persons or groups respond in certain ways” (p. 130). A *phenomenon* is a term used to answer the question, “What is going on here?” (Strauss & Corbin, 1998) Several other terms are useful in understanding the process of analysis, thereby helping to interpret the findings. Categories (themes) are developed according to its specific properties and dimensions. *Properties* are “the general or specific characteristics or attributes of a category,” (p. 117), whereas *dimensions* “represent the location of a property along a continuum or range” (p. 117). For example, within the category of men's experience with prostate cancer are two properties, physical side effects and psychosocial side effects. Within each of these properties lay dimensions indicative of the severity of a problem or concern. Subsequent chapters offer description of each main component of the model, along with an argument for its relationship with other parts of the model, based on their properties and dimensions. Pertinent literature reviewed before conducting interviews, in addition to scientific findings published up to the time of writing this manuscript, is included as part of this discussion.

Identification of the Central Category

Later stages of axial coding (exploration of the interrelationship between and within categories) and selective coding (identification of a principal theme), led to the identification of the central category which integrates all other categories (A Strauss & Corbin, 1998). The central category is an indicator or phenomenon representing a synergy between coping and adaptation. Merriam-Webster (2003) defines the word *cope*

as meaning “to deal with and attempt to overcome problems and difficulties.” *Adaptation* is defined as “modification of an organism or its parts that make it more fit for existence under the conditions of its environment” (Merriam-Webster, 2003). Coping and adaptation to life’s circumstances were seen in the choices and behaviors of men interviewed. Coping and adaptation become properties of life and are instilled within notions of quality of life, each with its own dimensions.

Coping and adaptation is considered the central category within this study, and was so selected due to its congruence with the six criteria suggested by Strauss (1987). First, each and every category shares a relationship with coping and adaptation. Second, themes from the central category appeared frequently in the data. Other themes and sub-themes are shown appearing sequentially before or after coping and adaptation chronologically (time-wise), in addition to having shared interactions, direct and indirect. For example, relationships with friends (social support) may potentially impact and enhance successful coping and adaptation. The role or influence of a spouse is likely to have an even greater influence. Additionally, the nature and degree (dimensions) of side effects serves as the parameter determining the need or effort put into coping and adaptation.

For the third criterion, explanation found in the following pages offers description that the relationship between categories has been done in a way that, for the reader, is intended to be logical and consistent. The fourth criterion, naming the central category *coping and adaptation* was done to allow abstract visualization of constructs, thus supporting further research questions. The fifth criterion requires that the central category be “analytically refined and integrated” (p. 36) to support the growth of additional theory that is strengthened via greater depth and explanatory power. Finally, the sixth criterion

states that concepts within the central category illustrate the main point of the data, in addition to being able to “explain and account for variation” (p. 36). As leisure attitudes and behavior following prostate cancer and treatment is a central focal point of this study, discussion of leisure participation serves well as a property of coping and adaptation.

Outline of the Report of Findings

This chapter offers an introduction to the findings and comprehensive examples of data comprised in the next two chapters. Coding and categorization of data from interview transcripts resulted in identification of key themes pertaining to quality of life. Different perspectives regarding leisure were the focus of Chapter 5. Men’s experience with prostate cancer, from reaction to diagnosis to the process of selecting and receiving treatment and coping with subsequent side-effects, has been documented in Chapter 6.

In Chapter 5, quality of life is explored as being a multi-faceted concept that was regarded and described differently by participants. One representation of quality of life was the filling of important roles (e.g., father, provider, or leader). Another parameter of quality of life was the recognition of and respect for certain values and personal characteristics (e.g., loyalty, fiscal security, or religious faith). One’s relationship with a spouse, friends, and family, along with enjoying good health, was yet another quality-of-life perspective. Maintaining a certain level of activity and being productive was also mentioned as important to older men. Other aspects of men’s lives deemed of value were notions of masculinity, how the sense of one’s masculinity interfaced with sexuality, and how men acted in a generative manner – wherein they interacted with their posterity to pass along valuable wisdom and traits. Leisure was also portrayed within Chapter 5 as a concept with different meanings and can be interpreted as unique to person, place, and situation. Leisure was illustrated as including components of: (a) time, (b) activity, (c)

participation and involvement in life experience, (d) leisure within a relationship context, and (e) leisure as an antithesis to work. Other factors influencing leisure, such as the motivation and meaning of leisure and potential constraining variables, were also identified.

In Chapter 6, men in this study are shown to have experienced differences and similarities as they engaged the health care system for treatment of prostate cancer. The side effects of the treatment modalities were placed in two categories – physical side effects and psychosocial side effects. Physical side effects were differentiated as hot flashes, breast growth and tenderness, pain and fatigue, incontinence, and erectile dysfunction. Psychosocial and emotional side effects were documented as shock, denial, anxiety, worry, anger, depression, isolation, and/or embarrassment. Men's comments relative to the threat of reoccurrence were noted, as were thoughts about the role of religion and spiritual involvement during their experience.

In summary, this chapter has provided an overview of the conceptual model, selective coding as a process for the identification of the central category, and an outline of information that follows in the next two chapters. The conceptualization provided described the process whereby the lives of older men consist of, among other things, views about quality of life and leisure's role in one's life. As older men experience life transitions such as retirement and changes within family and interpersonal relationships, health conditions (due to age or illness) serve to challenge and impact life. Being diagnosed with prostate cancer, receiving treatment, and coping with side effects of a physical or psychosocial nature were part of these men's experience. Men dealing with prostate cancer cope with and attempt to make the best of their life situation. Though

modified or changed, leisure continues to be an important part of their lives. Experiences had while coping with physical or psychosocial side effects, either successes or failures, interacts with perceptions of quality of life and leisure's role within it.

CHAPTER 5:
OLDER MEN'S LIVES AND THE MANY FACES OF LEISURE

Defining Quality of Life

In the first chapter, quality of life was defined as individual response to physical, mental, and social effects of illness that significantly influence the extent to which personal satisfaction with life circumstances can be achieved (Bowling, 1997). When asked the question, "What does quality of life mean to you?" study participants shared perspectives that, in most instances, mirror what is found in present literature that exists on the topic. Quality of life, for some men in the study, was based on family and interpersonal relationships. Others incorporated the necessity and appreciation of having good health or fiscal stability. For other men, quality of life meant still being active and productive. Interpretation of the data resulted in the formation of five primary thematic categories: (a) fulfillment of masculine roles, (b) personal values and characteristics, (c) relationships with spouse and family, (d) appreciation of health, (e) productivity and involvement in activity, and (f) other parameters of quality of life, including retirement transition, notions of masculinity, masculinity and attitudes regarding sexuality, and generativity.

Fulfillment of Masculine Roles

Several men cited their belief that adhering to and acting in accordance with particular roles was important to their sense of self and well-being -- to their quality of life. At one point, Frank stated simply, "To be a man, being a man is a role." After a brief interruption, he continued:

In some respects, manhood is a role that we play, you know, part of which certainly is being a provider -- it's being a father, it's being a director, being a leader I think that's the kind of noble traditional way of looking at it.

When asked if his spirituality influenced his perception of being a man, he replied:

Oh, definitely yes. Um, I mean, in the way, that I perceive, it is, God has placed us in a role, you know. I am the spiritual head of my family. I also try to be a spiritual head in the church -- I am a deacon. And as I said, to me, leadership and servitude are really, the best leaders are the ones who serve.

Frank also cited the influence of his father, along with his experience with prostate cancer, as important to his conceptualization of manhood. At one point in the interview, I said to him, "When you were growing up, you mentioned doing sports...." He replied:

Yeah, I did. I did baseball, basketball, rugby, softball, soccer, those kind of sports -- the ones that went on at school. I had a chance to play in the Yankee organization in baseball when I was about 17, and my father wouldn't let me. I cursed him, and then [he laughs], I thanked him...I mean, I would have gone down to California or something in the rookie league or some crazy place.

Leroy described similar feelings. When asked about what was important as a man, he stated, "Being a role model. And, a man should be a leader." Jack made reference to his role as husband, one that has evolved with time. He commented, "At this age, I, of course, it is different now than 40 years ago, but at this age, being a man is treating your wife with respect." He extended that sentiment to others by adding, "And your children. And treating neighbors, friends, associates, with compassion."

Another man, Eric, spoke to being a father, where being a man and a father embodied certain traits. He stated, "I've never had any doubts about my masculinity. I like to think of myself as a gentle person, a sympathetic person, an understanding person. I have tried to set a good example for my boys." Alan too, spoke of his posterity. He described part of being a father was "letting my children know I'm proud of them." Martin also spoke of being a father and the satisfaction found in "loyalty, and seeing your

children grow up.” Charles, a father of two, mentioned that a primary objective for himself as a man throughout the years was in “providing for my family.”

Personal Values and Characteristics

Akin to simply being involved in activities was the notion that the quality of that involvement was an important component of quality of life, almost as a manifestation of one’s personal values or inner characteristics. For many, their current appraisal of quality of life may have been impacted by earlier experiences in their life. Norm stated, “I was a child of the Depression, and that affected quality of life, too.” Leroy shared that it was important for a man to have certain traits. He stated, “A man should be responsible. A man should be law-abiding.”

Ken suggested that along with physical health, “fiscal security” was important to his quality of life. Eric described himself as “just living like the average person: middle-class, average middle-class.” His comment, “I count my pennies,” adds to the argument that fiscal responsibility and material possessions likely factor into quality of life. Jack commented:

I was raised very poor. I recall being hungry on occasion -- and had outdoor plumbing until the age of 17. That did not sit well with me. Most of my friends have a little higher standard of living, and it was tough for me, but I survived.

I reflected, “You appear to live a very comfortable life now...,” to which Jack replied, “I have been fortunate.” He added even more clarity to his perspective by continuing:

Quality of life, I think, is doing the best you can with what you have. However, I would prefer a higher quality of life than a lesser, but I am saying, well, the old saying, if you have a lemon then make lemonade.

For some men, quality of life was not so much a state or an end, but the means or method one uses as a guide for personal development and interaction with others. Norm commented, “I think a lot of it. I think if a person is happy with his life, as it pertains to

Christ, Jesus Christ, that in itself is a major factor in quality of life -- in fact, I know it is.”

This comment reflects the view of several men that, for many, personal religious views were central to quality of life in general, and particularly in times of crisis or challenge.

More attention is given to spirituality and religiosity later in this manuscript.

Harold’s life situation, and his experience with prostate cancer and treatment, provided an opportunity to understand a unique, but not necessarily uncommon, perspective that clearly impacted his perception of quality of life. Harold identified himself as being a transgendered man. He explained that:

The atmosphere around me growing up was that men are not as good as women, and the best person that you can be would be a woman. And so I couldn’t be the best person that I could be as a male As far back as I can remember, I’ve been interested in being a woman, but I’ve never had attraction to a man. That’s not the way that transgender works. There are people with gay feelings, lesbian orientation, or bisexual, but I’m in that other one, which is transgender.

Harold stated having “a value that is still part of me, if I ever am going to be the best that I could be, before I die, somehow I will have to become a female.” He also explained:

With the ambivalence that I have had, I have tried to forget about this desire to be a woman, or the feeling of the need to be a woman. I tried to forget about it, I’ve tried to extinguish it, I’ve tried to figure out what to do about it, and now I’m trying to explore it, and celebrate it.

He was then asked if his exploration was something he did by himself, or if he had involved other people or counselors. He answered:

I have been going to counselors and therapists, and talking about it for many decades -- trying to deal with it -- and also marriage counseling about it. The marriage counseling was almost always about the mental health problems that my wife has, but it also involved this other aspect -- gender dysphoria, if you want to call it that.

During an earlier part of the interview when Harold was first disclosing his feelings of being transgendered, I made the comment that there are many people who choose to undergo surgery and therapies to change their sex and Harold indicated he was aware of

that. When asked if he might consider such a course of action, he answered, “I have fantasized about sex reassignment surgery -- there is a pull in that direction.” Being a transgendered man, Harold experiences life quite differently than the other men in the study. When asked, “What does quality of life mean to you?” Harold replied:

Quality of life -- I think meaningfulness is an aspect of it, and morality is an aspect of it. So fulfillment and meaningfulness I think are big aspects of it. The ethical and moral aspect of it I think are part of quality of life.

I then made a comment about a person benefiting from there being meaning within choices and activities, along with a value system, and Harold spoke, “Yeah, value system is important. What you make of your life, a precious gift not to waste, but to be as fully developed as you can and also to be moral and ethical in your treatment of other people.” I reflected, “So much of it involves relationships...,” and Harold replied, “Oh yeah, your relationships with your fellow man, woman, whatever.”

To conclude this brief, yet in-depth look at Harold and his views about quality of life, it needs to be mentioned that Harold elected radiation treatment for treatment of his prostate cancer and, at the time of the interview, continued to receive hormone therapy. In a later section of this chapter, the side effects of hormone treatment will be discussed, one of which is something that most men dislike – increased breast size or tenderness of the nipples. Given what has been shared about Harold’s perception of himself as transgendered, and his desire to explore and celebrate his “interest in being a woman,” his answer to the question, “Has your definition or experience of quality of life changed due to your experience with prostate cancer and treatment?” was simply, “Well, I’m happier getting some breast enlargement.” Though Harold’s situation was unique within the study, focus will not be given to his feelings of being transgendered within the rest of this manuscript.

Relationships with Spouse and Family

Eight men cited aspects of family and relationships with others as key determinants of quality of life. As Charles stated, “Family is quality of life.” When probed, he elaborated that quality of life to him meant having:

A happy family . . . seeing your children do well, seeing your wife happy and in good health, interacting with your neighbors. I tend to open up to neighbors, and certainly the family. Family to me is all-important . . . [and] I find children to me are the most wonderful thing in the world.

The importance of relationships with family was stressed by Darren in his statement that, “The thing that I enjoy most right now is my relationship with my family. Money can’t buy what I have.” Norm concurred when sharing what he thought was most important, “Your wife, your family . . . good family, good kids, good grandkids, I have all of that.” For Jack, he saw quality of life as more than his own satisfaction with his own relationship -- he felt it was important that others experience the same. He stated, “Quality of life for me would be more fortunate people who have good family and good friends.”

Though not specifically probed for clarification, the use of the word *good* is noteworthy because it seemed to reflect a stronger connection, a greater emotion, and sense of pride. Being fortunate to have good family and good friends was not a unique attribute of Jack’s. Eric, when asked, “What other parts of your life do you really treasure or value?” answered after nearly a minute had elapsed and tears had formed in his eyes. The extended silence added to the heavy emotion with which he spoke, “I have had, I think, one of the best relationships with my boys, as their father.” Jack, who was interviewed while sitting on the back porch of his home overlooking a large lake on a beautiful, sunny day, noted, “Quality of life when you are young may be having a nice

car and going to a movie and having a girlfriend.” For Norm, aging meant changes as children grew and left the home. He stated that when his youngest child left home it “opened up different avenues, different doors” where he and his spouse were able to travel extensively and “thoroughly enjoyed the opportunity to do that without having family.”

The roles played by spouses, other family members and friends were often talked about by men sharing different aspects of their experience with prostate cancer.

Appreciation of Health

Health was mentioned by nine men as being a contributor to quality of life. This seemed to be especially emphasized when there was an appreciation for good health, or conversely when lamenting poorer health, either prostate cancer or some other health conditions, including those attributed to the normal consequences of aging. Norm stated:

Well, you know, I lived until I was 75 years of age, and I can truthfully say that I never had any debilitating illnesses. I have never been in the hospital, I have never been admitted. So when you say, how was your quality of life? From a point of view of a healthy life, well, superb! You know, to the point where I never even thought about it.

For Norm, having good health contributed to his quality of life inasmuch as it had not prevented him from doing things both at work and in leisure that were important to him. In a sense, poor health had not been a deterrence to him or his aspirations in life.

Frank also expressed feelings that good health, both physical and mental, was something to cherish. When asked, “What are the major attributes of quality of life for you?” he replied:

Strong body and strong mind -- that doesn't take much thought for me. I mean I have always tried to combine these two things . . . I don't mind living long, but as long as I am living I want to have my faculties, physically and mentally . . . I would not like to not have my mind and be around . . . I know that I will not be able to continue the physical activities as I do now. I am blessed.

Another man made similar comments about the importance not only of physical health, but mental health as well. Having just spoken about his attitudes at the time of his retirement and his desire to play golf, Gus stated:

I thought at that time, and I'm not sure where I stand now, that I thought I could endure anything except my mind going. Any kind of physical injury, even to the point of being blind, but I always thought that was the thing I wanted to have more than anything – a strong mind.

At another level, facing the eventuality of declining health is a process that may occur suddenly or may happen gradually with time. Ken spoke of physical health as being a primary aspect of quality of life, but, with a smile on his face, acknowledged that “It’s going to hell with old age.” Another man, Darren, when queried if he associated health with quality of life, answered:

Yeah, yet I’ve always, up until the time that I was 65 years old, I didn’t have anything wrong . . . the first twenty-something years that we lived here, I never spent overnight in the hospital. I mean, I just didn’t. And then, all of a sudden, it came crowding in on me.

Darren went on to list several conditions and surgeries that had been completed for his heart and his hands, but stated, “The Lord says He won’t give you anything more than you can handle.” This statement, along with several others made by this man when discussing other events in his life, made it clear that religiousness and spirituality played a significant role in his outlook on life. This theme of religiousness and spirituality, as shall be shown later, was prominent for many men as they discussed their experience of dealing with prostate cancer.

Aging influences health. The aging process is experienced as a combination of physical, emotional, and social growth and maturation. As a subjective construct, quality of life means many things to different people. Based in qualitative methodology and grounded theory, this research study aimed to determine how participants viewed quality

of life in general, aspects of aging and gender in relation to quality of life in order to assist in the process of exploring the impact of prostate cancer on these men's lives. Some men described aging as a process where activities and priorities change. Frank stated that the aging process is one where certain things (i.e., physical capabilities) are going to diminish within a "natural course of events," and that you "gotta make hay while the sun shines." Therein, he suggests that people "don't take [anything] for granted and enjoy it while you can."

Productivity and Involvement in Activity

Staying active was a principal theme in men's descriptions of quality of life. An activity, per se, may be defined as executing a task or doing something specific, having been motivated for a specific reason with a particular end or desired outcome in mind. This concept of activity will be further defined and explored in Chapter Six as properties and dimensions of particular themes are discussed. As Martin stated in a simple manner, "I try to keep active." When asked why it was important for him to stay active, he responded, "Well, you know, the more active I am, it is keeping me going . . . the more that I move around, the better I'll feel." His friend, Leroy, who was interviewed at the same time, interjected a similar feeling stating, "I want to wear out, rather than rust out." Staying active and being involved in things that were meaningful and satisfying was clearly a factor in most men's perception of quality of life.

As expected, the precise nature of activity varied from man to man. Many, if not all, of these activities fall within conceptualizations of leisure. Jack stated, "Gardening is a big part of my life," and Gus and Darren both expressed a passion for "playing golf." Gus also mentioned that upon retirement, and aside from golf, he'd looked forward to opportunities to cook. Another man, Norm, commented, "Well, there are many other

definitions, I'm sure, of quality of life. I mean, I enjoy good food, good music, good art."

Charles shared a similar outlook, after disclosing an interest in gardening:

[Quality of life] is in good books, good food, good wine, but not in excess -- we are not an excessive people I do enjoy good music -- I love music -- and sometimes movies, and reading -- I love to read.

Another man, Eric, spoke specifically about his taste in music, "I enjoy classical music. I enjoy good hard rock music. I enjoy any kind of good music, as long as it is done by someone who really knows what they're doing, with few exceptions." Several men spoke of service and activities done for the sake of learning. Frank commented, "I believe in lifelong learning. I believe in using my mind." For Irving, opportunities to serve others were central to his quality of life, and he gave examples of serving as a consultant for a local university, serving in ecclesiastical positions for his church, and serving meals to the poor. Leroy stated simply, "I would like to make a contribution to the community in which I grew up," and he shared examples of his involvement with his church and service on a Board of Trustees for a nearby community college.

Eric stated, "I enjoy the out-of-doors." Later in the interview, I commented, "You mentioned enjoying the out-of-doors. Is that something you usually do with other people, or do you enjoy being out-of-doors by yourself?" He replied:

With my boys, I've enjoyed that very much. I enjoyed that, it's something that, to really enjoy, well, you can do it yourself or you can do [outdoor activities] with just a few people -- I don't care to do it in a crowd. I like to have it quiet, I like to hear and see and so forth. If you have someone who is dragging through the woods and making a lot of noise you're not [going] to see anything and you're not [able] to hear much. But [to] truly appreciate it, to truly observe it, one has to be quiet. But, I love to share it with someone too.

This comment provided more information that brought up aspects of activity that, for him, made being out-of-doors more meaningful. For Eric, being out-of-doors was most satisfying when sharing time with his sons in a setting that was undisturbed and

peaceful. Jack echoed similar feelings about nature when asked, “Has your definition of quality of life changed, then, as you have grown older?”

Oh, I think when we are young we have a very narrow approach to life...But you find as you get older that you appreciate the lake, and the wildlife . . . the lake is awesome.

Other Parameters of Quality of Life

These previous comments and quotations highlight the fact that these men viewed being active and being in activities as important within their appraisal of what constituted quality of life. Undoubtedly, the nature and rate of activity changed throughout their lifetime due to a number of potential factors or variables. The transition(s) surrounding retirement, notions of masculinity and its relationship to sexuality or sexual expression, and interaction with posterity for the sake of generativity are hereafter explored.

The retirement transition

Unmistakably, the transition from work to retirement – whether that impact is emotional, psychological, or social and how it affects one’s self-image or self-esteem – is present within the experience of many older men’s lives. The experience of retirement is one that many look forward to with some combination of dread and excitement. For some, depending on the resources available, retirement offers the opportunity to realize plans to travel, spend more time with a spouse or loved ones, or play golf now that free time is in greater abundance. For others, though, retirement may co-exist with challenges associated with declining health, death of a spouse or partner, and a loss of one’s earlier identity. During the interviews, many men included information and feelings about retirement within the description of their life. When asked, “So are you retired now?” Charles shared, “Yeah...I have to accept bumbling through life.” While speaking with Alan who was rapidly approaching retirement, the conversation began when I said, “Let

me just ask you what it means, then, to be a man? What is a man like today?" Alan replied by offering the words of his surgeon, to whom he had asked the same question. He said the surgeon stated, "Well, look, you're able to do your work, you're carrying on your daily activities, you're able to do the Lord's work, you know, be thankful." Alan followed that up by saying:

I think there is a lot of truth to that, and of course, when I'm retired I won't be having a livelihood occupation, but I'll still be able to do a lot of things, you know. You've got husband, got grandfather. I've got a grandchild coming to visit us this week, and I hope to spend cultivating time with our family, you know, letting my children know I'm proud of them. And I thought, I'd like to visit those kids, this is an important time in their lives, before they go off for college, and it's way the heck across the country -- you can't do that when you got a job.

He was then asked if that was one of those things he would like to do after retirement and he stated, "Yeah, I think so. Like, if one of them has a graduation or something, we could go out and help them celebrate, you know. And maybe be some influence with them. Those kids could really, you know, they are at the age when they can do a lot." I replied, "I'm sure they are," to which, expressing a wish for his grandchildren, he added, "Especially if they have good self-confidence," seeing himself as one who could help that self-confidence grow.

Darren was asked, "So, are you retired now, officially?" He responded, "I retired officially in '96. It was just a good thing for me to do, for me and my family." At this point of the interview, he described mental health challenges of some 5-10 years earlier which were of such severity that he stated, "I never want to do that again," because "it was just a toll on my family, which I'm very close to. I said, 'I will not go through that again and I don't know what I'm going to have to do in order to not do it,' but I said, 'I'll do whatever.'" He then explained how he followed the suggestions of relatives and retired, which he was able to do, in part, because his wife owned her own business. His

transition from retirement, he said, lasted about a year, and “at first I felt guilty . . . the only thing I did was play a lot of golf for three months.”

When interviewing Frank, I said, “What do see yourself doing then when you retire and you have the whole day to yourself?” He replied:

Well, I have thought about this, and I said this to many people, yes, I don’t see myself retiring, I can’t retire and sit down. I mean, I can’t. To me, retirement is being able to do what I want to do, when I want to do it, for however long I want to do it. And if I wake up and I decided on this day that I don’t want to do it, then I don’t have to. Retirement adds a whole lot of flexibility. It’s getting out of that routine.

When asked if that entailed becoming a creature of “un-habit,” he replied, “Yes, but by no means becoming an inactive creature. Activities for me, how shall I put it, personal satisfaction, psyche, etc., I am going to have to be active, mentally and physically, the rest of my life. That is how I will be happy.”

Jack stated he had retired at the age of 59, seven years previous to the time of the interview, and he experienced a quick transition. He was asked, “Was there a big switch for you, in terms of transition from work, work, work, to a life of retirement?” His response was:

Yes, and it lasted about a day [he laughs]. I wasn’t able to get my desk cleaned out until about 6:30 p.m. that last day. And on my way home, I called my buddies, and I talked to them on the phone, and I cried. Because for 40 years, all of a sudden you’re leaving, and like I said, it lasted about a day, and I loved my job, but I haven’t missed it a second.

While talking to Norm about retirement, the question was asked, “Was there much of a transition period there?” He commented first about his partner, stating, “[My wife] was getting along fine.” In turning his focus to himself, however, he stated:

I didn’t adjust to it as well. I wasn’t lamenting and moaning about, ‘Oh, I wish...’ I suddenly missed all of my contacts and friends, and I guess I had enough ego to realize that, yeah, a lot of people depended on me, and I wondered how they are

getting along.... Of course this was back in [stated name of city], and you hear from people time to time, people asking for a letter of reference, etc.

Norm said he still was interested in providing those reference letters, and that, “In most cases they got the job. But, I think, it was difficult to turn loose . . . So, my life touched a lot of these lives, and, you know, in different ways, and I missed it, I guess I really did. Looking back on it, yeah, I missed it. [My wife] would say, ‘He missed it.’...” Speaking more to the topic of retirement and activities he was interested in, he said, “We’ve been very active here, I am very active in my church. I am the commander of the American Legion post, for six years now.” Later, he commented:

Now, there are some people that we know that have [the free-time of retirement], but don’t really enjoy it. Oh, I won’t say they are miserable, but there are people who I know who are retired, and they say, ‘Oh, I wish I was still working,’ or ‘That old job of mine, I wish I could get it back.’ And, you know, what are you talking about man, you [laughing] have worked all your life, you want to go back. I thoroughly enjoyed my job, but I don’t want to go back.

The experience of retirement, though not a primary focus of this study, was found to be a relevant theme as it described a stage or phase of life that most of these men had encountered and made his reality. This reality provided much of the context within which they then experienced prostate cancer.

Notions of masculinity

What it means to be a man, or one’s sense of manhood as it relates to parameters regarding quality of life, is a topic that has been explored, particularly related to the impact of prostate cancer (Galbraith, Ramirez, & Pedro, 2001). Men who were interviewed were willing to share their opinions about masculinity and, like many other themes, a diversity of perspectives were shared.

Darren, in answering the question, “What kind of describing words or adjectives would you associate with manhood, if someone says ‘Be a man’?” stated, “I have always

enjoyed my masculinity. I enjoy sports, of course.” Many men, in fact ten of the fourteen interviewed, cited their father as being influential on their outlook about masculinity. To

Alan the question was asked, “Is this an outlook you gained from your father, or earlier?”

He replied:

Probably grew up with it. Yeah, it was a world of work, work, work, you know? Everybody works or you don’t make it, you know, and that kind of thing. And I used to have a lot of slogans, proverbs back in those days, you know, “What you don’t have in your head, you’ve gotta have on your back.”

Charles, when asked a similar question, commented:

I have a difficult time even saying what it is today, because some of the havoc. It was a rather uncertain childhood, being raised by grandparents and two old maid aunts in a big house. And then going to my parents’ home, and he [his father] was very happy-go-lucky, he was a great guy. Unfortunately, we found out that he was not too good a father. [laughing] He loved women, and it was all right in [mentioned a South American country], it was sort of accepted. As long as you did not cause the family to lose face. But dad took that beyond that.

Charles was then asked about the time he spent in South America with its particular

notion toward masculinity. He replied:

My problem is that I was being raised by two cultures. By [a particular South American] culture, the man is supposed to go out and be nothing but a sperm dispenser. He will have two or three mistresses, because you don’t have slaves, you have servants, and you have lots of extracurricular activities. Men from these nice families would be down at the whorehouse, very openly. And it was seen as being unseemly and unmanly if you didn’t participate. But my, I was raised by grandparents, by my grandfather, that were very strict, very honest, known throughout the town as an honest man; and two old maid sisters, so I was protected from the carousing end. So all that was expected . . . Families knew that the father would have other separate families, and if his visit didn’t interfere with them, it was tolerated. In fact, it was considered to be the manly thing to do. On the U.S. side though, Dad was the abnormality.

Brian, who was the only man interviewed who had not been married, was asked, “What do you think about masculinity and its place in your life, now or in the past or in the

future?” He replied, “Ah, masculinity, [it’s] an issue I don’t think I’ve given much

thought.” When asked for his definition of masculinity, he hesitated, then said:

Um, I don't know if I have one, um, I am just lost on being a "man" I have never given much thought in my life about being a man. I am not a macho type at all, never was. So I maybe subconsciously, maybe I went through things when I was younger, I don't worry much about it now. You know, I suppose every teenager has to resolve, or at least try to resolve, or make an effort at it.

Curious if Brian's experience with resolving masculinity issues were somehow tied to what is sometimes viewed as a spouse's role in the co-construction of gendered roles or attitudes, I followed up his statement by inquiring, "Haven't had much reason to?" He replied, "Well, one goes through life and you ask a pretty girl for a date, and then you start thinking, 'Well, what's the matter with my "masculinity"?' Am I presenting the right, the proper image?" Asked if he was referring to gender roles, he stated, "Yeah, when I was younger I suppose I thought about that. As an old man, I can't be bothered too much about that." He was then asked, "Do you remember a time in your life when it was a bigger deal?" He answered, "Well, sure, when I was a teenager I'm sure it was a bigger deal. It depends on how you define it."

Gus was asked, "Throughout your life, what has it been like being a man – your sense of manhood, or masculinity?" He, after a pause, stated:

I don't think I have much concept of that. I look upon myself as a human being that relates, hopefully, very intimately with one or two other human beings. And then, I have a goodly number of acquaintances. [My wife] is probably the most important thing in my life, I really was the luckiest guy in the world to find her – I really was. She is a great person. So, but I've really never thought of anything in terms of masculinity. Not really, maybe when I was playing baseball or soccer or something of that nature.

Darren shared a different experience. When asked if he had thought about what it's been like to be a man, the concept of masculinity, and his father's influence, he replied:

No, I was the baby of the family. I have a brother who was six years older than me, and a sister ten years older than me, and a brother twelve years older than me. And he was pretty rough on them. Except my brother who was just older than me, was one of those perfect kids. And he was.

He was asked, “In his father’s eyes? In everyone’s eyes?” and he continued:

In everyone’s eyes. He and I are the only ones still living, but he just, he just was a real good kid. He did what he was told to do. He went to work when he was twelve or 13 years old -- milking cows -- he would get up at four or five o’clock in the morning and, of course, they didn’t have automatic milkers back then, and so he did it by hand . . . and then he would get home from school, do his homework, do his chores, and then he’d go back over there and milk them again. I think there was something like 15 cows that he had to milk every morning and every afternoon. But anyway, he just didn’t give either one of them, my mother or Daddy, any problems. And my dad ruled our house with an iron hand, I mean, that was the way he was raised. All my mother’s and daddy’s people are from [mentioned Southern state] and they...[pause] it was just the way it was done.

When asked if that trickled down to him or not, he replied,

No, no, in fact, I was just the opposite. I have never had much trouble . . . It wasn’t him, you know? He just didn’t, he wasn’t subjected to it as a kid himself. His father, my grandfather, was mean. That was what he knew. He probably didn’t know how but, the only thing, when I came along he had mellowed out. He had quit drinking for the most part. And I got away with things that my other two brothers would have gotten half-killed for. Now he beat the living hell out of me two times, and I remember both of them distinctly. But, uh, he, when I was in first or second grade, and I don’t remember which one... I can pretty well read the newspaper. And he would get me up on his lap and have me read for him. And, uh, as far as any kind, I can’t remember any time when just he and I did something.

When asked about the origins of his sense of masculinity and manhood, Eric responded, “Yeah, I suppose from my dad, I have no doubts about him being a man.”

Harold’s response to a similar question was:

Well, my model was my father. I saw him as a person who used his strengths in a caring way, a helpful way, usually in a gentle way. With the exception of personal problems that he had, because he was raised by a mentally ill mother who had a vitamin deficiency that led to insanity. His mother would love him one minute, and beat him the next, so he had an emotional roller coaster growing up which took its toll on him. So he would have moods of anger and blusteriness and shouting, especially at my mother . . . But, fortunately, there was the other side, too, when he would use his manly strengths, both mentally and spiritually and physically, in a beneficial way, like being protective of us children and mother, and helping other people. His main focus of his ministry was visiting the sick. So he had a very tender, caring side. He had a lot of physical strength in his younger years, and I admired that. And his ability to do heavy physical jobs....

He was then asked if he saw himself more or less following in his father's footsteps, sharing similar attributes of manliness, and he answered, touching upon his feelings of being transgendered and his own experience in addressing femininity, "I think so, I think so -- except, there is a difference. Well, I don't know about his experience of femininity in his manhood."

Norm, within a context and place in the interview when we were discussing leisure activities, was asked, "So, what do you attribute to your ability to enjoy?" He answered:

Probably the role model of my mother and father. They enjoyed life, they were out dancing, they played cards with their neighbors, they would participate, my father was involved with baseball. He loved to pitch horseshoes, and I love to pitch horseshoes. And so, you pick up things like that.

He then also recounted times when his father helped him get work. He explained, "My dad said that there was some property for sale up in Rhode Island, on a lake. And why don't I take my talents, I was always good with my hands and working." Norm then shared that he and a friend had gone to this location and spent time working on a cabin on this property. He also mentioned his father had been instrumental in helping him gain admission to college.

Masculinity and attitudes regarding sexuality

Several men shared ideas and attitudes that led to exploration of sexuality as a component of masculinity. When discussing with Frank thoughts about quality of life, he was asked to tie that into what he sensed about being a man and manhood. He commented:

Well certainly, you know, it's funny, I grew up in an age where masculinity, well you didn't talk about masculinity [and sexuality]. I mean, they were definitely related, but you didn't talk about masculinity and sexuality kind of as the same thing.

When it was reflected back to him that perhaps people did not discuss as much as they do now, he said, “Right, they definitely didn’t. Uh, at least not in my circles.” I asked, “So you’re saying it has shifted for you, then?” He stated simply, “Yes, it definitely has.” Again, I inquired, “Manhood was this, but now manhood is something different?” He said, “Um, I don’t think it’s really different, I think my perception is different. You know, having had prostate cancer changed my way of thinking. Things that I took for granted [he sighed deeply], I don’t any longer.” The comment was then made to Frank, “You mentioned earlier perhaps a change in the notion of manhood, that these days there is more of a connection with sexuality of some sort. What do you mean?” He explained:

Well, yeah, I didn’t, well prior to my exposure to prostate cancer, I didn’t... and I don’t, [he paused to reflect], how should I put it? I don’t measure my manliness by my sexuality. But, as a man, I was fortunate to have sexuality, which, in many ways, I kind of try to suppress, again, for whatever reason. Just because of the way I think I was brought up.

I asked, “There is a need to suppress it to some degree?”

He replied:

Well, yeah, I felt that there was, uh huh. I didn’t deny it, but that wasn’t, like I didn’t, I felt like I didn’t want to talk about it too much, but that wasn’t, I didn’t want anyone, and I still don’t want anybody measuring my manliness by my sexuality, you know? I took certain things for granted, like, to be honest, like getting an erection. And in fact, in growing up, there were times that I regretted this ability to get an erection, because it could be [began saying the word ‘embarrassing’]. I was very self-conscious, and, ‘Why does this thing happen to me?’ I can remember many times in my life when I wish I couldn’t, or didn’t have one, and needless to say....

Frank, who spoke freely of his opinions regarding masculinity and sexuality, commented about how his prostate cancer experience had reshaped some of his attitudes:

As I’ve shared already, the broadening of my, my attitudes about my own sexuality, the opening of my mind to be receptive to other things. And I really believe, although I have not personally achieved all of that, that even if I couldn’t

ever get an erection again like I used to, that I can still enjoy my sexuality with my wife, you know, with alternative ways. And I mean, there, there is more to being a man, I really believe this, there is more to being a man than getting an erection, it is something that if it doesn't happen I would dearly miss, but, there is a whole lot more to it. I, so in many ways, it really has really deepened my own personal sense of man, I know that I am not a man because of the big erection I could get. There is a whole lot more to that...

Alan, too, expressed an opinion that spoke to the conflict that can sometimes occur when comparing masculinity and sexuality. When asked about the impact of prostate cancer treatment on his sexuality, he answered, "No, not whatever. It's just an inconvenience, it's another problem to deal with, you know. But, no, if being a man depended on getting an erection, ah, we'd have some funny standards, you know."

Brian also was asked about this issue, specifically regarding his worries about sexual ability. He responded:

Well, I worry about it. I mean, and if I got married, no prospects [he laughed], but you know, even as a bachelor, somehow that is limiting your function as a male in the world, or something like that. But, I think if I really thought about it, I would not be much concerned with that since I'm 65 and I'm probably not going to get married, so it's not much to worry about.

It was then suggested that sexuality isn't just necessarily a marriage thing, and he replied, "Yeah, but I'm not homosexual and uh, I don't have any ladies that I am currently having sex with." He was then asked about sexuality and being a man. He shared:

Ah, they're inseparable, I suppose. Well, but that's a rather philosophical statement [he laughed]. Ah, well now, me personally at 65, I think my sex interests will probably decline over time. It will probably decline taking this hormone therapy, since it knocks out your testosterone. So, ah, it's not that strong right now anyway. So, I don't think it's a big issue for me. As time goes on, if I were married, you know, and had a sexual relationship with a wife, I think it would be much more of a thing to worry about.

Charles, when first asked, "So, being a man, what attributes or characteristics would you subscribe to manhood?" replied with a single word, "Honesty. More than

sexuality, honesty.” When the idea of relationships began to be brought up, he shared, “Not only in relationships, with yourself, your family, and providing for your family was very, very -- that’s the other thing that I think was important.”

Later, when discussing aspects of his treatment experience, Charles lamented, “Ah, the frustration of not being able to satisfy your wife. Not necessarily yourself, but satisfy your wife, it wears on you. And we’re the generation where oral sex isn’t going to be the solution.” It was suggested that in modern society it was more the norm and he agreed, however, it was a behavior not condoned by his spouse. He commented:

Oh, it is taboo. I proposed it to my wife, and oh, there’s no way. Because it’s not self-satisfaction, it’s providing satisfaction for somebody else. That’s what manliness really is to me, on a sexual level. And, I came across this as you get into life -- it’s not self-satisfaction, it is to make sure that your wife is enjoying it as much as you are. That, that became the thrust of sex for me -- making sure that she was satisfied, that she climaxed, that it was pleasant for her. And that is the frustrating thing about impotency.

Darren, who served in the military, was asked, “Have you had significant relationships with women aside from your wife, prior to meeting your wife, marrying her, in between? [Note: Darren and his partner had been married to one another twice before, and divorced, before marrying for the third time some thirty years before this interview.]

Darren replied, chuckling, “Oh God, yeah.” I stated, “Okay,” and he continued:

Remember, I told you I fought the Battle of Piccadilly. When I got to England I was 17 years old, and [laughing] when I got up in the morning I had to slam the bathroom door on that thing to get it [an erection] to go down.

Darren elaborated on what he mentioned as the “Battle of Piccadilly” as being a location in London where alcohol and sexuality were found in abundance. He shared what he stated was the view and criticism of the British citizenry regarding American servicemen in that they were “over-paid, over-sexed, and over here.”

For Eric, sexuality was an identified part of his masculinity. Being in a time when he was challenged by the side-effects of hormone therapy that is known to reduce libido, he commented:

The desire, for the most part, goes out the window. However, when a person is in love with a lady, and she has passion, and even though I lack the ability to have an erection, I still have the desire to be very, very, very close to the one I love. And so, that very thing [the connection between masculinity and sexuality], yes, has entered my mind. And I enjoy it, and I am able to have my loved one enjoy it also, and that gives me pleasure. And, for that I feel that my manlyhood, my manhood, has not completely been robbed. I have not been robbed of it completely.

Gus spoke to the same issue, but used a few simple words. He was asked, “Did the impact toward the experience with prostate cancer change your sense of being a man? Going back to masculinity, did it reshape or redefine....?” He replied, “Only to the extent that things were affected by the treatment, but that is all.” Jack, when he was asked a similar question, referring to his prostate cancer experience and its impact on sexuality, stated:

Oh my, it has been devastating, and devastating is too strong a word, but it has been very difficult. Occasionally, I had had fleeting thoughts of why not just not have it cut out, and then have a good ten years, and then hang it up. But, I probably wouldn't go back, but I've had those thoughts.

Wishing to explore more about his opinions about the psychological, social, or emotional impact, Jack was then asked about how his own self-image of who he is, what he is, and its impact on him. After a pause that lasted some fifteen seconds, he responded:

I don't think it had an impact. I mean, I miss it terribly, but I always thought I was a pretty strong person. And again, it's 'que sera sera' -- what the hell can I do about it? I would probably go through a very major, traumatic surgery, to restore...

And I asked, “You are talking about potency then?” and he said, “Yeah, yeah...it hasn't [changed me], I don't think. Of course, my wife may say something different, but, I don't think it's changed me much....” It was then inquired of Jack:

It's hard to measure the extent of change, if any, that has occurred through the experience. But would you say there has been some change or transformation, looking at before and after, the way you approach things, the way you feel about yourself, life, your priorities?

Again, another lengthy pause ensued (of a little more than twenty seconds), and then he spoke:

Well, you can't have fantasies anymore. I think, [and he chuckled] sort of like Jimmy Carter, I have often had a lot of private thoughts, you know, I see a woman, and 'wowie.' But now, I think about it about three seconds, and [with a slight laugh and shrug of his shoulders], damn it, what the hell could I do about it? And it's, that's devastating, it really is. Not that I ever did, you know, I was always faithful.

Martin and Leroy, who were interviewed together, discussed feelings about what it meant to be man. Within that discussion, Leroy made the comment, "Well, I'm not as fortunate as he [Martin], but a man's role is to be a role model." I replied, "So being a role model is part of being a man?" and Leroy added, "You started off saying that you are not as fortunate as [Martin]..." and he added a simple clarification by stating, "With children."

Norm was another man who shared feelings specific to manhood, sexuality, and procreation. He commented:

Well, manhood is, I uh, I had mumps at an early age. I was about 15, in high school. I had a severe case, and the doctor said because of atrophy of one of the testicles, that, you know, it may be difficult, if not impossible, for you to have children...and, so, I learned that when I was 15. I started to think about being married, and [he laughed], that was always in the back of my mind, and of course, when we were married, my wife knew about it, knew of it, but we had the three children...she had one miscarriage [miscarriage].

Generativity: Interacting with posterity

Generativity is a concept contrived by Erikson (1959) that suggests older men may be invested in their posterity and wish to dedicate time and energy to ensure wisdom is passed on to the next generation. Some of Alan's comments fit this concept. "I've got a

grandchild coming to visit us this week, and uh, I hope to spend cultivating time with our family, you know, letting my children know I'm proud of them." Alan then described a situation involving his brother's grandchildren who he wished to connect with, stating he believed they were nearly finished with high school. Of them, he commented:

I want to look up my brother's grandchildren . . . They [his brother and his wife] have four lovely children, and they look like him, but they're brown [he laughed]. And, they are now reaching the end of high school age you know, and I thought, here are these kids who don't have much sense of family, they don't know their family in [names a Midwestern state] at all, and he tried to keep them away from the other family as much as he could, so they don't know them either. And I thought, I'd like to visit those kids, this is an important time in their lives, before they go off for college.

For Charles, he expressed happiness in "seeing [my] children do well." He elaborated his feelings and tied it into a perspective inclusive of his view of leisure in this statement:

My family is much more important to me, seeing the kids do well, the grandkids, I worry about the grandkids now. You know, it's frightening now but they have their lives to lead . . . So, right now the satisfaction I'm looking forward to is seeing my grandchildren become nice people. That really is our leisure -- visiting with the grandkids, enjoying them as they go through their phases . . . seeing them get through their things, and they are dancing. I find children to me are the most wonderful thing in the world.

Irving shared a desire to be with and pass on to his posterity, and spoke of regret about not having spent more time with his own children. He spoke of a desire "to have fun with my grandchildren, who are growing too fast," and later stated:

I would have loved to have been more involved with the kids. For example, I love the game of cricket, and not one of my boys played cricket. The reason for that, in my mind, is that I never spent the time. Yeah, so looking back, if I had it to do over again, I would have spent more time with my children rather than being involved with everything.

This type of comment may be simply construed as regret yet may also factor into greater motivation for effort later spent with grandchildren.

When interviewing Jack, the question was asked, “So a lot of your free time, then, it sounds like, revolved around your children’s recreation and play time?” He responded, “Yeah, but not as much as I look back and wish that I had done more. I wish that I had spent more time with them.” When then asked what a typical day in his life now looked like, he answered:

Up early, sunrise, I love the morning. Nobody has screwed it up -- it’s a brand new day. I told my granddaughter the other day, who is eight years old, I showed her the sunrise and I said, ‘This day has never happened before.’ And, of course, I don’t think she quite grasped it, but maybe I planted a seed in her head.

Leroy, who had mentioned his friend Martin’s good fortune of having many children, elaborated on his own situation, “I only had one son, who died of pneumonia at the age of 1½.” I said, “Okay, something about having children and rearing a family is an important thing,” and he stated, “Yeah.” I then suggested, “But, you’re not any less of a man because...” and he replied, “You wanted to know what I thought a man’s mission was?” and I commented, “It’s hard to go back and say, ‘What if?’ but what if you had raised [your son] to adulthood, would your life have been much different, do you think?” His comment was, “I don’t know that it would have been a whole lot of difference, because I’m helping with my sister’s children.” Leroy then spoke at some length about those children and their accomplishments. It was then stated, “Okay, so you are involved with their lives?” and he replied, “Yeah.” I asked, “And that is important to you?” and he commented, “They are not my children, but I help with them.”

Martin, when he was asked what things are important to him, replied smiling, “My family – very important. Next important will be trying to get my baby son through college.” When asked if his son was just starting school, he said, “He is starting in

January. I want to see him get a degree.” He was asked why that was important to him and he replied, “I will feel like my work is done.”

Harold expressed similar desires, and shared his intent to complete a writing project. He stated, “I’m almost finished writing a book . . . [and] I’m going to finish writing this book, before adding anything else to my schedule.” Following a comment that he appeared focused on that task, he replied:

Oh, yeah, I don’t want to die and have this book not written. When I die, I want the family to have as much information about family history as possible. And I want it to be in some kind of formal or informal archive.

In summary of this section, quality of life was described by participants as a concept with several dimensions. These dimensions included: (a) the importance and value placed on being able to fulfill certain roles, (b) being able to maintain and continue certain traits and personal characteristics (e.g., loyalty, having fiscal security or exercising religious faith), (c) allegiance to relationships with spouse, friends and family, (d) perception of having good health, and (e) remaining active and productive.

Older Men’s Lives – Discussion about Quality of Life

Quality of life and its combination of social, emotional, familial, economic, and health-related factors are challenging to understand (Hunt, 1997). Overall, for men in this study, the definition and personal satisfaction of quality of life was multi-faceted, and found within sub-themes such as fulfillment of significant roles (e.g., those associated with manhood), personal values and characteristics, relationships with spouse and family, health status, and being active and involved in important activities. Life circumstances were seen, for example, playing out in terms of appreciation for health and one’s retirement status. Within this study, men were asked to define quality of life as they believed it to be. Frank declared that, “God has placed us in a role,” and that being a

father, director, and leader is important. Charles maintained his view that being a provider was key to his quality of life, and Ken emphasized having “fiscal security.” Jack asserted that “treating your wife with respect” is essential, and Eric shared the importance of “letting my children know I’m proud of them.” Leroy believed a man should be “responsible” and “law-abiding.” Norm placed much of his perception of quality of life around being happy, a happiness for him that centered around religious convictions. All of these are examples of values, each with their own dimensions, that serve to describe the larger theme of quality of life.

Understanding the parameters and definitions used by men to thereby understand how they viewed quality of life was central to the data. In Chapter 1, quality of life in relation to the possibility of encountering threats to health was defined as the individual response to physical, mental, and social effects of illness that significantly influence the extent to which personal satisfaction with life circumstances can be achieved (Bowling, 1997). Further, these physical, mental, and social effects of illness and treatment interacted with the unique personality and other life experiences that were part of the man’s life at the time, and helped determine how much satisfaction had been achieved. Recognizing there are many components of quality of life (Livneh & Antonak, 1997), including healthy leisure and recreation participation, understanding the coping and adaptation process aids understanding about quality of life and is thus an important focus of study (Bishop & Feist-Price, 2001; Hunt, 1997; Renwick & Friefeld, 1996).

Further illustrating the importance of interpersonal relationships, Charles plainly stated, “Family is quality of life.” Darren, too, expressed this sentiment when he said, “The thing I enjoy most right now is my relationship with my family. Money can’t buy

what I have.” Jack shared that “fortunate people” are those who “have good family and good friends.” As a property of quality of life, health was described as a feature, one that was associated with advancing age. Frank’s assertion that having a “strong body and strong mind” illustrated the importance of good health. Gus, too, cited the desire to have a “strong mind,” and Ken spoke of advantages to having physical health, but stated, “It’s going to hell with old age.”

In the face of getting older, men seemed to accept that physical health would likely diminish. Frank said, “I know that I will not be able to continue the physical activities as I do now,” and that you “Gotta make hay while the sun shines.” Martin’s comment that “I try to keep active,” and that “the more active I am . . . the more that I move around, the better I’ll feel,” is indicative of men’s view that maintaining activity is paramount to quality of life (J. Kelly, 1993). Charles’ and Jack’s interest in gardening and Gus’ and Darren’s passion for golfing entail being able to be active enough to physically possess the ability to execute the tasks needed to participate. Likewise, Gus’ enjoyment in cooking requires physical and mental execution of certain functions. Jack’s and Eric’s pleasure is taken from being out of doors, as Jack stated being able to “appreciate the lake and the wildlife” does require being active to the degree one is mobile and can get to places where one can participate and be part of nature. Eric’s enjoyment of music requires being able to operate audio equipment. Irving’s interest in volunteer work requires various physical and mental competencies. Leroy’s desire to also be of service, embodied in his statement that “I want to wear out, rather than rust out,” is important to being able “to make a contribution to the community” that he grew up in. While being able to execute tasks is an essential feature of being active, being active and engaging in activities is

central to participating and being involved in life events that are deemed important (World Health Organization, 2001). These statements from men in this study illustrate the similarities within this sample compared to general knowledge already available in scientific literature (Livneh & Antonak, 1997). In summary, quality of life was described by participants as a concept with several dimensions. These dimensions included: (a) the importance and value placed on being able to fulfill certain roles, (b) being able to maintain and continue certain traits and personal characteristics (e.g., loyalty, having fiscal security or exercising religious faith), (c) allegiance to relationships with spouse, friends and family, (d) perception of having good health, and (e) remaining active and productive.

Discussion of Older Men's Life Transitions

Models and theoretical depictions of life stages and aging proposed by Erikson (1959) and Levinson, et al. (1978), were cited earlier in Chapter 2 as having provided the basis from which subsequent theories of aging emerged. Levinson, et al.'s (1978) conceptualization of aging is also given merit by comments of men in this study. Levinson, et al. believed men's lives evolve in a sequence of stable periods or "eras." Transitional periods lead from one era to the next, and late adulthood, according to Levinson, is one where people are affected by personal and societal response to bodily decline, have an awareness of one's own mortality (often via medical situations), observe serious illness or death of loved ones, see their professional and social status diminish, and possibly change life philosophies.

Men in this study talked about these types of experiences and their places in transitions. Ken's admission that his health was "going to hell with old age," and Frank's suggestion that you have to take advantage of good health "while the sun shines,"

illustrate men's awareness that health is a fragile thing. Without a doubt, their experience with prostate cancer brought about an increased awareness of their own mortality. Gus stated his reaction was simply, "Horror." Darren indicated the news of his diagnosis was such that "You could have knocked me down with a feather."

Erickson's (1959) conceptualization of human development deals with the necessity of mastering key developmental tasks and the resolving of associated psychological crises in eight phases. The latter two of these phases, middle adulthood and late adulthood, are salient to this study. *Middle adulthood* (spanning from 35 to 55 or 65 years of age) consists of dealing with crises related to an individual's focus on creative and meaningful work (paid or not), as well as family issues. Within this stage, the significant task is one of generativity versus self-absorption. The last stage, labeled *late adulthood* (55 or 65 until death), involves a crisis of integrity versus despair. Integrity consists of the experience and associated feelings when an older adult reflects on their life and is happy, content, and satisfied with his or her contributions, accepts mistakes made, and believes their life had meaning. On the other hand, despair is experienced if meaning, purpose, and contentment are not the result of their recollection (Erickson, 1959).

Generativity was seen in the accounts of several men in this study. Generativity, as described in Chapter 2, means to preserve cultural values by passing them on to younger generations, caring for others, and contributing to society (Erickson, 1959). Self-absorption, also referred to as stagnation, results from inactivity and fear associated with failing to find a satisfactory meaning or purpose for life. Jack reported interacting with his granddaughter, where he showed her the sunrise and told her, "This day has never

happened before,” and hoped that “maybe I planted a seed in her head.” Martin, in sharing the support given to his youngest son in order for him to get a degree, stated that, “I will feel like my work is done.” Alan and Leroy both spoke of desires to be involved with extended family members, offspring of siblings, hoping, as Alan stated, that he’d like to visit them before they went off to college because “this is an important time in their lives” and that it was important for them to “have good self-confidence.” Harold’s writing of a book was based on his desire for “the family to have as much information about family history as possible.” These are all accounts of men wishing to be involved in the lives of their posterity and illustrate examples of their desire to remain influential.

The transition into retirement is significant for most older men (Gradman, 1994). This retirement transition also serves as an appropriate time to explore other theories of aging, such as role theory, activity theory, disengagement theory, and continuity theory. *Role theory* states that aging brings with it the likelihood of a decline of familiar roles. For men, many of these roles are work-related, but do include familial ones, and all roles usually consist of well-defined behaviors and expectations. As one’s familiar roles diminish, challenges may occur. As circumstances challenge or change a man’s ability to fulfill important roles, similar to what Frank mentioned as being a “leader,” or Charles’ desire to be a provider, stress may occur. *Activity theory* holds that decreases in one’s customary levels of meaningful activity equates to a diminished sense of well-being. Charles stated that for him, retirement meant he had to “accept bumbling through life.” For Frank, who was not yet retired, “Retirement is being able to do what I want, when I want to do it, for however long I want to do it.” He shared that he “can’t retire and sit down,” that he will have to get used to a different routine – but that entails “by no means

becoming an inactive creature...I am going to have to be active, mentally and physically, the rest of my life.”

Disengagement theory, primary to the retirement transition issue, suggests that men are less involved with institutions of society and its members. Outside of the retirement issue, deteriorating strength is thought to result in fewer or changed relationships. Norm's experience is a good example of what this disengagement looks like. He stated that “I didn't adjust to it as well,” and that “I suddenly missed all of my contacts and friends.” He realized that he “had touched a lot of lives,” and that “looking back on it, yeah, I missed it.” *Continuity theory* allows for the loss of traditional roles and disengagement from social institutions, but believes that the person's personality and unique behavioral traits (i.e., leisure interests) help the individual meet his challenges and provides a sense of continuity and contentment (Fry, 1992). Alan had explained that retirement meant not “having a livelihood occupation,” but that he still will “be able to do a lot of things.” Norm, who lamented his retirement early on, later talked about the importance of continued activity in church and civic opportunities and stated, “I thoroughly enjoyed my job, but I don't want to go back.”

Though discussion of leisure-related information will occur more in depth later in this chapter, it should be noted that leisure has been studied for its relevance to the concepts of continuity and change. Freysinger (1999) examined leisure behavior as a function of both concepts across the human lifespan. *Continuity* was seen as present when the same types of activities are engaged in over time, and occurs because they are familiar to the participants and enjoyment and satisfaction continue to be experienced. Examples of this include Alan's involvement with tractors, Irving's interest in cricket,

Franks' persistent running, Charles' love of art and reading, Darren's continued following of sports via the television, and Leroy's devotion to religious activity. For these men, leisure has served as a vehicle by which continuity has been achieved, and thereby, life has greater meaning and satisfaction (McGuire et al., 1999).

The Many Faces of Leisure

Leisure can be defined in many ways and, indeed, the men in this study shared attitudes and opinions that illustrate the diverse perspectives that exist surrounding the word leisure and its meaning. The following examples from the data demonstrate and give insight into the different perspectives, attitudes, and experiences in which men contemplate use of their free time. These examples are grouped according to the following themes: (a) time, (b) activity, (c) participation and involvement in life events, (d) relationships and leisure, and (e) antithesis of work. Other factors, such as illustrations of leisure motivation and meaning, along with leisure constraints, are also included.

Time

Several men expressed opinions of leisure as having to do with time, either as a time frame in which a recreation activity or hobby occurred, or as time spent not doing something else affiliated with some other label, such as work. For some, leisure as time was a commodity that one decided where and how it passed. Frank stated:

Leisure connotes to me, um, time outside work, you know. Now, fortunately for me, I enjoy my work which has always been very important to me, so it's not a matter of enjoyment, but as I said, it's definitely a time outside of work.

Gus, when asked how he would define leisure, mentioned having read a lot over the years, watching TV and using a computer as examples of, "That's how I spend my time . . . that would be what I do" Irving was asked what leisure meant to him and replied, "Leisure is finding *time* to relax" [italics added].

To Leroy, the question was asked, “What does leisure mean to you, in your life now, in the past, how has it changed?” Leroy replied:

Well, leisure, I think, is how I spend it . . . To me, it adds years to my life, how I spend it. It means a time to let up, leisure. To find something to do with it, positively . . . If I were defining the word leisure, that means, spare time, in my dictionary.

Norm was asked to reply to the same question, and he described leisure in these words, “It’s time, I guess it’s the ability to use that time in the way that is most pleasing to me, or for someone who has leisure, or has the availability of leisure.”

Activity

Leisure choices that manifest themselves as leisure behavior or activity were frequently noted in the data. Darren was asked, “If you are asked to define leisure, what is it for you?” His reply included both the feeling that it involved *being active*, as well as being *involved in activities* – ones that change with time. He commented:

I’m not as active as I used to be, I mean as far as, we used to go up and tube down the [name of a river]. And, uh, we would get out, especially my youngest daughter’s, um, husband, we would get out with my grandson and throw a baseball around, and footballs you know. And things like that, but as far as anything active, swimming or anything like that, I just don’t do it anymore . . . Leisure to me is, uh, watching sports, following teams, I have given up on major league baseball, though I love college baseball. We have functions here -- Christmas, Thanksgiving.

For Alan, a comment of his was similar, but included his feeling that activities were things that produced something desirable. He said, “I might take up bird carving, I could imagine that, or something, but it’s hard for me to imagine an activity that doesn’t result in something.” For Charles, he stated his definition of leisure was also something that had changed over the years. He commented, “It’s changed. It used to be basically reading, listening to music, talking. Ah, I love working out in the yard. The plants don’t talk back

to you.” There was mutual laughter, and I agreed, “No, they don’t, nor do books . . . those are activities. What does it [leisure] mean?” He answered simply, “Tranquility.”

Eric, after having shared his thoughts about quality of life, was asked, “What types of things have you enjoyed doing throughout your life that you constitute as leisure activities, or part of leisure lifestyle?” He replied:

Making furniture. Designing many of the pieces that I’ve made. Woodwork is what we called it then, cabinetmaking. I enjoy the out of doors very much. I am definitely an environmentalist. I did live for a number of years in the middle of a 30-acre woodlot. I enjoyed that immensely.

Ken had mentioned gardening as a leisure interest. He was asked, “What were your reasons for gardening in the first place?” He replied, “Have something to do,” to which I prodded, “Just something to do?” He added, “Yeah, and I’ll be honest with you, to make things grow.” Frank, when asked about activities as part of his leisure, responded, “Activities for me, how shall I put it, personal satisfaction, psyche, etc., I am going to have to be active, mentally and physically the rest of my life. That is how I will be happy.” Leroy stated simply that leisure meant, “To find something to do with it, positively.” Martin, who was interviewed with Leroy, added his perspective about leisure during a typical day in these words:

Well, leisure, that means that I would have pulled up a chair, and sit down, and not do a thing -- you know, we’d all sit there. But this was more like recreation, we got out, and just, being active, and cleaning up.

Gus was also asked for his definition of leisure in his life. He replied:

For most of my life it was reading, and I did a lot of it. Now I would have to say it’s watching the news on television, or using the computer. That’s how I spend my time – I’m home quite a bit. I’ll read the paper, but I get more news out of the television or the computer. So that would be what I do.

During a later part of the interview, when discussing the topic of leisure, Harold said, “One of my recreational, playful things that I do, is to explore cross-dressing –

gender exploration.” I then replied, “That would fit with what you have [previously] talked about.” For Harold, this would be an activity that fits within being transgendered and is an expression of his identity.

Participation and Involvement in Life Events

Leisure was often described as more than its relation to time or work, one’s state of activity or the activities themselves being participated in. Men also talked about leisure as experience and participation in life’s events, participation that came with expectation and emotion, and perhaps resulted in an outcome. The following examples offer insight into this.

Harold, who had mentioned exercise as a favorite activity, said, “Writing is a great form of expression for me. It’s not completely recreational, but it’s an outlet, it’s a self-expression, a self development, it expresses and develops me to do journaling and to write stories.” Using this as an example, writing itself is an activity. When used in order to produce something, like a journal entry or a story, it becomes participation and a leisure experience. When prodded for other recreational or leisure activities Harold participated in, he added, “I mentioned singing barbershop, and I sing in my church choir. Music is a great outlet for me, I even wrote a song recently, a simple barbershop song.”

Alan, when asked about leisure, replied:

Yeah, and that’s always been kind of a difficult thing for me, as to what do you do for fun -- you know, something that doesn’t need to be done, because usually, my thinking is connected with work, or something productive. For instance, people who play cards. I guess I did a little of that as a kid, but mostly, I can’t imagine why anyone would have fun playing cards. You sort them all around, move them here and there, and when you’re finished you shuffle them all together – nothing’s, nothing’s been done! You know?

I reflected, “Same deck of cards...,” and he continued:

Yeah, and who cares what order? Ah, some other things are that way. Um, my wife one night said, “Why don’t you learn to play golf or something?” Well, for one thing it’s an expensive game and for another thing it seems to be a consuming game for those who get into it, you know. They have to practice, they have to do this, and for another thing you spend all that money for a bag of tools that don’t do anything, you know.

For Gus, though, who happened to enjoy the game of golf, he was asked about why he chose the activities he participated in. He commented:

Well, in golf it is the challenge of the game. You know, you can play against yourself, in fact you do most of the time, even though you may be playing with others. Now, I’m not competitive. When we were on the island, I played golf there. I think I was Treasurer of a golf club for awhile, and so I used to play tournaments. But I found that I didn’t have the drive to play tournaments.

Brian, after he’d given his definition of leisure, was asked, “You’ve mentioned activities, but what is it that you look for in an activity to be interesting or enjoyable for you?” He said, “Well, okay, music. If I had a piano I would play the piano, so I would consider that leisure, but I don’t have one....” Prodded more to further explore his conceptualization of leisure, he continued:

Well, it’s restful, it’s therapeutic, piano has always been, I don’t read music, I just, when I was a kid, we had an old upright and I used to sit there and plunk away. And so I’ve just carried that through my life. And so I enjoy that, that’s leisure.

For Charles, who had associated the word “tranquility” with leisure, he was asked about other attributes he connected with leisure. He replied:

Oh, just self-satisfaction with what you’re doing. I don’t think, I don’t care what it is. If I don’t, I don’t do things that don’t make me feel good, and that’s not in a physical way, it’s emotionally, you know. I like movies, if they can get to me emotionally. I’m very demanding in a movie, but I find myself crying in movies. The last time was, uh, *Beautiful Mind* . . . Music will bring me to tears. And tears can be a source of satisfaction, just an emotional type of thing. Uh, visiting with people. I’m not asking to bare souls, I mean that gets pretty heavy. I’m just talking, it’s just enjoying company, laughing, wordplay is very pleasurable to me and I love jokes.

Martin, who had expressed interest in watching game shows on TV, said he'd been doing so for a long time and felt that ones like Wheel of Fortune and Jeopardy were educational, though he might only get a couple of questions correct before the TV contestants. To Jack, the inquiry was made, "Thinking of some of the activities you mentioned, artifact hunting, carpentry and such, what do you get out of doing those activities, aside from simply passing time?" He replied:

I've often thought about it. For instance, when you find an Indian stone point, or an arrowhead, when you pick that up, I don't know how to describe the feeling, but [speaking emphatically], it is awesome to hold in your hand something that maybe hasn't been touch for 10,000 years, and you try to picture...

I reflected, "The last person who touched it maybe?" He continued, "Yeah, the native or the Indian. But, yeah, just to hold that in your hand, I don't know how to describe what I feel. And I think some of that feeling is coming home and showing people, showing your wife." Once again I mirrored his comment, "To share the experience with others..." He concluded, "Yeah, yeah, uh huh. Sharing is very important."

Frank mentioned that for him, leisure and work sometimes occur at the same time. He commented, "I like to, sometimes I'm guilty of [having] combined work and leisure...like the last three years I have been coaching [track and field]." Norm, who spent some of his leisure time facilitating Man-to-Man meetings, mentioned traveling to other cities to see how other gatherings were conducted. He commented:

We tried to get around to different things, going to [mentions two city names]. I've enjoyed it, it's interesting. I don't know that everyone can find something that they would like to find in the Man-to-Man thing. Some men that are more at home, talking or not, about what cancer is about, others are still in denial, just never really have accepted it...

Norm also shared that ice hockey was an activity he had participated in when he was younger, and brought up the idea that competence in an activity may correlate with the enjoyment that is experienced. He stated, “Ice hockey, I was always good at it, and there was an ice hockey team there at high school, so I enjoyed that.”

Relationships

Norm’s recollection of his experience also serves as an example of how recreation and leisure help construct the context within which relationships with other people are either formed or maintained. Often times, those relationships pertaining to recreation and leisure are familial. Through relationships, additional experiences (leisure or otherwise) are fostered.

Alan spoke of driving and dancing with his wife; Charles enjoyed viewing art with his spouse. In thinking back to earlier days, Norm mentioned:

In my last two years, actually the last year and a half of high school, I grew interested in tennis. Actually, I really was interested in a girl who played tennis [shared laughter]. Through her companionship, I learned how to play tennis, and I went out for the tennis team, and made the team.

It was then asked, “Once you got married, and had a family, did the nature of your leisure or recreation change?” He stated, “Boating probably took over. We all liked to water ski. I taught my kids how to water ski, and we had boats to ski with, and we had places where we could ski.” When asked about how things changed as the children grew older, he responded, “Scouting began, and they became involved in Scouts, and Girl Scouts.” I then suggested, “I take it there is some type of satisfaction that comes from doing those things?” He replied, “Oh, I guess if there wasn’t satisfaction, we wouldn’t be doing it. To tell you the truth, I think it’s the satisfaction of doing it, it keeps you

involved in doing, opening the doors to other things.” When asked if the satisfaction he expected to get out of it was the motivation for doing it in the first place, he shared:

No, I think the satisfaction comes as maybe the second thing, through the back door. You do it, and then, like this trip [to a nearby city]... we [church members] started doing it a couple months ago, and we just like spaghetti, and so all of a sudden, the added satisfaction of having a good meal, and then people to enjoy with. I guess that satisfaction comes after the initial effort to do it in the first place.

For Ken, who suggested he was dissatisfied with his lack of a social network, friendships often came through and because of his spouse. He stated, “We’ve had a social life, but she has more or less been the source of that. I’ve made friends with people she’s made friends with.”

Antithesis of Work

Many men, in the context of describing leisure, made comments that led to categorizing one dimension of leisure as opposite of work, or paid employment. When interviewing Charles, the comment was made, “Most people don’t think about life in terms of what they do in their free time.” Charles replied, “No, no, they don’t. Unless they are a professional fisherman, in which case it’s no longer leisure, it’s a job and it becomes work.” Alan stated similarly, “You know, farming is fun, if you don’t have to make money at it. You know, if you can make a living at something else and farm for fun, then it’s okay, but if you have to make a living from it, it becomes a burden.”

Brian expressed, “Well, what is leisure? I like researching things. I don’t know if you’d call that leisure or not, if you take money for it, it’s not leisure.” He added his own question, “If you don’t make money from it, is it leisure?” Frank’s comments were similar to those already mentioned. He stated:

Leisure connotes to me, um, time outside work, you know. Now fortunately for me, I enjoy my work, which has always been very important to me. So it’s not a matter of enjoyment, but as I said, it’s definitely a time outside of work.

Norm was asked, “That word, leisure, what does that mean for you?” He replied:

[It is] the opposite of work. But, there are people that, not everyone, but it may have been the way the good Lord planned it, not everyone was destined to thoroughly enjoy leisure. Some people work, and they are so geared, that leisure is, it’s almost as if they have to be taught how to use it.

Other Factors Pertaining to Leisure

There are other avenues through which one can attempt to understand leisure behavior. Examining the motivating factors that lead to participation, the meaning derived from leisure and the barriers or constraints that restrict or alter the leisure experience are also valuable. The examples that follow, are shared to illustrate how leisure is further examined to get a clear and holistic picture of the experiences had by men in these circumstances.

Motivation and meaning of leisure

Comments made by men allowed insight into the motives that lead to selection of and participation in leisure and recreation, along with suggesting the meaning attached to those activities. Leisure motivation has been defined as something “that sparks an interest so powerful that a client would act in spite of pain, boredom, fear or poor self-esteem” (Shank & Coyle, 2002). The meaning attached to leisure as experienced by older adults is particularly insightful. Understanding meaning helps to answer the question, “What does the activity do for me?” (Settersten, 2002; Watkins, 2000).

Alan commented about some of his leisure interests by stating, “It’s hard for me to imagine an activity that doesn’t result in something.” For him, activity, including leisure, needs to have an outcome that is tangible – whether as something that can be seen and felt, or a desired emotional state. In talking about past free-time activity, he stated, “Sometimes just for relaxation, we’d just go out for a drive.” Nearing retirement, Alan

recounted, “People keep saying, what are you going to do when you retire?” and when asked if leisure is currently an important aspect of his life, he shared, “I look forward to having more of it when I retire here. And I tell them one of the things I am going to do is start working on that list of unfinished things I have, you know. I have a hobby of antique farm tractors.” When asked if that meant collecting them or restoring them, he replied:

Yeah, right, and I find out they take a lot of work, even when you have one in perfect shape, it doesn’t stay in perfect shape by itself, you have to keep looking after it, you know. You let it stand, and the first thing you know it won’t start.

Agreement was then made stating this hobby probably involved a lot more work than anyone gives it credit for, and Alan replied, “Well, yeah, and you learn, you know.” Brian also shared this general philosophy toward leisure -- that something tangible should result from participation. He stated:

If you don’t make money from it, is it leisure? I’m not quite sure. I guess if you’re doing, if you’re looking into something, and it’s not like prostate which is something that I have to do. But, something that I do well, for instance, for awhile I was examining the Koran and I could do searches for references to the word, like Christian, where I was curious about what the Koran said about Christians... so, if you call that leisure or not, I don’t know.

The comment was then made to him, “Okay, it sounds like you’re saying that leisure involves learning -- that you enjoy [something] when you gain something from it.” He replied, “Yeah, I don’t think of it as learning, but I mean, that I guess is unavoidable.” Before moving to another topic, he was asked, “Leisure is a part of our lives, we don’t spend a lot of time thinking about it, it just happens. But is there anything else on the area of leisure you would like to comment on?” He shared, “Well, I have my websites. I think that’s more as a cause, I suppose, but in a way it’s leisure. I have a large web site on the subject of legal reform.” I asked, “And, again, it’s leisure because?” He explained:

Well, I love it, you know, I enjoy it. It's a little disappointing because I don't know if it changes that much. I mean, it's, social structure is very slow to, um, in some areas I see movement, and then others I don't. I guess in a way, you might call that leisure.

For Charles, his explanation of his fascination for art began with his wife's interest.

He stated:

Through [my wife], we came in contact with lots of the Bohemian artist community. And I found it fascinating. I had never met that sort of people before. I mean, these people were really loose cannons, and were very successful. One of them, have you ever heard of the painter Botero?

I admitted, "No, I don't think I have." He went on to explain:

[Botero] painted black people. We could've bought for 500 bucks when we were down there in 1964. His stuff now is a quarter of a million bucks. I enjoyed that, and I found that I had an affinity for art, ah, it was a gut thing. I didn't understand why, and I got pretty good at it, I could call the good ones from the bad ones.

Sensing that Charles appreciated being in control of his environment and things within that environment, he was asked, "Control -- how important is it to you to be in control of what is happening?" He replied, referring to his experience with prostate cancer:

Ah, that is a very good question, a very good question. My control over what is happening to me was knowing as much as I could about the disease, about the treatment, then I could take it. That gave me power. I have always told, as I've talked to people about [prostate cancer], that knowledge gave me a sense of power. And that's how I went about it. Controlling, and when I want to control my life I want to be able to do things I want to do.

Drawing the conversation back to leisure, a comment was made wondering if he thought that control played a part in his choice of leisure activities. He replied:

Certainly, you have some sense of control over most of the leisure things that I can think of – sports, because you control the training, you do it yourself. I've always felt that some things you don't have control of. Yes, when I'm reading and I get leisure out of it, but is there control there? I don't know. It's always what you do with the information after you get it, I think. Fishing, or outside activities, you have less control of, other than preparation and experience.

For Darren, golf was stated as an enjoyable leisure experience. In the interview, he stated, “The best I ever shot on the regulation course was par. And I shot a 75 four or five times, and then the best golf I ever played was when I had 11 consecutive rounds in the ‘70s,” to which I replied, “Really? [That is] Tiger Woods’ type of consistency.” He commented, “Yeah, now you don’t get that, now playing golf is like playing poker, the Gods of golf will smile on you, or they won’t.” I agreed, “It’s either there or it’s not, and there’s nothing you can do about it?” He then added:

You bet. You stroke it through, you just keep stroking it. Now the pastor of my church, and I love him to death, he has all the necessary tools to be a terrific golfer. He’s got good upper body strength. But he’s the kind of guy who is well grounded, he’s not flighty or anything, but he’ll read a book about here’s how to do this, here’s how to swing, and if he gets out on a course and he doesn’t like that, and he doesn’t shoot par golf, he gets disturbed. And I said, the hell with you, you’re going to pay your dues just like the rest of us, you’re going to hack it around.

Frank, who was still working at the time of the interview, described himself as always needing to stay and be busy, to keep up certain habits and workaholic features. When it was asked how he would use the additional free-time that comes with retirement and his need to remain active and engaged in activities, he replied:

Yes, but by no means becoming an inactive creature. Activities for me, how shall I put it, personal satisfaction, psyche, etc., I am going to have to be active, mentally and physically the rest of my life. That is how I will be happy.

Harold was asked the question, “Are there any parts or times of your life when you’re involved in recreation or leisure activities that were really meaningful to you?” He answered:

Well, yes, in the recreational and playful, uh, leisure activities that I have had. I’ve had girlfriends that I’ve enjoyed being affectionate with. And, uh, that has a downside just as well, because of breaking up with all, so many different women. It has been a deep sadness in my life to say goodbye to all those people.

Meaningful, for Harold, brought up the idea that leisure and the activities experienced also included memories that are not always positive. To Irving, who shared an interest in viewing sports, it was asked, “What is it that interests you and intrigues you so much about these sports and watching people play?” He replied:

I guess it is the competition, the competition. Once you [see], and it doesn't matter, chess, it doesn't matter, I get fascinated. I give an example, I never played at hand of Bridge in my life, yet I read every Bridge thing in the paper. I play the game by watching the paper, and how I would play. And I suspect it wouldn't take me long to actually catch on and play myself.

Jack's attitudes toward leisure present other common views. During the course of the interview, he was asked, “I want to mention to you another term, and I'm interested to know how you define it, and that is leisure. What does leisure mean to you, what is it?” He said:

Leisure to me, this may not fit, but leisure to me is enjoying yourself whether it is making the yard look neat, or whether it is reading a book. Or walking slowly through the woods, or watching the sunrise or set - what I really enjoyed doing. Of course, if it is physically taxing, then it would be hard to call it leisure, but, if you are enjoying it then it would still be great.

The comment was then made that the activities he described, aside from visiting with friends, were ones that he could do or might do by himself, and he responded, “By myself?” I said, “Yeah.” He then mentioned, “Reading, carpentry work, cabinetwork, artifact hunting, taking care of the house, I do by myself.” When then asked if he preferred activities that were more solitary, he answered, “No, not all. I enjoy people. We have a monthly neighborhood TGIF,” which he explained was a function where different people took turns hosting neighbors for an evening of conversation and food.

Norm, whose experiences with a church group and traveling to eat at a restaurant added another piece to the meaning of leisure, shared, “Last time we were there, and

there were thirteen of us that went down...it will probably become a group, a church activity.”

When asked about why that activity was meaningful, he explained:

You get to be with people, people you enjoy. You get to know more about them as you recreate with them. You learn more about them than you would in a Sunday School setting, or even in a church setting . . . In most churches that I have been involved in, you have to get people away from the physical church and such to get to know them. And then you know more about them, and then the relationships in the church make more sense.

Further inquiry was then made about whether there is some type of satisfaction that comes from doing those things, and he responded, “Oh, I guess if there wasn’t satisfaction, we wouldn’t be doing it. To tell you the truth, I think it’s the satisfaction of doing it, it keeps you involved in doing, opening the doors to other things.”

Various reasons motivate people and factor into their decision to participate in specific leisure activities. For Alan, who mentioned an interest in antique farm tractors, doing so was something that derived from experiences earlier in life. He stated, “But I told my wife, if I’m going to buy a tractor, I might as well buy one I used to drive when I was a teenager.” Activities that provide a link to the past may serve as greater incentive for participation.

For Charles, who cited a love for books and good music, stated leisure meant seeking tranquility, and obtaining certain physical and psychological outcomes – some apparently to offset consequences of treatments for prostate cancer. When asked, “What does it [leisure] mean?” he answered:

Tranquility. I’m talking to myself as I’m working in the garden. I started working out now, working out getting my body back in shape. I want to make my body attractive, I don’t know why, because there is a tremendous amount of emphasis there. My body has to look good – I’ve lost 20 pounds. I work out three times a week with weights and I do three miles three times a week, also. I can’t jog, but I can jog the last half mile. I gotta get my body down so that it looks good in the

mirror, and so that my wife finds it looking good, too. She is a very thin woman, a very good-looking woman. And I just, it surprises me that she found me attractive when I was pot-bellied and was overweight by twenty-five pounds. Now that I have this impotence sort of problem, that's important and I find I want to make myself attractive, it doesn't make any sense, does it?

When asked about his motivation to resume leisure activities soon after receiving treatment, Charles was asked about being able to resume activities of his choosing. He commented:

There was never any question in my mind that I was not going to be alright. I don't know if others feel that way, but I didn't think I was going to be in bed, incapacitated the rest of my life. It never entered my mind that things weren't going to go back to normal -- or, as normal as it could be.

Frank, who spoke of his dedication to family, was asked, "Do you do particular things with your family that would be considered leisure or recreation?" He replied:

Oh yes, I do. I did more, but again, as I indicated earlier, my life has changed, and there are times when I am busier than others. I like to, sometimes I'm guilty of, I have combined work and leisure. I have to consider, like the last three years I have been coaching. In some respects that was leisure because I had to take time away from this task [teaching] to do that, and I did it because I enjoyed it. I also did it because it gave me, I mean the main reason I did it was that they gave me an opportunity to do something with my daughter, something that she wanted to do and to help her do it.

When prodded for what he thinks about leisure, how he experiences leisure, he commented:

I would eventually like to get my life back to the point where I can do the things that I strictly considered leisure. Like I like to go out, to be able to leave the office and *leave the office* [said with emphasis], and go home and sit down, and whether I watch TV or visit with my family, you know, without 10 million other things being on my brain, you know, thinking how much, what papers I have to grade or what tasks I have to do. Going to a movie, I go to about maybe two movies a year. Not that I can't enjoy them, but it's an important part of my makeup; obviously, I don't sit still very long.

For Gus, leisure was mentioned as often encompassing reading. I asked him, "You mentioned reading a lot -- is that reading tied to your church?" He commented, "Yeah, it

still is, theological books,” and I followed up, “Do you read outside of theological books?” His comment, “Not very much. I’m quite fascinated by them, particularly some of the new issues that have come up, to see how theology deals with it,” carried with it meaning as to how his leisure past-time of reading carried over from work.

Harold, when asked about preferred leisure activity, responded:

The best recreational activity would be to be a pioneer and that kind of thing -- cooking out-of-doors, sitting in front of a fireplace. When I cook out-of-doors, I don’t use gas, and I don’t use charcoal, I use wood, regular wood. So I like the primitive type of camping.

Norm shared his reasoning behind participation in spending portions of his free-time working with the American Legion. He stated:

I never, I never dreamed of becoming the commander [he laughed]. I pushed it off two or three years, but the delegation came to my house one day and said, “We’re very serious now, we would like you to be our commander.” I said, “Well, you’ve been after me for three years, maybe this is something the good Lord wants me to do, so sign me up.” And I’ve been doing it ever since.

Constraining variables

Just as certain things (intrinsic or extrinsic to the individual) motivate people to participate in leisure, other factors can be identified as a barrier to leisure activity and are viewed as constraints. These are things that constrain or prevent participation in a manner that otherwise would occur, were it not for something tangible (i.e., lack of transportation) or intangible (i.e., a negative attitude or regulation; (Jackson & Scott, 1999).

Alan recounted that his wife had said to him on one occasion, “Why don’t you learn to play golf or something?” And he mentioned to me:

Well, for one thing it’s an expensive game and for another thing it seems to be a consuming game for those who get into it, you know. They have to practice, they have to do this, and for another thing you spend all that money for a bag of tools that don’t do anything, you know.

The need to see a “result” after an activity is an attitude that makes it so that Alan only chooses from certain possibilities, which may not be a constraint, inasmuch as it helps him refine his choices to certain ones that will produce the outcome he desires. Speaking of a time earlier in his life, Alan also identified another barrier to leisure that many people encounter -- that of financial limitation, or a lack of money. He mentioned, “The fact is we did not have much money. You know, overseas clergy were at minimum and the house, every expense of living was higher there, you know?” Brian suggested the same constraint also impacts how much time he spends in certain activities – that money has been a factor in choosing and participating in free-time events.

Another constraint or barrier to leisure, as well as returning to gainful employment, experienced by several men was that of incontinence. Alan stated:

Yeah, still now. Uh, I thought I could take a trip. Now with this urinary container, see with a van you can stop the vehicle, drop on one knee, and there's the space between the seats, you can empty your bladder, close your pants, get out and gas up the van, get out and do whatever you were going to do, and uh, so I figured that out, and uh, I went on a trip for two or three weeks I guess. I picked up my brother, we went out to [Midwestern state] and back and I got pretty good at changing those things and looking for places where I could change and stuff.

Alan was then asked if he was able to resume life activities as normal, or if there were significant changes. He replied:

Yeah, I came back to work in two months, and actually, I think it might have been better if I had come back half-days. I could have come back to work sooner if I could have worked half-days. That would have been the wisest thing because I found out after noon I got so tired.

Speaking of times when he would talk to other men facing the uncertainty of prostate cancer, he said:

And back when I was wearing pads [to help with incontinence], I told them, “I’m wearing pads, and well, that’s not so bad.” So, one guy said that he wouldn’t be able to go out of the house until he can hold his urine, see. And there are some guys, you know, that stop going to church, they stop going to movies; those are

things where you do have to watch out for, because you sit for a long time. But, I don't recommend the condom catheter and bag to men, because they say, psychologically, while you are trying to get control, don't wear them because, psychologically [he made a motion with his hand to the location of where a catheter/bag would be] this says, "I'm safe now, I won't leak."

Alan also mentioned a problem that some men have if they sit too long. He said:

Yeah, okay, well I learned with pads, don't sit still too long. If I attend a lecture, I make sure I shift around on the edge of the chair or stand up a little bit or something, because if I sit there for forty minutes and stand up, that stream of urine hits those pads. They absorb alright, but sometimes they don't absorb so fast.

Charles spoke directly about how prostate cancer had impacted some of his leisure activity and, like Alan, mentioned the art of sitting just right. He stated:

How has prostate cancer affected me? At first, very much so because the incontinence -- it interrupted your trips, your travel. [When] travel[ing] you had to deal with pads, or with things that were inconvenient. Ah, if you are driving, and there is a tendency when you drive, where you're sitting, how you sit affects your bladder, and after thirty miles you hope the state you're traveling in has comfort stations.

When it was mentioned that he earlier stated knowing where every bathroom was, he said, "Yes, and every single station between here and [mentions a Midwestern state]. That, that was difficult because you, [pause] it restricts your pleasure in traveling – the discomfort, the uncomfortableness of travel, the inability to travel at ease, that sort of thing."

A later statement demonstrated that this constraint to his leisure past-time of travel was alleviated. He commented:

Traveling the United States is expensive, you'd be surprised. But I really enjoy that, that is real leisure and it [the cancer] doesn't impact that any more. It did for the first year and a half, we were very restricted, carrying pads along and finding out where every bathroom was.

Charles, who also experienced radiation treatment for his prostate cancer, suggested another potential constraint – fatigue. He stated:

To me leisure is reading, walking, working out, jogging, fishing, finding out about what happened in New England, that sort of thing. And after the initial six months, where you are still recuperating from the treatment you have had, the radiation -- it doesn't impact you right away, but it really makes you very weak. And then, there are all the problems with urination which I had, the urine blockage where I had to self catheter for six weeks. There was no leisure, because every six hours I had to go in and self-catheter myself in the bathroom.

For Darren, he cited physical concerns, other than the prostate cancer, as ones that can and do impact people, particularly older adults. Explaining a condition on his hands, he shared:

Both of my hands have been cut to pieces within the last five years. [Reaching out his hand] You see this knot right here? [I nodded] That has come back since they did the operation, but the whole palm of my hand used to be covered up with those, and the contracture draws your hand in like this. It's genetic -- my father had it, my older brother had it, and two of my father's brothers had it.

He was then asked if he felt the treatments he had received had been successful. He smiled, and stated, "Oh yes, as far as function. I lost the grip of my golf club, but I can adjust to that." When asked if the prostate cancer treatments had impacted his leisure [he was interviewed just a couple of months following the last of his radiation treatments], he said, "Um, it has, I haven't played golf," to which I followed up by asking, "Due to that experience?" He responded, "Yeah, because it's, uh, first off, I found it very debilitating. Especially the medications they were giving me; the fact that I have little or no warning...[he paused]," and I suggested, "For bathroom time?" He then continued:

Yeah, boy, the amount of pleasure you get out of it, but when you can do it. I'm getting more and more, like in the last week I have done more, but I told my wife, I said, "I am going stir crazy." My yard has gone to hell.

Within his experience, Frank mentioned that time, or that absence of free-time, is something that constrains his leisure. He was asked, "When you are resting, are you just simply resting or are you doing something while you rest, like reading or listening to music?" He replied:

I don't have very much time to do that. And as I said, I am, you know, rest and eating in some respects could be considered leisure, but to me they are more, if I don't do those two things, and about the only two reasons I do them most of the time is to be sustained and survival.

Gus also spoke of how being busy at times caused a lack of time with his wife and that he "didn't have time to go out to dinner or take in a movie." His experience with prostate cancer created other difficulties. He stated:

I lost all control of my bladder, I became incontinent, and really seriously incontinent -- for a while I couldn't play golf...I didn't want to play, it was too embarrassing. I still have that problem. I haven't played seriously now for a month now, because I can't take in enough liquids. Between July and October [realizing he lives in Florida's heat and humidity], I don't play golf -- that's a new thing for me.

He also spoke, as did others, about incontinence creating challenges never experienced before. He said:

And just not being able to feel comfortable going to functions, a lot of things that I might go to, or with people that I, [but] because I was going to the bathroom, to the men's room probably every 20 minutes, and, you know, I never had to do that before.

Ken, who had experienced other health problems previous and concurrent to his being treated for prostate cancer, mentioned enjoying gardening. He said he used to grow, "Beans, okra, carrots. I had a plot, about ten by twelve -- a few rows in it, with stakes in it for things to climb on. [He laughed] The birds were very aggressive." Agreement was made by saying, "A constant battle I imagine to keep them out of your stuff," and he lamented that other challenges were part of his life:

But I finally took all that stuff down, I took it all out. So, really, my big problem is just getting stuff and things done. I've spent a lot of time [he paused] I'm seeing a shrink right now, but this is one thing that I am trying to overcome, this fear of failure. Fear of doing something, even a little bit wrong.

When asked about what he was describing as a high-pressure, stressful environment, he replied, "I created a high-pressure, stressful environment." It was

mentioned, “You say you created it?” and he agreed, “I’ve created it, and feel I would go through hell to make sure it was alright.”

Norm was asked, “What types of things have gotten in the way of you doing meaningful leisure activities?” He replied, “Mostly, time. I mean, I’d have to say, not that my calendar goes from eight in the morning till midnight; it’s a pretty busy calendar. We both enjoy life.” A probing question was then asked about things he could do taking on a greater importance because of what he might not be able to do, and he answered, “Yeah, I can see that working, I hadn’t thought about it. I can begin to see it working in me when there is going to be that time when I’m going to want to do more things than I can physically do.”

To summarize this section on the many faces of leisure, this phenomenon, like quality of life, is a concept with varied possible interpretations. Leisure was explored as multi-layered and included elements of: (a) time, (b) activity, (c) participation and involvement in life experience, (d) experience as part of relationships and (e) leisure as opposite of views regarding work. In addition, other aspects that interact with the leisure phenomenon, such as motivation and the meaning of leisure, along with possible constraints or barriers and potential constraining variables, were illustrated.

Older Men’s Lives – Discussion about Leisure Attitudes and Behavior

Consistent with most studies that have explored leisure and its meaning for older persons, men in this study saw recreation and leisure as congruent with their quality of life (Godbey, 1999; R. Mannell, 1999; McGuire et al., 1999). As is shown in Figure 2 below, quality of life and leisure, as separate categories, shared many of the same conditions and properties. Properties such as values, relationships, health, activities, and participation are illustrated as sharing connection with both quality of life and leisure.

The concept of *roles* is shown as an exclusive feature of the conceptualization of quality of life, as are *time* and *antithesis to work* independently connect to the leisure category.

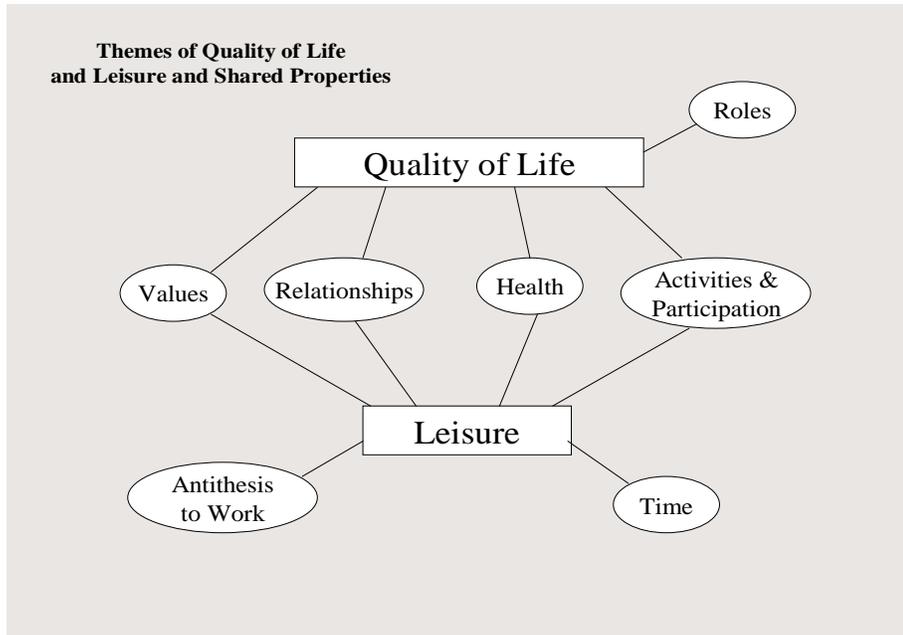


Figure 2 – Shared Properties of Quality of Life and Leisure

Men in this study used different words and defined leisure differently. As a whole, the myriad ways leisure has been conceptualized in the literature was evidenced by men in this study. For example, leisure is sometimes viewed simply as free time and how time is used. In this study, Gus described leisure as “how I spend my time.” In order to relax, a generally accepted outcome of leisure (Goodale & Godbey, 1988), Irving stated leisure was a matter of “finding time.” Similarly, Leroy shared, “Leisure, I think, is how I spend it,” that it is “spare time.” Norm expanded this notion with his idea that leisure is “time,” consisting of “the ability to use that time in the way that is most pleasing.” Leisure is made up of concepts such as attitudes and behaviors, and is a central component of the quality of life of older men (Freysinger, 1999). Its importance does not diminish for changes in health status or when confronting the possibility of disabling conditions (Roehrer Institute, 1989).

Literature has also spoken of leisure conceptually as a set of activities (or certain behaviors) that are done for any one of a myriad of reasons. They can be done for the sake of diversion, perhaps relaxation, or to achieve an outcome such as improving relationships or becoming physically fit through exercise. Many activities are done for the sake of being involved in life events or achieving an outcome that is seen as desirable (Driver, Brown, & Peterson, 1991). For example, as mentioned above, Gus used leisure to relax, just as Charles viewed leisure pursuits as an avenue to “tranquility.” Alan stated, “It’s hard for me to imagine an activity that doesn’t result in something,” seeing leisure as the opportunity to be productive. For Alan and Darren, who both cited previous involvement in leisure of a more physical nature, participation had changed to seeking outcomes that were more centered around simply enjoying watching others or being with loved ones. For example, Darren stated, “As far as anything active, swimming or anything like that, I just don’t do it anymore,” but that he liked to “watch sports” and that having functions such as Christmas or Thanksgiving allowed for interaction with loved ones. For Eric, making furniture was a similar experience, one that often included “designing many of the pieces” he made. For Charles, leisure was a matter of time spent exercising, aiming to achieve a greater degree of fitness, and increased physical attractiveness. For Ken, gardening was more than simply “something to do,” it was “to make things grow.” Frank described his leisure as key to “personal satisfaction,” to the well-being of his “psyche.” Jack described leisure as “enjoying yourself, whether it is making the yard look neat, or whether it is reading a book.”

Several men reported that too much physical exertion decreased an activity’s role as leisure. Jack stated, “If it is physically taxing, then it would be hard to call it leisure,”

despite it still being enjoyable. Brian, relating his experience as an English teacher, commented, “If you don’t take money from it, is it leisure? I’m not quite sure.” This type of statement lends credence to the belief that leisure is not something that one is financially compensated for. Receipt of money for participation in any activity is believed to likely and dramatically change the psychological appearance. Leisure science has often noted the differences between activity done for the sake of the activity and what occurs when financial remuneration takes place (Mannell & Kleiber, 1997).

Published scientific literature has also sought to understand leisure as a state of mind – one where a person can escape from stress that may be present in everyday life or spend time contemplating priorities and meanings regarding one’s life (Roger Mannell & Kleiber, 1997). This may be seen in the mere expression of the emotion that emerges from leisure involvement. This type of view toward leisure was also evident in the findings of this study. A common term used to describe leisure was “enjoyment.” Alan described leisure and his tinkering with the piano as something “therapeutic.” Charles stated liking movies, “If they can get to me emotionally.” Obtaining emotional outcomes was often a motivation for men (Godbey, 1999).

Recreation and play, as concepts different from leisure, were defined within Chapter 2. Questions posed to men about leisure led to data illustrating that some men’s attitudes were consistent with common definitions of recreation and play, in addition to the traditional understanding of leisure. Recreation is defined as activity that is more structured, likely includes more of a physical component, and is often done with or in the presence of others. Recreation typically has externally-reinforced consequences, such as a declared winner or a new personal high score (Godbey, 1999). Using this definition, this

study contained numerous examples of men's free-time involvement being viewed as recreation pursuit. For example, several men cited their interest in golf and their desire to perform well according to the rules and structure of the game. Eric's desire to design and create furniture, along with Alan's consideration of building bird houses, is consistent with a recreation perspective toward free time use. Likewise, Charles' and Ken's interest in gardening and Frank's love of running all are activities that have a physical component complete with external reinforcements by which they are able to measure the results of their involvement. It is also important to point out that data provided examples of how participation in the same activity by different men had varied motivations and different outcomes. Likewise, an activity can be described by one man as meeting the definition of leisure, while another man participating in the same type of activity may talk about it as recreation. For example, as shared before, Martin talked about being out and doing yard work. He stated:

Well, leisure, that means that I would have pulled up a chair, and sit down and not do a thing – you know, we'd all sit there. But this was more like recreation, we got out and just, being active, and cleaning up.

Play conceptually occurs within activities that have inherent traits of behavior that are spontaneous and carefree (Ellis, 1973; Godbey, 1999). Although recreational aspects of leisure-time involvement were found within the data, there were very few indicators that older men engaged in play, as defined above. The scarcity of examples of play may be due to men's experiences. Their recollection of activity as "play" may less likely occur because the term "play" is often believed to be something that children and younger people do (Eisert & Lamorey, 1996). Leisure, as viewed and participated in by older adults, tends to not include descriptions that involve being carefree and spontaneous. Free-time activity that might be considered as play include Harold's interest in singing,

Brian's plunking away at the piano, and Irving's "playing" bridge via following along with newspaper accounts. Jack's experience with discovering Indian stone points may capture playfulness in that it produces spontaneous moments of elation and satisfaction. Even structured activities like golf may produce moments of play as participants experience moments of carefree or light-hearted pleasure, ingredients thought of as part of "play" (Ellis, 1973).

Leisure has been explored in terms of its relationship to retirement, as people (often 60 years of age or older) experience a transition and as certain types of activities become more salient (Freysinger, 1999; Tinsley et al., 1987). It was mentioned in Chapter 2 that research suggested that men who experienced less change within their leisure adapted best to their retirement (Long, 1987). Sinick (1980) stated men's attitudes when confronting retirement ranged from anticipation and excitement to varying degrees of anxiety and fear. This study supports the notion that some men view retirement as a chance to devote more time doing activities they have great interest in, while others encounter a sense of loss or identity and a certain emptiness.

McGuire et al. (1999) has emphasized the importance of activities as part of successful aging, stating that different types of activities typically produce different benefits. Furthermore, it has been theorized that activities that are perceived as productive and social in nature result in increased functioning and longevity for older adults (Settersten, 2002). Harold's participation in singing with a Barbershop quartet, Irving's and Alan's volunteer work, and Charles' and Norm's involvement with Man-to-Man meetings all indicate a desire to maintain productive involvement. On the other hand, activities that are of a more solitary nature tend to have greater psychological benefits,

produce continuity, and foster renewed meaning about life (Herzog et al., 1998).

Examples of this include Eric's and Jack's involvement in the out-of-doors, Leroy's and Martin's enjoyment of television, and Alan's continuation of his involvement with the restoration of farm tractors.

CHAPTER 6: MEN'S EXPERIENCE WITH PROSTATE CANCER

Men within this study shared their experiences with cancer using their own words, each from within the backdrop of a unique, individual life. Many spoke of similar issues and feelings, but usually in different terms. Others spoke of divergent topics, but used common means of expressing emotions and ideas. This chapter illustrates the words of men interviewed in sections labeled: (a) reacting to the diagnosis of cancer, (b) selecting treatment, (c) coping with physical side effects, and (d) coping with psychosocial side effects. Discussion of this data and its impact on leisure attitudes and behaviors is found later in this chapter. Note that some of the same statements or quotations from participants may be provided within sections that first tell the overall story of men's experience with prostate cancer, followed by sections wherein discussion occurs.

Reacting to the Diagnosis of Cancer

When asked how they reacted to the news of being told they had prostate cancer, some men stated feeling horror, others remained calm; some acted with hesitation, others with haste. These reactions were predicated by things such as the information they had at the time of diagnosis, the degree to which they felt they were at risk, and the surrounding context of their life situation (e.g., health status and relationships). It should be noted that the duration of one's reaction to the diagnosis is a difficult thing to measure. Emotional and psychological reaction to the diagnosis often blended with reaction to finding out about treatment options and reaction to discovery of likely side effects of varied medical approaches. Thus, this theme or category of data will include reactions to incidents

throughout the entire experience of dealing with prostate cancer. Men's comments are organized based on themes of shock and denial, anxiety, depression, and calm and acceptance.

Shock and Denial

Many men indicated feeling some element of shock when they got the news of having prostate cancer. Gus replied simply to the question, "What was your immediate reaction?" with a one word answer, "Horror." Darren shared:

It shook me up and, because I just never had had much problem before . . . they took eight little pieces of flesh from the prostate, four were benign and the other four were malignant. And, you could have knocked me down with a feather . . . when she [a health care provider] told me that I had prostate cancer. It had far more effect on me than anything that had to do with my heart, or the aortic aneurysm, it had far more effect, and I think it's the "C" word, I think. I grew up a long ways back. When you heard somebody had cancer, he could start writing out their epitaph, you know. But, you know, and of course medicine has progressed, the technology and what have you has progressed so much since then. But, I think it was just that "I have cancer," and boom!

Darren also stated that this immediate reaction was soon followed by assurance.

When asked how long his reaction of shock lasted, he reported:

It lasted, in fact I had trouble walking out to my car, but when I got there to the car, I sat there for awhile, and I said, "Alright boy, what are you going to do about this?" I said, "You can't walk around like this the rest of your life." And [mentioned my name], I bowed my head and prayed, and I said, "God I'm not strong enough to handle this, and I'm going to put it in your hands." And I picked up the phone and called my wife, and told her. But I've never really worried about it, since then.

Frank, with a family history of prostate cancer where a brother and his father had died due to the illness, was ready to act when he got the news. His comments also address the fact that the diagnosis often affects more than one person – its impact is felt by others.

He said:

Hey, I want this thing out, [and] this is the route I am going to go. And if I'm going to do it, let's do it now. I want the first available opportunity, that's what I stated.

And my doctor suggested self-depositing blood, so I immediately started going to the blood bank. And then, of course, there was the whole thing of dealing with first my family, my brothers and my mom. She, going through the whole thing with my father. I am, my mom lives here . . . and I'm the one that is closest to her in terms of doing stuff. And I was the one, when my dad was alive, that was commuting back and forth doing stuff, every weekend and sometimes several times a week. And so it was hard on both of us. And for her to even, although things were positive, if something were to happen to me, it was very hard at first. And when the surgery was, it was like she was going to be here, I knew that. My wife, you know, said [to his mom], "Oh, you don't have to come." [He laughed and stated very matter-of-fact], oh, she was going to be here!

Some men recalled their reaction as one more aligned with not wanting to believe what they were being told. Alan reported:

Well, I was a little surprised, I guess. You know, denial sees you through a lot of things. Even though I was doing the most obvious things for prostate cancer, you know, I mean, uh, it's like it wasn't real until you get the report . . . I don't know, I guess there was still denial with it, you know, even while I was planning treatment.

Recalling his opportunities to talk to other men facing the same news, he said, "I know when I meet patients here [Alan worked in a hospital setting] and I say to them, you know, and they just recently have had the diagnosis, and I say to them, you know, I remember that sinking feeling right here [gave motion with hand pushing down from ribcage to stomach] when the doctor said that."

Anxiety and Depressive Symptoms

Early stages of coding revealed that half of the participants reported feelings of anxiety or uncertainty as a part of their experience with prostate cancer. Emotions labeled as anxiety and uncertainty associated with other aspects of the prostate cancer experience (i.e., selecting treatment or coping with side effects) are discussed later in this chapter. Relative to anxiety stemming from learning of his diagnosis, two examples are offered. Brian recalled his experience and his feeling within his reaction, "Oh, I've got cancer." After I stated, "That 'C' word . . .," and he said:

Yeah, it's the "C" word, it's cancer I was quite worried about it for a while So, by all rights, if I had done what most people think, "Oh my God, I've got cancer, I've got to get this thing out of me," you know? So they go for surgery or radiation or something. It didn't affect me that way.

In later discussion about how he thought prostate cancer or treatment might affect his sexuality, he commented, "I think if I really thought about it, I would not be much concerned with that since I'm 65 and I'm probably not going to get married, so it's not much to worry about." Herein, his age and relationship status and the latter's apparent connection to opportunities of sexual expression, impacted on his perception of whether or not the issue was one to cause anxiety. Another participant spoke openly about his experience being akin to depression, albeit short-term. Frank's reaction to having prostate cancer was described in the following manner:

I probably took it as well as most, I guess, but it was emotional. It sent me on a new emotional. . . . [pause] I very rarely get anything close to depression, I'm a pretty upbeat, what you see right now is pretty much normal, how I've been most of my life. But I, it sent me on an emotional roller coaster. I began to question, "Why me? What had I done to deserve this? Did you desert me Lord?" You know, and I cried a couple times, you know, it hurts, you know, I don't cry easily. You know, the whole gamut.

Wondering how long these emotions lasted, he was asked if he worked through it over time. His answer, "Yeah, pretty quickly too," illustrates the short-term nature of his rather intense emotional state.

Calm and Acceptance

Several men, granted time may have softened their recollection of the intensity of initial emotions felt at the time of hearing their diagnosis, reported they accepted the news with relative calm and assurance. When asked about the time he was told, Martin replied, "When [the doctor] told me that they did find a cancer in me. And, ah, you know, it's not a death sentence." I checked in, "That's what they told you, or" He replied:

No, this is what I'm thinking, you know. If I'm not mistaken, I believe he said, "It's not a death sentence." You can, I'm thinking that the doctor said, "It's not a death sentence, because you have prostate cancer, because there are things that can be done."

Charles accepted the news in more of a matter-of-fact manner, and other reactions came from a motivation to learn more about the illness and possible ramifications of treatment. He recalled:

So, I had my biopsy, and it was positive. I had, uh, but even then I wasn't terribly concerned, I keep my concerns very internal, almost so, I have a very laid-back look about myself. But I started to, the doctor, an unbelievable urologist, he recommended that I learned about as much as I could about the disease. Go to a support group, Man-to-Man.

I followed along, saying "[To] hear what they have to say?" He agreed:

Hear what they have to say, sit in on their conversations and, I started reading, but not too fast. But what picked me up was going to the Man-to-Man discussions. Hey, this has some consequences that are not too attractive. The more I read, the more I read, the more I talked -- about that I've got prostate cancer and I've got to find out as much about it. I was very undecided, but it was still no fear. No "Why me?" No anger, nothing like that. It was just finding out about it It was not a big thing, it was, uh, it was, "Okay, let's find out about it, let's do something about it."

Norm, however, was not caught totally off-guard. He stated, "It [a prostate cancer screening] was being followed by my regular doctor for almost three years, so it didn't come to me as an overnight shock."

Harold's recollection of events was similar. In our conversation, it was stated to him, "You're diagnosed with prostate cancer, what effect did that have on you?" He stated, "Oh, I thought, 'How serious is it?' And, 'What can I do about it? What can I do to save my life?'" Ken expressed a similar reaction, [he laughed] "Well, I got to get after this one." Leroy shared, "I remember what I thought, I asked the question, 'Where to from here? What do we do next?'"

Spousal Reaction to Diagnosis

Some men shared information about how their spouse reacted to the news. Frank stated, “My wife handled it better than I [he paused],” and I asked, “In terms of what?”

He explained:

Well, I mean, she was very supportive, she’s always been there. I mean she kind of reacted to me. And, you know, we talked, and of course then, you know, you’re dealing with all the doctor’s talk about the two “I’s” -- you know, impotence and the incontinence. But, [he] said that this can be dealt with. You know, typical urological speech. You know, she rolled with it very well.

Irving also spoke of his wife’s response by saying, “She was always involved, but when it happened, I wasn’t too worried.” It was then reflected back to him, “You weren’t too worried about it? Okay,” and he continued, “At that time. But I was unsure, and what was I going to do about this?” Jack shared a slightly different experience when discussion changed from the reaction to diagnosis to “What now?” and “What do I do about it?” He stated, “Of course, my wife was devastated by it, because she has had cancer on both sides of her family, I mean a lot of cancer.”

Discussion about Men’s Experience with Prostate Cancer

Men who are diagnosed with prostate cancer and go through the process of selecting and receiving treatment are known to have to cope with a variety of factors that might impact their physical (e.g., Bacon, Giovannucci, Testa, & Kawachi, 2001) and psychosocial well-being (Kunkel et al., 2000). Given the qualitative nature of this research, findings of this study provide illustration and narrative about the physical and psychosocial side effects that do occur after prostate cancer treatment.

The previous two chapters contain extensive narration of men’s experience from when they were first diagnosed, the process of selecting treatment, receiving that treatment, and the side effects encountered. As was discovered, and given place on the

model created from this study, older men who were interviewed were unique individuals in unique situations. For example, the status of their physical health, the nature of their relationships, and their past and present medical conditions all interacted with their individual cancer experiences to create a sampling of what it is like to undergo these challenges.

As described briefly at the beginning of this chapter, categories (themes) emerged from the data. Themes were formed around the phenomenon of men's reactions to news of their diagnosis and the emotions encountered throughout the experience, in addition to how they went about selecting treatment and the role spouses played in these situations. Other themes of side effects based on physical problems and psychosocial side effects were also formed.

Several men stated experiencing a rush of emotions at the onset of their experience. For some, news of the diagnosis brought horror (Gus), for others it produced shock (Darren). Alan stated that, "Denial sees you through a lot of things," and Brian and Darren each referred to sensing the stigma associated with cancer. Frank reported his reaction as being sent on an "emotional roller coaster," one that took him "close to depression." Charles' experience initially was calm, that he "wasn't terribly concerned," that he adopted an approach of, "Let's find out about it, let's do something about it." This was similar to Leroy, who stated, "Where to from here? What do we do next?"

While men's accounts of their reactions to their diagnosis, including thoughts and feelings, can be viewed independently as sub-themes, things such as anger, anxiety, or frustration exist as properties of larger categories (i.e., psychosocial side effects). Whether a person experienced a little or a lot of a particular emotion varied and indicates

the further need to explore each theme's dimensions. For example, one dimension might be a short duration of anxiety versus another dimension of a chronic, long-lasting episode of worry.

Selecting Treatment

The process men engaged in to select treatment for prostate cancer is important to explore. Just as reacting to the news, "You've got prostate cancer," brought varied reaction and emotional states, each man's approach to gaining information and formulating a decision of how to proceed was different. Brian, who actually chose against active treatment and opted for watchful waiting, when asked about the decision process replied, "The process?" and I said, "Yeah." He responded, "Well, okay, I guess that's a very elegant word for it. [Mutual laughter] It's not really a process, anyway." Brian then took a couple of minutes sharing some of his thoughts about what, for him, didn't feel much like a process. When asked how knowing about side effects played into his decision-making, he commented:

Yeah, I look at things and their probability. I know there are people who, when they are told, "You have prostate cancer," they will think, "I've got to get this thing out of here. I've got to get this thing out of here." That doesn't bother me. If I can contain it, the psychological impact of having "cancer" doesn't bother me that much. It's just all a matter of what is the best approach to treat it, whether it stays in me, or whether to get it out.

Brian also stated:

And my PSA at that time was pretty low, and then I went to literature and I said, "Well, I've got some time here." And I didn't want all of the possible effects from an operation, the incontinence, the bowel problems, etc., etc.

The acronym PSA stands for prostate specific antigen and the use of this acronym refers to blood tests done to monitor the existence or growth of any cancerous tumors. In his statement, Brian described feeling that he had time to wait, to see what transpired and

what newer medical approaches and knowledge might become available to meet his needs. Referring to the likelihood that he could stall the serious need to seek treatment, he stated, “I figure there is a very good chance that I can jump from one piece of floating debris to another piece of floating debris.”

When Charles was asked how he went about selecting treatment, he talked first about events leading up to his diagnosis. He described:

Every six months, every year, I was having my [PSA checked], in ‘92 I would’ve been fifty-four [years old], so I bumped into that, getting my PSA’s. And I followed [its] course, it went up slowly. Right before I retired in ‘96, it had reached 5.5 or 6.0.

A question was then asked, “So it went from 4 to 2 and then slowly started increasing up to 5 or 6?” He answered:

Five or six. And, I’m still unaware of the significance of prostate cancer. I remember a doctor telling me at one time, “You know, men are going to get prostate cancer. It’s one of the easiest things because it’s very slow.” He said, “If I had a choice of cancers, I would choose prostate cancer [shared laughter].” I don’t know that I would make that kind of statement By the time we settled down [into retirement] and found a urologist, it [the PSA] was elevated. It had gone to a little past 6, and the doctor recommended a biopsy, and this was right at Christmas time, so this was not a good time to be going through a biopsy and things. So I said, “Okay, I’ll wait till after January.” Luckily, I mean I was going to go on and even wait more, and luckily my son-in-law’s father was a doctor and he said, “You don’t want to put this thing off, this is serious.” So, I had my biopsy, and it was positive. I had, uh, but even then I wasn’t terribly concerned, I keep my concerns very internal, almost so, I have a very laid-back look about myself. But I started to, the doctor, an unbelievable urologist, he recommended that I learned about as much as I could about the disease. Go to a support group, Man-to-Man.

As has been stated earlier in terms of Charles’ reaction to his diagnosis, he pursued attendance at Man-to-Man discussion groups and gained information from other men’s experiences that some of the potential consequences of prostate cancer and its treatment were “not too attractive.” This led to more reading, and more talking, and the realization

that, “I’ve got to find out as much about it. I was very undecided, but it was still no fear.

No ‘Why me?’ No anger, nothing like that. It was just finding out about it.”

Charles shared parts of what he learned about the various treatment approaches and made a comment that offered insight into a perspective including priorities:

It’s not that this is better than anything else -- what you’re interested in is your satisfaction in your treatment. I think that’s important. After that, there’s not a whole lot you can do. I hope that you never come down to it, the selection process and the side effects are not pleasant. But there are other things in life.

In sharing more about the things he read about prostate cancer, he stated, “I started reading on it, and, my gosh, I became concerned. They kept talking about two things. One was incontinence and the other was impotence. And that concerned me. I said, ‘You know, where do we go from here?’” Charles talked more about what he saw and heard from attending Man-to-Man meetings:

I’m not saying there were horror stories, I’m glib with words, it’s not horror stories; people were asking questions and they were being answered by people. I was just sitting back listening, because I didn’t have questions at that time. Most of the people had had radical [prostatectomy], and they’ll talk about impotence and incontinence, and . . . that started sinking in to me what the possible consequences were going to be no matter what procedure I chose.

When asked, “How serious?” he stated, “Serious? Not in life-threatening, but the side effects were not going to be pleasant. And one of these things, man, I thought, it’s not going to happen to me.” He continued:

After the first couple of meetings, and then the second couple of meetings, it started sinking in. And at that time, I told the doctor that I wanted a radical. I hadn’t read very much, but it seemed like this is one way that I know it’s going to be out, and so on and so forth. And the more I found out [that] the people with radicals are the ones most outspoken, with the strongest side effects. And this is when I changed my mind, and I said, radiation seemed to have better percentages, better odds on both incontinence and impotence. Although life expectancy is not a whole lot different, or recurrence, five to ten years, and is not a whole lot different. Yes, I heard the basic comparison was against radical prostatectomy, and I went back to the doctor and changed my mind, [saying] “Doctor, I want to talk to a radiologist.”

And he did, he made the arrangements, and it so happened, [but] I'm putting off treatment until my son gets his MBA. [Note: This delay meant about 3-4 months]

Harold's description of his process was simply stated, yet indicated that other health concerns played a role in his experience. He was then asked how he made his decision. He replied:

Well, I told my doctor that I was concerned about my heart, and even if I had not had heart troubles, I want to avoid general anesthesia when I can, because general anesthesia is a calculated risk. So, I talked to the doctor and he agreed with me, that it would be a safer route for me to do radiation.

Irving stated, "I read, got as much information, and I think I went to Man-to-Man, and I spoke with the group's facilitator." He was then asked, "That was part of the process of learning about things?" He said:

Yeah, to find out what people were saying, and then I had to make up my mind about what I would do. I had a problem with surgery because, some years back, I had fainted [he described a prior medical condition and apparent heart condition, along with medication being taken to control it]. And so I went to the surgeon, who was the one who did the biopsy, and he looked my history, and [the surgeon] said, "To be honest, I wouldn't recommend surgery."

I inquired, "So, you decided on another treatment option?" He agreed, "So I had to look at the other options. I finally ended up looking at the option of external beam radiation, but focused, conformal, on the particular area [of the cancer]. A doctor here recommended the seed implants."

Ken's description of his treatment selection was also one of learning as much as he could. He stated, "I had the usual choice of therapies," which was followed by the question, "How did you decide between the different therapies?" He replied, "Oh, well, I studied real hard It looked like really the best, there was several, there were always new ones But, what really was the best was the proton-beam therapy." I stated,

“Radiation then?” He replied, “Which was, then, only offered in California, Loma Linda. What I finally settled on was radiation.”

Eric spoke somewhat bitterly about how his experience had not produced what, in his mind, were the best possible results, and he expressed his conviction to let other men know. He said:

Whenever I am out among men I bring the subject up. If I can save someone from having to go through the experiences that I have, if I can have someone see about getting something done, when they get a reading, but PSA reading of two or more, instead of waiting until it gets to be 4.0 or more, I will make every attempt to do so. Because I have undergone this, and because it has been rather hush-hush among some part of the population, it's not hush-hush for me, I want everybody to know. When it gets to be 2.0, you start doing something about it. You inquire, you find out, you get on the Internet, go to the doctor, go to the urologist.

For Eric, part of his process in dealing with the experience was to try to help others so they would not experience the same misfortune. Information found later in this chapter details similar desires of men wishing that their participation in this study might be of some benefit for others. After this comment, it was suggested to Eric that there are a lot of information sources available to men and he continued:

There is a lot of information out there. Yeah. I only wish that I had caught this earlier, I wish that I had kept up with my yearly PSA and digital exams. Had I done so, I might have been spared what I go through now, on a daily basis.

Jack described his interaction with his doctor that was part of his decision-making process. He stated:

So he sits me down to him, and he said, “You're a good candidate for seed implantation, and thus and thus and thus.” It sounded pretty cool and pretty neat. And we talked for an hour and, of course, I paid dearly for it. And then he talked about the pinpoint radiation, which is another procedure, and he pretty much covered the negative side, but not entirely. The seed implantation and radiation, the seed implantation, I think, only has about a ten-year track record, I think that's correct, don't write that down.

The remark was then made that it appeared he had investigated all the potential side effects, and he was asked if knowledge of the side effects influenced his thinking. Jack responded, using an analogy:

I learned that you need to be your own advocate. It's like going out and buying your car. There are fourteen brands on the streets, you have to decide yourself which one is best for you. Nobody can tell you which one is best, you have to make up your own mind. And, of course, cancer being a big thing in people's lives. So that's what we did, and how we arrived at it. Oh, I'm not sure where you are going with this, but, then I jumped on the [Internet], which [he laughed] is a dangerous place to be sometimes.

I then stated, "It can be a wealth of information," and he agreed [still laughing], "Yes, information you say, you didn't say accuracy," and I concurred [sharing the lighter moment], "No, I didn't say that." Jack continued:

So, we jumped on there and found a doctor [in southern Florida], and he had a web site. And this website, of course, was written in his favor. And he had testimonials on there. Of course, he only invited testimonials that had flowers. He didn't invite me to testify on there. But his first patient was on there, with a testimonial. His first laparoscopic patient was on there, very glowing report, being the first patient. [That] was impressive to me. And he had done over 100 at that point, and was nearing 200 So, we wound up doing that.

In further discussion about approaches such as chemotherapy, Jack stated, "I would have to look at that very closely, because if I only had a year to live, I don't want to live with chemicals in my body that I can't stand to get out of bed." It was then commented, "Uh huh. So, it certainly sounds that a quality of life is much more important to you than a quantity," and he explained:

You feel that, until you come down to making a decision, and then you [he laughed], the doctor says, "Well, without treatment, you'll live 18 months, with treatment you'll live 24." I don't think you make a decision until you are at that point, in the doctor's office, saying are you going to opt for treatment and live 24, or are you going to do nothing and live 18?

Darren shared information about part of his experience in selecting treatment and feelings had after the fact. He said, "I went up there to the Hope Lodge [site of Man-to-

Man meeting] this past Monday night, two weeks ago If I had done that before I ever started, I would not have had the radiation.” He was then asked why he felt that way and he responded:

Because there was a number of guys there that night . . . that had had [radiation], and of course, I would read about it and all the literature and stuff, my God, I wish you could see, I’ve got it here somewhere, this book my wife’s secretary gave us, and is very professionally done, covering everything When I first went up there, and they started to talk to me about, “You’re going to be incontinent.” I didn’t like that. And they said, “You’re going to be impotent,” and I, oh shit, there has got to be another way. And they said, “Well, we haven’t found it.” And at that time I said, “This is where the watch and wait comes into it.”

Leroy shared part of a conversation he had with his doctor. “Leroy,’ [the doctor] said, ‘In your condition, I would recommend, now you can have whatever of the three that you wish, I would recommend radiation for you . . . and it’s, ah, five days a week, for eight weeks, forty treatments.’” Martin, who is married, talked about consulting with his wife, and that after tests and x-rays indicated the cancer had not spread beyond the prostate. Paraphrasing the doctor, he said:

“What I can do is go in and remove it.” So, I said, “Well, I have cancer, and I want to get it out of me, you know.” And so, he did. We all agreed. The decision made, he acted quickly. I asked him, I said, “Well, you know, when can you remove it?” He said, “I can do it anytime. I can give you a [hormone] shot today, and do it tomorrow.” Well, I said, “My wife is at a school and she’ll be there to help me,” you know. And he said, “Well I can do it Monday,” and this was on a Friday. And so I said, “That’s fine.”

Norm shared his process of decision-making. He said his doctor told him:

I think we ought to see about this, it’s certainly very small, the area that is involved. So, he said, “I don’t think you want to put off and do watchful waiting, I think you would be better to consider [pause] . . .” And I said [to the doctor], “Would it hurt your feelings,” my intention was to ask him if he had no problems with a second opinion, and [the doctor] said, “Oh, no, I was going to suggest that before you asked me.” So I went over to Mayo, one of the best places in the country the findings came back exactly one, two, three what he had said.

He was then asked about his motivation for seeking a second opinion and he answered:

Well, I felt there was, I decided, I had read some where, not about prostate cancer, just in terms of people facing major surgery or things of that type, the reasons for getting a second opinion. Peace of mind, knowing that two different entities saying, “Yes, you’ve got it.”

Norm was then asked about his decision process and he replied:

The urologist outlined very carefully all of the different options. He was a surgeon, of course, so he wanted to do his favorite, the surgery. He said, “You have no problem with your age, or your health.” He said, “Your health is good,” and he said, “But it’s up to you.” So, I asked around. I went back to my primary doctor, I said, “Dr. [name of physician], I’m sort of on the fence, I don’t know which way to go with this. Tell me what your experience has been with people who have had surgery, radiation, seed implantation.” He said, “I can’t tell you how it’s going to be in your case, but I will tell you what my history has been, since you’re asking me.” He said, “In recent times, I’ve been more concerned about the surgical procedure because there seems to be more, more things happening in those surgeries that I didn’t realize were happening.”

When asked if he meant in terms of side-effects, he replied affirmatively, “Yeah, afterward. And so, [the doctor] said, ‘From what I’ve seen so far, I would tend to lean personally toward radiation. But,’ he said, ‘That doesn’t mean that you should do it.’” I commented, “You have to make your own decision,” and Norm said, “I respected him, that’s what I was paying good money for [pause for laughter], so we chose radiation.”

For men who were married, the role of his spouse during the process of selecting treatment should be noted. From Norm’s comment that “we chose radiation,” how and when and why men turned to their wives is of interest. Conversely, however, some men did not approach or include their spouse much at all. Again, this varied on a case by case basis. Some sought help with the decision – others needed and asked only for emotional support. Alan stated, “But you know, everyone is putting on a good front. But in any case, I went home and told my wife.” Charles stated, “The doctor called me on the phone and told me, ‘Will you please bring you and your wife? I would like to talk to you.’”

After he’d been told of the diagnosis and given the suggestion to learn about his options,

he recounted, “So I let the stuff simmer, and then after it had simmered for a couple weeks, my wife and I didn’t discuss it a whole lot, she was a little bit more concerned than I was.” I asked, “She told you so, or you just” He continued, “No, after 30 or 40 years of marriage [laughter], you don’t have to. She finishes my sentences, I finish hers, that sort of thing. Something happened after the 25th year, it’s just the empathy that you develop living with a person.” He was then asked when and how he then shared that with his wife, wondering if she just went along with things. He answered:

No, she had no input, she didn’t want to have any input. She wanted, she was aware of the side effects, she said, “That’s not important.” I said, [laughing] “To you it’s not.” But, she reassured me that, “Hey, there is life after impotency. And we can take care of these things.” She said, “Whatever you decide, we’ll be fine, you just make a decision that you and your doctor feel you are confident with.” And she would go with me to the meetings, and she would sit there, and listen. She didn’t have a whole lot of questions to ask, and I had heard that the women seem to have more questions She was fine with it, there was no . . . she has never even complained about the side effects afterwards.

For Gus, he was fortunate to have a spouse who happened to work at a local chapter of the American Cancer Society. When discussing the process he would go through if cancer reoccurred and he had to decide once again on treatment, he stated, “My wife would have a share in that decision, it would be harder for her than for me.” Wondering if she was a part of the decision-making process the first time around, he replied, “Oh yes. She was a big strength to me, and I was very lucky because she had so much information that I could read.”

Jack’s situation also included spouse involvement. He reported, “Yeah, I think my wife helped me.” He was then asked about his wife’s involvement in the process, and he said:

Oh, she, she was definitely involved, for lots of reasons. I think one of the defining moments, and I’m not sure how to put this, was, I’ve sort of lost track of my thoughts a little bit. Oh, the radiation was almost for sure, and to me one of the

negative things of radiation is the fact that they really don't know if they have removed or killed all the cancer [he paused].

I questioned, "Less certainty?" and he stated, "Yes. And I think that was a deciding moment, it was a very easy procedure versus the radical. But by doing the radical, when they take the prostate out and lay it on the bench, and eyeball it, and they can almost with certainty say, "There is no more cancer." I said, "Right," and he continued:

It did not escape, it's a very high percentage. And of course, with removal, you are at least for sure, temporarily impotent and incontinent for sure. And my wife, I think, she finally said, "Look, I would rather have the cancer laying on the damn laboratory bench." She'd trade that for the impotence. So I think that was a defining moment.

When Martin was asked about his wife's role, he reported:

Well, he [the doctor] had a meeting with us, and he explained everything to her. And I asked her, and she said, "Whatever you think is best." And I said, "I think this way is the best way to go. Let's go in, and take this thing out of me, then I'm free of it."

When conversing with Norm about his wife, he shared:

Well, as you could imagine, [she was] totally supportive. I think, that, she was very interested, and, I think, if the situation was reversed, and she was diagnosed with breast cancer, I would certainly be supportive. And so she said, "Well, what did Dr. [physician's name] say?" I said, "He kind of leans toward radiation, but he's not saying, do it, but from what he's seen recently." I said, "We've had a good sex life together . . . I wouldn't see it as the end of the world, if something were to happen that would curtail that." She said, "What does radiation speak to that?" I said, "Well, it speaks the same way as surgery. There are some unknowns, and some things, but we'll just toss the dice, and see what happens."

Discussion about Role of Spouse

As men discussed their recollections of how they reacted to the diagnosis of prostate cancer, some men included information about how their spouse reacted to the news. Frank simply stated that his "wife handled it better than I," and that in terms of dealing with possible incontinence and erectile dysfunction, he reported that "she rolled with it very well." Irving's wife had experienced cancer in her background, reason for the

news of his prostate cancer to negatively impact her more. He stated, “My wife was devastated by it, because she has had cancer on both sides of her family, I mean a lot of cancer.”

Spousal involvement in selecting treatment is also worth discussion. For those who spoke of it, wives played a role. For Charles, who stated that though “my wife...was a little bit more concerned than I was,” when asked about her involvement with making decisions, reported, “No, she had no input, she didn’t want to have any input.” Remembering that his wife was aware of the possible side effects, he remembered her saying, “That’s not important,” and after he told her, “To you it’s not,” she reassured him, that “there is life after impotency . . . we can take care of these things.” Charles said his wife, in addition to attending Man-to-Man meetings with him, also told him, “Whatever you decide, we’ll be fine, you just make a decision that you and your doctor feel you are confident with.” He also reported that “she has never even complained about the side effects.”

Gus, whose spouse worked for the American Cancer Society, reported her as “a big strength to me,” and stated that she provides ample amounts of information for him to read. Likewise, Jack reported, “Yeah, I think my wife helped me,” and that she was “definitely involved, for lots of reasons.” Remembering her participation when discussing options with his doctor, Jack recalls her helping him decide on surgery. He told of her saying, “Look, I would rather have the cancer lying on the damn laboratory bench,” and considering his wife, said, “She’d trade that for the impotence. So I think that was a defining moment.” Martin, who also selected surgery, shared his experience of having

met with the doctor. He stated the doctor “had a meeting with us, and he explained everything to her. And I asked her, and she said, ‘Whatever you think is best.’”

Literature exists pertaining to the role spouses play during their husband’s prostate cancer experience. Generally speaking, wives have been shown to shoulder responsibility for the health maintenance of their husbands (Norcross et al., 1996), and interestingly, married men were found to show less interest than single men relative to self-care information about prostate cancer (Davison et al., 1995). This same study also reported that most physicians encourage wives to participate in visits where treatment decisions are discussed, but did not provide information about the role wives actually played. A recent study found that many men are not inclined to share much with their wives about their prostate-related problems and that some men choose treatment without much spousal consideration (Boehmer & Clark, 2001). O’Rourke (1999) discovered that although both spouses may participate in treatment decisions, there is a likely difference in their perception of the risks and benefits of each alternative. For example, their study concluded that women tend to focus more on longevity and survival, while men are more concerned about side effects.

Discussion of the Process of Selecting Treatment

A variety of conditions were present in the lives of men who underwent treatment for prostate cancer. Each man differed in terms of his age, his overall health, the stage of his cancer, the doctor(s) who provided care, and other concurrent medical conditions. Likewise, the different treatments constituted separate conditions men encountered. Similarities between men existed such as: (a) the need to gather information, (b) the interaction between themselves and their spouse, and (c) commitment and follow through with their decision. Most men felt the need to gather information to make a decision

regarding their care. How men went about getting that information differed, however. As a whole, these similarities helped shape a process that seems to fit for most men. Brian's experience, in choosing the watch-and-wait approach, was unique. Yet, when asking about the "process you have used to make decisions," Brian scoffed at it being a process. He stated, "The process? I guess that's a very elegant word for it. It's not really a process." He then described what he thought other men do when dealing with treatment decisions, this being that they seek surgery thinking, "I've got to get this thing [cancer of the prostate] out of here." He also said, "The psychological impact of having cancer doesn't bother me that much. It's just a matter of what is the best approach to treat it, whether it stays in me, or whether to get it out." This came after knowledge of what his PSA (prostate specific antigen) score was, and led to seeking literature (using the Internet) that led him to feel, "I've got some time here." The fact that he "didn't want all of the possible effects from an operation, the incontinence, the bowel problems," also indicates a property of this condition that factored into his decision-making process. For Brian, his decision was to put off active treatment, believing that he had time and that he could bide his time until some treatment would come along in which he had confidence. He stated, "I figure there is a very good chance that I can jump from one piece of floating debris to another piece of floating debris." Kelly & Dodd (2001) report that because the rate of progression of localized prostate cancer is slow, watchful waiting and observation is appropriate for some men. Zepf (2003), in a review of a Scandinavian randomized, prospective trial comparing radical prostatectomy with watchful waiting, stated that "although observational studies have shown that prostatectomy lowers rates of cancer progression compared with expectant management, no overall survival benefit has been

demonstrated, even with more than 20 years of follow-up” (p. 599). This type of research underscores the need to wisely consider options against the potential consequences.

Other men, however, were unwilling to forego active treatment – yet engaged in a similar process of decision-making that resulted in a different conclusion as to how to proceed. Charles also reported tracking his PSA without understanding the ramifications of what it would mean were he diagnosed, that he was “unaware of the significance of prostate cancer,” but that a doctor had suggested prostate cancer was highly treatable. He recounted being told, “You know, men are going to get prostate cancer. It’s one of the easiest things [to treat] because it’s very slow...if I had my choice of cancers, I would choose prostate cancer.” While the attitude of this doctor likely affected Charles’ relaxed approach while the PSA was being monitored over a several year period, another doctor’s comment helped him to take action. Once his PSA had eclipsed 6.0 and a biopsy was recommended, he still was planning to wait a little longer. However, his son-in-law’s father was a doctor and he reported being told, “You don’t want to put this thing off, this is serious.” The biopsy was performed, and came back positive, yet Charles did not experience a serious emotional reaction. He shared his view, which was, “Even then I wasn’t terribly concerned.” He did, however, follow the advice of the doctor, that he learn “as much as I could about the disease,” attended a Man-to-Man support group, and began reading literature about the topic. Through these means he “became concerned” that the side effects were “not too attractive,” and this realization “started sinking in to me what the possible consequences were going to be no matter what procedure I chose.” Yet, he recounts his emotions were not of fear or anger, but of uncertainty. “I was very undecided,” he stated, followed later by a desire to move forward, “You know, where do

we go from here?” He shared feeling a sense of denial about actually experiencing the side effects about which he had learned saying, “the side effects were not going to be pleasant...I thought, it’s not going to happen to me.”

Some men had to consider other health conditions as part of their decision-making process. Harold, who received radiation treatments, mentioned that he was “concerned about my heart” and that his doctor agreed that surgery was not a good idea so as “to avoid general anesthesia.” Irving had a similar experience of reading about prostate cancer, going to Man-to-Man group meetings, speaking individually with other men, and ultimately having a concurrent medical condition and medication affect his decision about how to proceed with prostate cancer treatment. He said his doctor, after reviewing his history, told him, “To be honest, I wouldn’t recommend surgery.” He then was compelled to seek other treatment options – deciding to receive radiation and brachytherapy. Ken’s process was also one of learning. He stated that, “I studied real hard,” but then had his first choice for treatment (a particular form of radiation treatment) deemed unavailable because it was not being performed near where he lived.

Jack’s experience was that his doctor told him, “You’re a good candidate for seed implantation,” amidst a discussion of other treatment options. His statement that the doctor, “covered the negative side [of the treatment], but not entirely,” is an indication that he sought and received other information that broadened his understanding of the situation he was facing. He explained the decision as part of an analogy, prefaced by, “I learned that you need to be an advocate,” – wanting to make sure the decision was best for each individual was important. He said, “It’s like going out and buying a car. There are fourteen brands on the street. You have to decide yourself which one is best for you.”

And despite the plethora of information available about cars and treatments for prostate cancer, “Nobody can tell you which one is best, you have to make up your own mind.”

His statement of, “That’s what *we* did, and how *we* arrived at it,” illustrates that his spouse was a part of the final decision-making process and he shared using the Internet to find out about the doctor and the procedure he ended up receiving.

Norm was one who mentioned getting a second opinion, wishing to obtain additional medical advice. In his case, he found that, “the findings came back exactly one, two, three what [the first doctor] had said.” When asked why he had sought the second opinion, he indicated that he had done some reading about how other men had sought second opinions and that, for him, it provided “peace of mind” knowing that two different doctors agreed with the diagnosis. Once that part of the process was complete, his selection of treatment characterized that of others in the study. His doctor talked with him about his age and his health, and ruled them out as factors that would influence the decision. Norm’s uncertainty was characterized by his statement that, “I’m sort of on the fence, I don’t know which way to go with this.” He reported his doctor talked with him about the options for treatment, but that “we chose radiation.” He stated, “You have to make your own decision,” but his respect for the doctor’s expertise factored into choosing the recommended treatment of radiation.

Darren’s experience was one where he wished components of his decision-making process had occurred in a different order. His decision to opt for radiation was made with the assistance of professional literature. However, he did not go to a Man-to-Man meeting until after he had already received his radiation treatments. He stated he had attended his first meeting two weeks before the interview and that there were several men

at the meeting who had had radiation and shared their experience with side effects. Hearing their stories and their claims that, “You’re going to be incontinent” and “You’re going to be impotent” brought his reaction, “Oh shit, there has got to be another way.” He also stated, “If I had [attended the meeting] before I ever started [treatment], I would not have had the radiation.” His comment that, “This is where the watch and wait comes into it” is indicative of believing that had he had more time and more information, he may have opted for another form of treatment.

Discussion of Different Treatments as a Condition of Men’s Experience

Medical literature stated that surgery and radiation therapies are commonly performed. Surgery (radical prostatectomy) entails the surgical removal of the prostate gland and is typically done with use of either a retropubic or perineal methods. Six of the fourteen men interviewed had surgery. Radiation (radiotherapy) involves the delivery of controlled doses of radiation to the tumor and surrounding cancerous tissue. Seven men in the study chose this route. Brachytherapy, or the use of radioactive seeds inserted in the prostate, is another procedure commonly employed. In this study, five men had this procedure performed. Hormonal therapy, received by four men in this study, is an approach sometimes recommended to deter the growth of cancerous tissue and occasionally is used to shrink the prostate before surgery (W. Kelly & Dodd, 2001). Expectant therapy, or “watchful waiting,” is also an approach stated in the medical literature as one that is sometimes recommended. This approach consists of foregoing active treatment, thus avoiding many side effects, but maintaining careful observation (Ko & Bublely, 2001). In this study, only Brian chose this route. It should be noted that several of the study’s participant’s received more than one of these treatments.

Each of these treatment modalities constituted a different condition that factored into creating a unique experience for each of the men. The following sections offer an analytical look at the side effects men stated they experienced and the role these side effects had in the process of coping and adaptation.

Coping with Physical Side Effects

Physical side effects following treatment for prostate cancer have been well documented. The following sections illustrate, using the men's own words, their experiences. Surgery for prostate cancer typically results in the possibility of erectile dysfunction, incontinence, and pain or fatigue after the procedure. Radiation-based treatments may also result in erectile dysfunction, bowel and bladder incontinence, and fatigue. Hormone treatments are associated with hot flashes, breast growth and tenderness, and loss of libido. These sections are broken down into categories based upon the side effect noted, and it is important to remind the reader that most men in this study received one or more of the above treatment modalities.

Hot Flashes

Hot flashes are a commonly reported side effect of hormone treatments. Martin stated, "I talked to my doctor, and they gave me some shots, I can't remember what they were called. Well anyway, he was trying to shrink it." I asked, "Was it a hormone therapy?" He said, "I believe it was hormone, it made me have hot flashes."

Charles explained his situation after hormone injections:

Within certainly a month and a half I was beginning to show some side effects Toward the last couple of months, the hot flashes come on, and it's just heat, all at once, the hot flashes come and you just bake. It's just heat. All at once, you feel it coming and you just break out [in a sweat].

Eric stated he was given Lupron. He said:

I've had hot flashes, I remember one time I wanted to see just how often they were coming on but they were coming on every 25 or 45 minutes, and the duration of probably six minutes or so. And I would perspire profusely and that, very hot. I go to bed at night – you're either throwing the covers on or throwing them off.

Breast Growth/Tenderness

Charles also mentioned discomfort with tenderness of his nipples. He said,

I didn't know what they were first, ah, sensitivity in your nipples We're going to do the river trip, and that's when they put me on Lupron. Awful. It's no pain, but your breasts are sensitive, you're irritable, the whole bit, you know?

Harold, as explained earlier, did not mind growth of his breasts. He stated:

I persuaded my doctor that I wanted, that I needed to pursue my life the way I wanted to pursue my life -- that is with the breast enlargement. He came up with an old hormone treatment that is not much use any more, and he prescribed that for me, and I got on that, and just so you know my PSA has continued to be the lowest on the scale. And I feel safer from developing cancer again because, as my doctor explained, testosterone is the food of the prostate cancer.

Bowel Difficulty

Several men talked of having experienced bowel problems as a result of treatment.

When Gus was asked about other impacts of prostate cancer, he said, "Well, there was one other trouble, but thank goodness it cleared itself up, was that I had no control over the other end of me for a while [bowel]. That was even worse, but it didn't last for very long, thank goodness."

Irving stated:

The other thing too, was that I had bleeding for some time, blood in the stool, and so I went back to the doctor. I had a colonoscopy, and it turned out okay. They pointed out that there were red blood cells that are around, and he [doctor] said this is not unusual. And I received two treatments, and I don't see any more of that. But the thing that bothered me after that was the problem with bowel action. And knowing that I needed to go, and getting to the bathroom, being out, and then dashing back.

Fatigue

Fatigue was another factor that men mentioned as a result of treatment, usually as an immediate effect after treatment. Darren commented:

The way I feel now, what I am able to do right now, the energy that I have right now compared to what I was two or three weeks ago. I would sleep seven or eight hours, and I might take an hour nap in the morning and a two-hour nap in the afternoon. And it was because I wanted to, it was just because I was just [pause].

I suggested, “Wiped out?” and he said, “Wiped out, yeah. And I’m not even close to that now.” He shared more:

The biggest thing that I have against prostate cancer at this point, and it, I may be very premature in deciding this early, is the limitations it has put on me. Especially from an energy standpoint, because it took about two weeks for the radiation to start having any effect on me, and that was the exterior beam. And then, when I went up there for that last, for the last external beam radiation, and I went down and talked to Dr. [physician’s name], and I said, “Well, it’ll be going downhill from here?” And he said, “Your worst days are ahead of you.” And, hell, why didn’t someone tell me that, because it didn’t start out that bad. And he was right, oh man! And then for about five or six days after the [radioactive seed] implants it was pretty rough, but from that point on, like a steady progression, getting a little bit better.

Frank, recounting the days soon after his surgery, remembered, “I was going to try and get myself a cup of tea, as he [doctor] had allowed me to have, and I thought I was going to die, I mean, I was so weak.”

Charles, amidst discussion of what leisure was to him, stated, “And after the initial six months, where you are still recuperating from the treatment when you have had, radiation. It doesn’t impact you right away, but it really makes you very weak.”

Dry Mouth

Another known side effect is experiencing a dry mouth, a challenge that one man brought up during the interview. Eric described his situation in these words:

An interesting thing after you have the radiation, then you find out that you have a dry mouth, this is particularly noticeable at night. So anytime you get up to urinate,

you have a glass of water there to get a drink of water, at least I found that to be the case.

Pain

Pain after surgery is a common and expected side effect; yet, like other side effects, men experience it differently. Alan talked about the day after surgery and said:

Oh, my, my penis started to hurt, to burn like fire. Instead of that soft rubber tube, it felt like a barbed wire in there, see? I tried to walk, oh, that was worse. You tried to sit down, that's worse. You try to lie down, nothing helped, see? And I asked one of the other patients, he had surgery I think the day before or the day after I did, and said, "What do you do about pain?" He says, "I don't know what you're talking about, I don't have any problem like that."

I stated, "So, it was unique to you?" and he replied, "Oh boy, yeah."

Eric's experience was similar. He recounted:

When I had the prostate removed, I was up and walking around the first day. I had a catheter in me, and then I was in the hospital for four days. They ceased giving me pain killers, apparently, because after about the second and third and fourth day, it became apparent that, oh man, there's a heck of a lot of pain. And the nurses, ah, I'd say, "You know, I'm having a devil of a time here, this is very painful." And ah, that's natural, that's just natural. And I would not sit still now for what the nurses told me about this being the natural course of events.

When asked about side effects, Jack replied, "I stayed in the hospital one night. I went to a hotel room the second night, drove home the third day, my wife drove me. I could have driven, but it would have been a bitch. I was a sick puppy the second day," and after a brief pause he stated:

Yeah, yeah. I had more pain than I think I was led to believe, or that I interpreted. Of course, how do you interpret how much pain you might have? But, my wife says I was a mess. I had a great deal of pain in the urethra, up into where the root of the penis is attached. But I didn't take the pain pill that they gave me -- I'm sort of anti-chemical. I'll take them when I am dying, which only makes sense, but, heck no, pain is pain, what the heck, you know, you live with it.

Incontinence

Not surprisingly, many men were faced with having to cope with incontinence in the days, months, and years following treatment. Again, however, for some it was described as a significant hardship, others appeared to adapt more easily. Alan mentioned his experience in these words.

I took a trip, yeah, when we finally got that catheter out, and I thought, “I’m going to be off work.” There was an antique tractor show going to be held in [mentioned Midwestern state], and I thought, “I’d like to go to that.” My brother lives in [mentioned a different Midwestern state] and I thought, “I’ll go pick him up.” Oh, I had one of the tractors up in [Midwestern state] to be reconditioned and I thought, “I’ll go up and load that thing up and take it to Iowa,” and uh, these old time tractor shows are terrific, the nicest people in the world, you know, and uh, well, I had a Ford van for pulling the trailer. And, what I found was I had absolutely 100% urine leakage. Whatever drips out of the kidneys into the bladder runs out the other end, you know, no waiting.

So, I learned, I sampled every kind of absorbent pad in the store – diapers, pads, uh, things with rubber bands to hold the sides up, like a loin cloth you know – I tried a little bit of everything and found out which worked the best. I became an authority on those things [mutual chuckle] I came to the hospital to pick up one of those urinary, uh, things you know they have for bed patients to urinate in, with a cap. I thought, now traveling in a car, well, when you are sitting down on a chair like this [he scoots to the front edge of the chair with his back straight], your bladder will hold urine. The urethra runs out the bottom and just the slight pressure will keep the urethra closed Okay, but when I stood up, in standing there’s no obstacle [he stands up], whatever is in the bladder rushes out Yeah, okay, well I learned with pads, don’t sit still too long. If I attend a lecture, I make sure I shift around on the edge of the chair or stand up a little bit or something, because if I sit there for forty minutes and stand up, that stream of urine hits those pads. They absorb alright, but sometimes they don’t absorb so fast.

As shall be shown later, incontinence proved to Alan to be an interference with both leisure and his intimate relationship with his wife. Gus also experienced significant side effects from incontinence that affected his life. He shared this thoughts about incontinence and how it interfered with his normal routine:

That was part of it. And just not being able to feel comfortable going to functions, a lot of things that I might go to, or with people that I . . . because I was going to the

bathroom, to the men's room probably every 20 minutes, and, you know, I never had to do that before.

Charles, who enjoys traveling, was asked if incontinence interfered with his life:

At first, very much so because the incontinence, you, it interrupted your trips -- your travel. Travel you had to deal with pads, or with things that were inconvenient. If you are driving, and there is a tendency when you drive, where you're sitting, how you sit affects your bladder, and after thirty miles you hope the state you're traveling in has comfort stations [laughing].

It was stated that he had earlier mentioned knowing where every bathroom was, and he said, "Yes, and every single station between here and [mentioned Midwestern state]. That, that was difficult because you, it restricts your pleasure in traveling."

Darren explained more about his trip to a Man-to Man meeting, "When I first went up there, and they started to talk to me about, 'You're going to be incontinent,' I didn't like that." Irving briefly stated, "I have some side effects in terms of the bathroom you come to know where every bathroom is located. So if you ever needed, you could get to a bathroom fast, because if there was an urge" Frank still deals with incontinence, but it is something that he has been better able to cope with as time has passed. He shared:

I still suffer incontinence. I do really have incontinence, though I don't get up at night Yeah, at first I was very incontinent. It seemed like I didn't get to sleep for the first few days because of the urge to have to go. After a few days, it got better. I came back to work after six weeks, and there has just been a very gradual improvement, in both areas, incontinence and impotence.

Jack's experience was similar. He said, "So, I stepped in the shower, and pulled it [the catheter] out, and I was instantly incontinent. I mean it was just drip, drip, drip." He paused and I asked, "Is that something you are still experiencing?" He said:

Yeah, it's awful hard to describe the amount. I'm still incontinent, but it's greatly improved. But it's like saying a little bit pregnant, you know, there ain't such a thing. The hard part of incontinence is going into Wal-Mart and buying a pack of men's pads, and going to the checkout girl and buying them.

Reduction of Penis Size/Ejaculatory Changes

Within the realm of sexuality, a variety of side effects were mentioned by men who were interviewed. These side effects ranged from noticing a difference in penis size, dry orgasms (retrograde ejaculations), loss of libido, and erectile dysfunction. Some men commented that their penis had become smaller. Eric stated, “They don’t tell you when you have a prostatectomy that, ah, it shortens your penis. For me it was by two inches, I would guess.” Frank stated:

I’m sure you’ve heard of conversations about whether the procedure that reduces not only your ability but the size, as well as the ability. I mean, and it did, at first I was much smaller than I was before. And that, you know, is distressing . . . but it’s the ability to maintain an erection that is still somewhat of a problem.

He was asked if ejaculations were normal and Frank then described a problem within the context of having had a conversation with another man who was experiencing the same problem, stating that he does not ejaculate. I asked, “It’s dry?” and he said, “It’s dry, yes. Because the seminal vesicles are taken out, so we cannot have . . .” I asked, “But you can achieve orgasm?” and he stated, “Yes. And say, this is something that I did not know myself, you don’t even have an erection to achieve orgasm. You do not have to, I did not know that. And a lot of guys think, you know, you don’t have to have orgasm, I’m sorry, you don’t have to have ejaculate to have orgasm either . . . some men, and women, do miss that.”

Impact on Libido

Several men spoke about a loss of or change in sexual desire. Charles spoke of the impact of treatment on his libido. He shared:

It’s one of those things that the sex drive was cut off. It wasn’t a natural diminution of the drive – it was a cutting off of the drive. It was the cutting off, the abruptness of it . . . the fact that it was suddenly cut off, instead of just a natural slowing down

of the sex drive. Ah, and it happens, it becomes so frustrating it also blocks the sex drive It leads to a certain amount of impatience on my part.

Eric shared his experience, which he stated was directly related to taking hormone treatments. He said, “Once you take Lupron, it’s dead in water.” He later stated:

The desire, for the most part, goes out the window. However, when a person is in love with a lady, and she has passion, and even though I lack the ability to have an erection, I still have the desire to be very, very, very close to the one I love. And so, that very thing, yes, has entered my mind. And I enjoy it, and I am able to have my loved one enjoy it also, and that gives me pleasure. And for that I feel that my manlyhood, my manhood, has not completely been robbed. I have not been robbed of it completely . . . the inability to have an erection, which a loved one would dearly like to experience . . . but, when you have a ship that is dead in the water, it’s not going to be going into port very likely, is it?

He was then asked if he was optimistic about getting positive results regarding erectile ability in the future, and Eric mentioned his hope that, “I can bring something about with the pump. Perhaps Viagra will play a part in this, I don’t know. I hope it does, but it may not. Otherwise it will be, sex will be massaging, and it will be oral.”

Eric was also asked about impotence and masturbation. He answered, “Oh yes. Yeah Same mechanics, and desire also. The desire, for the most part, goes out the window.” Irving also talked about loss of sex drive. He shared, “There was some, later on, loss of libido. I didn’t feel like I wanted to have sex. But I thought that it would be just a matter of time.” I asked, “So was it a loss of libido as well as a loss of function?” and he said, “Oh, yes, I think most of it was a loss of libido, but you’re right, I wasn’t able to have much of an erection That came back, but still I worried more about the loss of libido, and I was anxious about it.”

Irving was asked, “Has your experience with prostate cancer impacted your relationship with other people, your wife?” He answered, “No, the wife, but it has, in the sense of, you know, well, we have discussed the sex problem I am more worried

about the desire, and the loss of desire, more than being able to have an erection.” Asked then if his libido hadn’t come back, Irving said, “Hasn’t come back in full, no. And, I may need to go to somebody for it to be treated. I didn’t want to begin to use Viagra, because of my heart. But I’m going to talk to a urologist when I come back from my next trip.”

In talking with Harold, the opportunity arose to explore the meaning he saw between the terms “impotent” and “erectile dysfunction.” He said, “Well, I was losing the ability to have an erection [pause] . . . I was losing it about the time that I started getting the Lupron shots.” He was then asked if it was already diminishing,” and he stated, “It was almost gone, and then the Lupron finished it off.”

Ken mentioned a similar experience, but one that began before having prostate cancer. He said, “I don’t have much sexual desire, or, I got the desire, I can think back and [laughs], and remember how nice it used to be, but . . . The medication is supposed to kill it too . . . I was having troubles before.” Then, inquiring about the difference before and after dealing with prostate cancer, I asked, “So there wasn’t really any noticeable change?” and he said, “Yeah. Maybe some slacking off, but nothing that compared to the heart pills.”

Erectile Dysfunction

Erectile dysfunction (ED) is a common side effect after prostate cancer treatment.

Alan was asked about his experience with sexual functioning after treatment. He said:

At first I was optimistic . . . I didn’t know that even the successful guys it takes about a year and a half, you know. But yeah, nothing. No stimulation, no sexual thoughts have, uh, any effect on it.

Charles expressed being “very disappointed with the impotence,” but recalled his wife’s reassuring him, “The important thing is that you are here, you are here with me.”

He mentioned:

I was very disappointed in [the ED] because, I had some very nice erections [laughs], wonderful things, I should have photographed it [continued laughter], but I think that they misprescribed some medication for me, and that’s when I think I became a little embittered because that’s when the impotency really set in.

When asked about the difference in his mind between the words “impotence,” which he used, and “erectile dysfunction,” he said:

It’s more than subtle meanings. Your libido is also dampened, to me. Erectile dysfunction means you cannot get an erection, or maintain one, whereas the other one, is the whole sexual drive, because you’ve become impotent. I remember one time, I had not quite known the word impotent, I had always thought it had to do with being fertile, and it’s not, because fertility has nothing to do with potency. It’s just that erectile dysfunction is a new connotation to me, I’m a traditionalist.

Darren experienced shock when he came to realize the effect of treatment on his sexual functioning, but also gave insight into the fact that one’s partner and their medical conditions and medications can play a role, too. He stated:

The only thing is, our sex life, because a lot of that was the medications I was on, Prozac, but it certainly didn't stop it, but it was not as often, plus she had had a hysterectomy which takes part of the drive away.

Frank commented about this experience:

And the impotence – again, that has gotten better, um, it’s not back, and it probably never will be back to where it was. But um, I have experimented with everything, because that is certainly something that is part of my life.

It was then mentioned that he stated previously that sexuality and sexual function was something that he had taken for granted, to which he replied, “Uh, huh.” I also asked if he had “looked at alternate means,” to which he replied, “You have an appreciation, when you can’t get an erection. An erection feels good when you want it, and when you

want to get one and you can't, it's really frustrating, really frustrating." He was then asked about his relationship. Frank stated:

Again, couples deal with that in different ways. You know, my wife is very accepting, and she certainly placed no pressure on me. In fact [he smiled] I wish that she would place more pressure on me Um, it's like, well, you know, if it doesn't happen, it doesn't happen, you know. I'm not saying that we are not able we can't make love like we used to without And even when I try I'm not able to penetrate, and that's really frustrating to be like that. I feel like I'm not functioning like I'm supposed to I still feel very much like a man, but I feel less, that I can't function Having had prostate cancer hasn't diminished my feeling of manhood. The symptoms, as I said, the symptoms really hasn't diminished my feeling. But in some ways, I, here is an analogy, hopefully it's getting better, but it's like I feel like I am a Ferrari, and I feel like I have a governor on.

Sharing his laughter which accompanied this last comment, I asked about the "governor coming off, at some point." [Note: A "governor" is a mechanism put on a race car engine to restrict how fast the car can go.] He said, "It seems to be, yes, it definitely is coming off. How well and whether it will ever fully come off or not, I don't know. It certainly, you know, it's off more than it was on before." Mentioning, then, his disappointment at losing penis size, he also stated, "But, I think, and certainly, if I can achieve the same size maybe, or certainly enough, but it's the ability to maintain an erection that is still somewhat of a problem."

For Gus, who had radiation treatment and experienced fatigue as an immediate result, he too has had to cope with erectile dysfunction. He stated, "That external beam stuff is really devastating. Um, I'm totally impotent." Harold stated "I had been impotent before I got on the hormones, I was already impotent." He was asked what other factors may have been involved, and he commented, "I don't know, I suppose, I don't know whether all men get impotent with age."

Jack shared his experience in coping with the same problem and was asked about this side effect. He shared, "I tried Viagra, one prescription, which was ten pills. Doctor recommended 50 mg, tried that. I tried 75mg, without his permission, I just did it. Then I tried 100mg. Zilch."

Leroy, having already heard Martin's comments, said, "Well, I have to agree with something that Mr. Buddy [this was the term he often used in referring to Martin] said. I guess we're all men, I can admit that I am sexually active. Ah, the erections are not as firm as they were." Martin then stated, "Right." Leroy continued, "As before, but they are there." I asked, "Did it take awhile, for an ability to have an erection to come back, or did it gradually?" He then said, "Well, I'm living here alone. And I have nocturnal erections, and I think, I think that is healthy."

Ken also shared his experience. He said:

One of the problems with the treatment is so-called potency. And, somewhere out of my early contacts with [mentioned hospital name], somewhere, I complained about having troubles having erections. Yeah, they introduced me to the vacuum pump. So I used the vacuum pump. I continued to use the vacuum pump. As far as sexual problems are concerned, actually I haven't had an ejaculation since about summer of last year.

Men also shared thoughts about how soon they felt that they might recover either their ability to be continent, and/or their sexual function. Charles stated, "I'm not at all upset about the consequences now. Incontinence is gone away, impotency has more or less resolved itself, and I'm fine." Eric stated, "I was off the Lupron, and I did have the ability then to get an erection again." Frank said, "It's not back, and it probably never will be back to where it was."

Jack shared his feeling that it wasn't anything that he'd worry about for some time. Having had surgery with the past six months, he was asked what his doctor told him

about sexual side effects and possible medication. He said, “Yeah, and according to my doctor, it’s a little bit early He said about a year you might want to start thinking about. I think I will wait at least a year until I go do anything.”

Coping with Psychosocial Side Effects

In addition to the physical side effects of prostate cancer and its treatment, men shared side effects that are psychosocial or emotional in nature. Some of these appeared to be directly tied to a physical symptom, others were not. This information is now presented according to sub-categories as discovered in the data – with examples illustrative of what was discovered. Note that several categories are similar to ones discussed earlier in reference to emotional reactions as a result of the diagnosis. These psychosocial side effects mentioned now are experiences reported to have occurred at later stages of men’s involvement with prostate cancer (e.g., following treatment).

Shock and Denial

Several men mentioned experiencing shock and/or denial. Darren, as has been chronicled previously, stated the prospect of certain side effects “shook me up.” For Gus, the experience “was shocking to me, because I had never had anything like it before, and I had never experienced anything like it.” Others shared feelings and thoughts that indicated denial. Charles, when also faced with the fact that there were “possible consequences . . . no matter what procedure I chose,” said, “The side effects were not going to be pleasant. And one of these things, man, I thought, ‘It’s not going to happen to me.’” Talking then about his experience of gathering information at Man-to-Man meetings and conversations with other men, he later stated, “No, no, if you’re talking to them, and they are all having the side effects, I said, ‘Fine, but that is not going to happen to me.’”

Norm, a facilitator of a Man-to-Man group, shared his opinion of how he sees other men face the reality of their situation when they come to the meetings. He said, “I don’t know that everyone can find something that they would like to find in the Man-to-Man thing. Some men that are more at home, talking or not, about what cancer is about; others are still in denial, just never really have accepted it.”

Anxiety and Uncertainty

Many men shared feelings of anxiety. These feelings came as a result of different conditions and the different ways men viewed their problems, or what they viewed as problematic. For Irving, he stated being, “Worried more about the loss of libido, and I was anxious about it.” He also stated concern about incontinence and the need for a bowel program, and that he was “working like mad now to control it and contain. But that is my worry, because I travel.”

Norm shared a comment about his mental approach toward dealing with cancer. He said, “I would imagine that some people would become very concerned about [cancer] – I’d hate to think that they would dwell on it, because dwelling on it won’t do any good . . . Anxiety itself causes other problems.” For Charles, much of his anxiety, as he described it, was centered about sexuality. He stated:

But uh, the sex thing has become much more important, after this experience with impotence It has become more of, uh, almost an angst, certainly I have to do the best I can with what I have. And that becomes . . . bothersome.

Charles also shared how this anxiety led into other frustrations and efforts to cope.

He stated:

It becomes so frustrating [when] it also blocks the sex drive It leads to a certain amount of impatience on my part, and it shows [in] impatience from my wife for some of the things that she does. Ah, the frustration of not being able to satisfy your wife, not necessarily yourself, but satisfy your wife, it wears on you . . . and we’re the generation where oral sex isn’t going to be the solution.

It was then stated that today it might be more the norm, and he said, “Today, it’s more of the norm.” It was then suggested that for his wife it was more “taboo,” and he shared the frustration of “impotency” as uncertainty involved with “making sure that she was satisfied, that she climaxed, that it was pleasant for her.” He also stated, “Viagra has helped, it’s not the same as always, but good enough. And like you say, my frustration with me is that I want to show my love by satisfying her. And, that’s the main thing to me.”

Frank mentioned feelings of anxiousness when exploring different methods of aiding sexual function – one of which is penile injections to induce erections. He said:

Um, the needle? That was sort of like a last resort. You know, who wants to stick themselves, much less there? And so, I haven’t had much success with that -- it’s very anxiety producing. In fact, one time, you know, my poor little fellow was shrinking, saying, “Don’t do that.” It was just retracting more at the thought.

Brian, who had chosen to follow a watch-and-wait approach, was asked if he worried about the possible effect of treatment on one’s sexual abilities. He stated, “Well, I worry about it,” and then stated this was minimal because he was not married, but that:

Even as a bachelor, somehow that is limiting your function as a male in the world or something like that. I think if I really thought about it I would not be much concerned with that since I’m 65 and I’m probably not going to get married, so it’s not much to worry about.

For Brian, some anxiety may have been present about potential side-effects and that may have factored into his decision to postpone active treatment. He commented:

Well, I think that it could be a very stressful option. About three or four years ago, I saw a surgeon, and he said, “You’ve got to get this done now.” And my PSA at that time was pretty low, and then I went to literature and I said “Well, I’ve got some time here.” And I didn’t want all of the possible effects from an operation, the incontinence, the bowel problems, etc.

For Gus, his experience was more aligned with pain. He said, “I prided myself on great intellect and all this kind of thing [he laughed], and I was just a basket case I

tried to mask it, but I was suffering, no question about it, I was suffering.” When asked why he was trying to mask it, he answered, laughing, “Ah, that may have been part of the man in me.”

Anger and Irritability

Like Gus, several men shared feelings indicative of irritability or that may be akin to the emotion of anger. This emotion or reaction, like others being explored, is certainly expected, and yet the intensity and duration varies from person to person. Many consider anger, particularly in situations like dealing with cancer, to be a natural and potentially positive effect when and if it serves to motivate a person to action.

Charles stated, in relation to side-effects that he experienced following treatment, “I think I became a little embittered because that’s when the impotency really set in.” When Gus was asked about the changes in his life “emotionally, psychologically, spiritually,” he replied:

Well, it was shocking to me, because I had never had anything like it before, and I had never experienced anything like it. I was angry -- sometimes angry with God. I would be short with [my wife] on occasion, which I never had before – something that I would not usually do, even with other people. I tried to get over that, and somehow not do it anymore, but it wears on you, coming out of that sort of anger, and “Why me?” And you say (laughing), “Why not me?”

Harold shared an experience he had within an aquatic exercise class. He said:

I had this angry exchange, and I was in the middle of my class, and I went over to him and I told him off. And that’s not typical of me that I would spontaneously go over and have an angry outburst. I told her [a counselor] about that, and she said that I may be more emotional because of the hormone [treatments].

For Irving, he experienced something similar as he remembered looking in the future to what having cancer meant. He said:

Yeah, you might say, my wife, I went through a period, a short period when I wasn’t tremendously interested in things . . . Yeah, yeah, I remember, I used to get, I mean, my wife, I like to read the papers, but there was a brief time I wasn’t

overly interested in. I just relaxed here, and watched shows or something, not the same type of enthusiasm like I have now to get [things] put together, or type up a sermon. But I have a hunch that there was a brief period of time, I'm not so sure what it was, but, my wife mentioned, "Eventually you'll get back into the flow of things."

For Jack, when asked how the whole experience had affected him personally, how it has "impacted your self-image," he spoke using these words, "Oh my, it has been devastating, and devastating is too strong a word, but it has been very difficult."

Similar to anger, irritability was another emotion mentioned or alluded to by men. Irritability, though, is perhaps best seen as a behavior stemming from other emotions. For example, Charles shared his experience on hormone therapy, wherein he described himself as irritable to the point of his wife telling him so. Gus expressed also being short with his wife, something he had never been before. Harold stated having "several emotional experiences since taking the hormones, that [his counselor] attributes to my becoming influenced by the hormones, and becoming more emotional." He also told of an experience that occurred during the time he was dealing with prostate cancer treatment when he had trouble with his automobile. As he sat waiting for 90 minutes for AAA to arrive, Harold stated, "I got frustrated, and I burst into tears. And ordinarily, I would just get angry and frustrated, and it would come out in anger, but I burst into tears I have more of a tendency to tear up."

Embarrassment and Isolation

For some men, their experience led to feelings of being isolated from others, often as a result of the fear or embarrassment. Leroy, when asked about his feelings of isolation, said:

There was a time when we didn't have these Man-to-Man, and you were pretty much isolated. You had your case, and you didn't have anybody else to exchange

with, and to hear other people's experiences, and how they are being affected -- it helps.

Gus also shared how he had to deal with aspects of this situation that may include isolation. He shared:

Well, I can remember a time when I was driving in a car with a guy, driving him home, and I needed to go to the bathroom. It just poured out of me, it gushed out all over the seat -- it was embarrassing. So, you tend to almost become a recluse.

I commented, "Staying away from . . ." and Gus completed the sentence, "From all sorts of things. I'm getting better now -- I'm better with it now. I have more control."

Threat of Reoccurrence

Several comments relative to the perceived threat of reoccurrence of prostate cancer are worthy of mention. For some men, it drew a lot of emotion, and for others was not much of an issue at all. For some, anxiety and irritability existed in conjunction with one another, as part of feeling threatened by the possibility of reoccurrence. For example, Norm shared:

I guess the one thing that I would have to say is that maybe other people, uh, I don't know what other people are saying about it, but I think that I have read enough and am into stuff deep enough to know that the chances of this recurring are very strong. And that if I am fortunate to live 10 or 12 more years, sometime in that period of time, there will be a flare up, of prostate, or prostate cancer They never get rid of every cancer cell In reality, in most of what I have read, it's something that doesn't come back in one or two years, but 10 or 12 years from now, I could be dead of a car crash, you know, you don't really dwell. But the fact is, up until now, no one is going to tell you that, hey, you are 100% cured, it will never bother you again, because, it's a condition, there's nothing you can do about it. You live with it I would imagine that some people would become very concerned about that, I'd hate to think that they would dwell on it, because dwelling on it won't do any good.

Charles was asked about how often he spends time thinking about a possible reoccurrence. He answered, "It happens when you go back and get checkups . . . you're concerned a little bit before then. What are you going to do if the damned PSA start rising

again? But I don't dwell on it." It was then asked if those thoughts were sort of fleeting, and he stated:

I'd dwell on it, in that everyone once in a while you get, somehow somebody gets my name because of a Viagra mailing list or what have you, and you get all these wonderful things that are worth reading about, potency medicines . . . they are horny, the type of reading [laughing], they have you swinging from the chandeliers, and at that time I think you are aware that it has impacted your potency But, it's not the cancer, it's the side effects that goes through your mind at the time. Not the fear of having reoccurrence.

Gus was asked "If it were to come back on you, what would you do?" and he answered, "Well, that would depend on the nature of it. I probably [he paused], wouldn't treat it." "Sort of a watchful waiting approach?" I asked, and he commented:

Well, I have no problem with death -- I have no fear of it. But I would not want to die, just yet. Depending on the nature of the cancer, I don't think I'd take radiation again. And so, I say that, but that's what I feel. My wife would have a share in that decision, it would be harder for her than for me.

Irving, when asked about the time spent thinking about reoccurrence, said:

Yeah, yeah. I'm pretty sure, you know, I'm not sure that it will come back, but I keep checking, and I have the yearly checks, and I want to monitor it. If it comes back, I know I have other types of treatment to deal with it. So I am not worried about it I would worry about it if I found out it was getting worse in terms of side effects, then it would be a real problem and I would worry about it if I couldn't work. But, as of now, no problem.

To Jack the same type question was posed. He stated succinctly, "No, screw it, you know [he laughed]. What the hell can I do about it?" He was then asked if it were to happen again, would he try the same kind of approach, and he answered simply, "You deal with it." Ken was another who did not worry too much. He stated, "No. I do my checkups, no." Martin, in a similar vein, answered, "No, I don't, not anymore When I go in [for a doctor's checkup], my mind is still set on 0 [PSA value], and I don't worry about it."

Religion and Spirituality

Spiritually-based activity or religious involvement typically occurs during free time for most people. Several men talked about their spiritual beliefs, their religious involvement, and the social support that some received via membership in a church or religious community as part of how they coped with circumstances of their illness and treatment. The following examples are offered to illustrate this involvement and what it meant as part of their experience of coping with the psychosocial side effects of prostate cancer.

Darren stated, “I developed a relationship with God when I was a kid . . . [and] the Lord says He won’t give you anything more than you can handle.” He described himself as “always [having] a spirituality.” He also stated:

Very few people call on God until they are terrified of something, they have about given up, and they need help that they can’t find anywhere else. And that is when they will go to Him. And I did it twice . . . after He pulled me out of the jams that I was in, I turned my back on Him and would go somewhere else, and I would think, “What kind of a fool am I?”

When talking about having been told about his diagnosis, Darren stated:

I bowed my head and prayed, and I said, “God, I’m not strong enough to handle this, and I’m going to put it in your hands.” . . . But I’ve never really worried about it since then. Not to say that I think it’s over with, but I think, I think one of the reasons I have done pretty well with it has been my attitude.

When asked about his control and the ability to cope, Darren stated, “Part of it is my faith . . . you know, things could go bad on me tomorrow, and if that’s the way it is, I have no fear of my mortality, I mean, I got rid of that some time ago.”

Frank stated:

I began to question, “Why me? What had I done to deserve this? Did you desert me Lord?” The first thing that I would say, and this comes from my own experience, in spite of the fact that I was a positive, and what most people would agree was a well-adjusted adult male, that I was, the first thing that I would say is there is life

after prostate cancer. Not only is it not the kiss of death, that it is, it can be a positive, you know, spirituality. God can take the most negative things and turn them into extremely positive things. And whether you believe in [he paused], and I hope everyone does, in a Creator, God, or not, still there are very positive things that can come out of this. Certainly, it has brought home, not a sense of mortality, I mean I know I am not immortal, and there will come a time, and I'm not ready for it yet, but it certainly has given me an appreciation for what I do have and what I can do. And, God willing, I will do it as long as I can.

Gus, whose lifelong employment was as a minister, shared that every day his life was filled with prayer, morning and night, along with regular reading of Scripture. He stated that "the Eucharist is very important to me." This devotion appeared to provide solace for him, and he stated his religiousness was part of keeping "the same pace, the same intensity" throughout the experience.

Irving, whose life since retirement also included some voluntary clergy-like responsibilities, was asked if his experience with prostate cancer had served as any type of turning point in life, if it had helped solidify what was important to him. He stated, "Maybe I have had some sort of spiritual connection in that way. That had to be, and just not about cancer, I am ready to face anything based on my own personal relationship with my God."

Leroy, who had served in the military, had shared his religious convictions and that for him, "My prayers were answered. I asked for the Lord to bring me back in one piece [from military action]." Both Martin and Leroy said their minister had visited them when they were diagnosed. Martin stated that his minister "came by the hospital when I had surgery, and he came by the house three or four times, three or four times he came by and prayed for me, and I thank him today." It was then asked if they felt their religious beliefs and participation in their church had helped with the experience of having had cancer. Martin answered, "Sure" and Leroy said, "I would think so, because I am a praying man.

I pray regularly.” Prayer was then suggested to be something that had helped, and they both answered affirmatively. Leroy added, “I think our preacher is very effective in that [prayer] too.” Martin said, “He is, he is that -- and his wife, too.” Leroy said, “She is a minister, too.”

Norm had mentioned the importance of religion and spirituality in his life. In regards to dealing with cancer, he stated:

I think there is an overall sense of calming that one’s religion can bring to the matter. I mean, if we learn to live with what you’ve been diagnosed, you pray that it [radiation] will be successful. I couldn’t conceive not having a religion to help you with these things. I’m sure there are people out there, and it must be very frustrating for them, but, uh, I’ve always, I’m not an overly religious person, but there are certain pieces of it that I find very meaningful to me.

It was then mentioned that perhaps, in addition to providing peace, his religiosity had also provided him some strength, and he said, “Oh yeah, definitely. Going back to my war experiences and things, you know, you always ask yourself, ‘How come this ship got sunk and not that one?’ In the final analysis, when it’s all done, and you are still alive, and well, there has got to be a reason for it.”

Darren spoke of the social support that he received when asked about his present free time and leisure interests. He mentioned, “I’m active with my church.” Frank, too, spoke of this part of his religious involvement. He said:

I have a very strong spiritual family base. I mean, I had people praying for me, and visiting the hospital, I mean, just the outpouring of love for me. I mean that’s, and as I said, I have no problems with people making me feel as though I have a self-worth. You know, I have a lot of support. My family right here, this job. You know, I felt that way before, but because of what happened and the way people responded to that, from my own family, and my spiritual family and my work family, so I mean, it certainly, I feel blessed because of that.

In a conversation with Eric about religion and spirituality, he shared the following that explained his perspective – one that demonstrated respect, but that Eric had a different attitude than other men already cited:

I went to daily Bible school, and that sort of thing. I think there is a need for religion, because if there wasn't a need it wouldn't exist. For my part, organized religion doesn't play a part in my life. I frankly am an atheist. I don't mean to suggest that everyone else be an atheist, for those people who need a religious background and enjoy it, and the community feeling that goes along with it, I'm all for it. For religion plays a part in the lives of many people, and a good part. By the same token, I see some people who have never wanted to go out and get a job and work for their livelihood who felt they wouldn't have to dirty their hands, by golly, I'll be a man of the cloth, and here I go. And we have some fine examples of this, Jimmy Swaggert, Pat Robertson, and some others, and a lot of people look to them as being good leaders. Well, they maybe for them, but not for me, and that's fine.

When asked if “spirituality” is different from religion or religiosity for him, Eric stated:

It might have, I think there's something to that, yes. Yes, I so admire the religion of the Indians for example. Believing in Mother Earth, taking care of Mother Earth, and being able to worship the Sun.

Frank, who was interviewed after Eric, was also asked to explore his feeling about the different concepts – religion versus spirituality. He said:

Well, I am a very spiritual person, or at least I try to be. I certainly, I want to be known as a spiritually-minded man. I have very strong Christian beliefs. I want to be known as someone who left the legacy of good morals, strong-minded person, who is very willing to put out for others. I consider myself observant. I believe, I don't believe I can, I'm not working my way to Heaven, but I believe as a result of an opportunity to go, I demonstrate thankfulness by doing what I do.

Of men who spoke of religion, Ken was one who disavowed religion and a different spiritual conviction, although he shared having had a considerable exposure to different religions in his life. When asked if he would describe himself as a spiritual man, Ken answered, “No,” and shared his philosophy: “We are in an infinite universe for an infinite amount of time, and an infinite amount of things could happen to us.”

Discussion of Side Effects as a Category

Consequences that resulted in problems following treatment were broken down according to the traditional conceptualization of physical and psychosocial phenomenon. The following pages offer discussion and supportive literature for side effects that effected men's physical bodies and functioning, followed by side effects of a psychological, emotional, or social nature.

Discussion about Physical Side Effects

Men shared having a variety of experiences with physical side effects from the prostate cancer treatment. Numerous studies have documented physical side effects as a result of prostate cancer treatment, often within the context of exploring health-related quality of life (e.g., Wei et al., 2002). Eric, Charles, and Brian all mentioned having experienced hot flashes associated with receiving hormone treatments, and Eric stated having had a "dry mouth" sensation. Charles mentioned having experienced tenderness of his breasts and sensitivity in his nipples, not an infrequent experience for men receiving hormone therapy (American Cancer Society, 2002).

Gus, Harold, and Irving shared having to deal with bowel problems at times, and all but Norm shared their experience with incontinence when interviewed. These experiences, of course, varied from man to man in terms of duration and intensity and are seen within information provided in Chapter 5. Incontinence is known to cause men problems and impact the way they conduct their daily lives (Adolfsson, Helgason, Dickman, & Steineck, 1998; Grise & Thurman, 2001). Experiences of men in this study ranged from little or no problem with incontinence to having to utilize a variety of aids to cope with significant or severe incontinence. All the men in this study, with the exception of Brian who had not undergone active treatment, had some experience with erectile

dysfunction. Like incontinence, the significance and duration of erectile dysfunction varied from man to man. Numerous research studies provide information about the prevalence of such disorders among this population (e.g., Eton & Lepore, 2002).

Discussion about Psychosocial Side Effects

The term *psychosocial* as it applies to side effects is one where psychological and social issues stem from the individual's response to disease or disability. This is known to potentially lead to decreased activity level, changes in behavior, diminished general health, and a lower overall quality of life (Kunkel et al., 2000; Morrow et al., 1978; Visser & van Andel, 2003).

The diagnosis of cancer is likely to result in some degree of anxiety or uncertainty. These emotions are believed to stem from fear and concern about loss of bodily functions, the possibility of encountering pain, concern about treatment and side effects, the potential loss of independence, possible social isolation, and concerns about returning to work or being able to continue important activities (American Cancer Society, 2002). Also, facing one's mortality, uncertainty about one's family, and concern about if or how relationships may change are common (Freidenbergs & Kaplan, 1999).

In this study, a variety of psychosocial factors were noted as having played some role in the lives of men challenged by prostate cancer. Several of the men shared some realization that they felt shock or denial about some portion of their experience. Half of the men (7) exhibited some aspect of anxiety or fear. Three of the men (Charles, Gus, and Harold) cited instances of irritability. Frank cited his experience approximated symptoms of depression, though short-term. It should be noted, however, that most of the men were interviewed an average of 4.1 years after their diagnosis; therefore, it is likely that what may have been a more emotional or even depressing experience for men had since been

softened in their minds and the precise nature of their struggles forgotten. Four of the men (Alan, Gus, Leroy, and Martin) stated instances where they were aware of emotions that may have led to isolation or withdrawal from situations they otherwise would have participated in (either differently or at all).

Other studies have established a connection between aspects of physical functioning and psychosocial functioning. For example, Kurtz, et al.'s (2001) study found an association between diminished physical functioning and depression. Psychosocial side effects are known to have the potential to negatively impact relationships, functioning in the workplace, and performing in other social settings (Freidenbergs & Kaplan, 1999; Livneh & Antonak, 1997), and may result in decreased or modified participation in free-time activities (Iwasaki & Mannel, 2000). Men in this study talked of instances where their relationships and their activities were influenced by the side effects of prostate cancer treatment. As activities and relationships were altered or impacted, so was their participation and involvement in life situations which were deemed to be important within their conceptualization of quality of life. Research has also shown that the impact of prostate cancer and treatment may impact daily routines and activities – including those associated with work, leisure, and family obligations (Gray et al., 2000).

The Impact of Prostate Cancer Experience on Leisure Attitudes and Choices

Each man who was interviewed cited examples about how prostate cancer treatment had, to some extent, interfered with their leisure and free time activity. As mentioned in Chapter 5, men expressed different perspectives about the definition and meaning of leisure. Likewise, as men shared experiences that illustrated how the prostate cancer experience impacted their leisure, that impact differed in terms of its nature and intensity.

Based on the order these men were interviewed, the following is offered as a summary of the many ways leisure was impacted. The physical and psychological side effects that have been documented also may have influenced the men's lives, having resulted in changes in attitudes and choices that include leisure, recreation, or play. More of these ideas and an emerging theory will be explored in the next chapter when discussing these findings.

The impact on Alan's leisure was seen in changes in how he went about engaging in activities. Alan stated an interest in restoring antique tractors and displaying them at shows. Alan's experience with incontinence ("I had absolutely 100% urine leakage") was one that he had to learn to cope with in order to continue participation in this activity. To that end he mentioned:

So, I learned. I sampled every kind of absorbent pad in the store – diapers, pads, things with rubber bands to hold the sides up, like a loin cloth you know – I tried a little bit of everything and found out which worked the best. I became an authority on those things [mutual chuckle]. I came to the hospital to pick up one of those urinary, uh, things you know they have for bed patients to urinate in, with a cap. I thought, now traveling in a car, well, when you are sitting down on a chair like this [he scooted to the front edge of the chair with his back straight], Your bladder will hold urine. The urethra runs out the bottom and just the slight pressure will keep the urethra closed...Uh, I thought I could take a trip. Now with this urinary container, see with a van you can stop the vehicle, drop on one knee, and there's the space between the seats, you can empty your bladder, close your pants, get out and gas up the van, get out and do whatever you were going to do, and uh, so I figured that out, and uh, I went on a trip for two or three weeks I guess. I picked up my brother, we went out to [identified a Midwestern state] and back and I got pretty good at changing those things and looking for places where I could change and stuff.

Alan was asked about his life activities after treatment and any significant changes.

He stated:

Yeah, I came back to work in two months, and actually, I think it might have been better if I had come back half-days. I could have come back to work sooner, if I could have worked half-days. That would have been the wisest thing because I found out after noon I got so tired.

Alan, as has already been mentioned as part of other sections, shared that incontinence made it so that he was not able to go swimming. He also experienced difficulty when riding his bike. He stated:

I actually used to ride the bicycle to work here, that's how I got my exercise. You know, if I were to ride a bicycle for fun, I wouldn't ride very much...you get on there, and you know, I'd go two or three miles, and my body says, "Okay let's get off," you know? And my mind would say, "No, I gotta get to work." See, so you have to keep going until you get there. But, it worked out alright. [But] what I found was that I could ride the bicycle without leaking urine, until I got off the bicycle, you know, same problem again [release of urine once pressure was taken off the urethra].

Charles' involvement with leisure activity as part of his dealing with prostate cancer is a poignant reflection of the diversity of issues. As part of his treatment process, he chose to receive hormone treatments for six months before proceeding with radiation. In essence, part of the rationale for this decision was dictated by the fact that his son was graduating approximately four months after finding out his diagnosis, and they had planned a graduation present/vacation around a rafting trip down the Colorado River – a trip that Charles still wanted to participate in. This demonstrated a commitment to family and the utilization of a leisure/recreation activity as a vehicle of maintaining and enhancing relationships.

Charles stated that after treatment his "recovery was that of resting," and the last thing he wanted was to engage in physically demanding activities until strength returned. However, he stated:

I was reading, you know, that will take your mind away from what you were going through. But, I wasn't dwelling on it, I wanted to get over it, you know, the side effects, the weakness, the self-cathetering, being able to hold my bladder, doing my kegel exercises. But not in that sense that I was frustrated because I couldn't do it, I was concentrating on just getting well.

Charles also shared that leisure time physical activity also served a purpose as he has a desire to gain and maintain a level of fitness to remain attractive to his spouse. One way to interpret this is as an effort to cope with and compensate for problems with sexual functioning.

Darren's statements about leisure are straightforward and indicate a change experienced in terms of the level of activity he preferred. He mentioned having a friend with whom he spent time on the golf course, "He's waiting for me to get over this [cancer], so where we can get back out there." He shared, "I haven't played golf [since his treatment]...I found it very debilitating. Especially the medications they were giving me; the fact that I have little or no warning [pause]." I mentioned, "For bathroom time?" He agreed, and later commented:

I had no idea how debilitated I was until I started getting well. And then I realized what kind of shape I was then -- it was approaching lethargy. But, everything is getting better now. I came off my medicine they had me on for diarrhea and spasms. I came off that about 10 days ago. I'm having pretty near normal BM's -- there is nowhere near the same urgency. I still, I mean when I know it's coming, I won't be planning an hour's jog. I am nowhere near as far as active as I will be, I hope. I'm not on an exercise program of any type, and I want to get back on that.

Speaking about being active around the house, something Darren was accustomed to doing since he was retired, he shared:

Yeah, boy, the amount of pleasure you get out of it, but when you can do it. I'm getting more and more, like in the last week I have done more, but I told my wife, I said, 'I am going stir crazy.' My yards have gone to hell. [Mentions a friend], bless his heart, has done his best to keep them cut and everything. . . . For the most part, I'm having normal BM's [bowel movements], I have enough warning, that it is not a problem, now it's more often than I'm used to. But ah, that will lessen in time, I'm sure, and I've got to give it that time. But I am anxious to work in my garage, and in my yard, to get back out and play some golf. I want to take some trips [he mentioned hopes to travel to Ireland].

Eric's leisure involvement at the time of being interviewed entailed time spent in the out-of-doors and time spent socializing. He mentioned visiting and enjoying

conversations with other men and that, “Whenever I am out among men, I bring the subject [of the threat of prostate cancer] up.” He also spoke about sexual activity as being, in his mind, a form of leisure. To that end, the negative impact of prostate cancer has been noted.

Frank saw an impact on his ability to exercise for a time after surgery, yet it also provided him an opportunity to gain a greater appreciation for running when he was able to return to that activity. As a man who had spent much of his free time throughout his life running, he was asked when he was able to get back to it and about his experience the first time after treatment. He reported:

I believe, I can remember I think it was either, it was exactly five months to the day, five months or six months, I can't remember. And needless to say, I was out walking within a couple weeks. And I walked until he gave me the okay to run, and then I was off. I think I may have run, I think what I did, I tried to be reasonably gradual. In my walk, I may have run for half a mile. And then I think, I, well, I say gradual, but I have run over a 100 miles a week at times in my life, so what I consider gradual [he smiled]. Actually, what happened, within a couple months of starting, I was running pretty regularly. After about three or four months, I probably had run more miles in that span of my life than had ever run in my life.

Frank was then asked if that was done as a celebration of being able to run once again. He said:

People were saying, why are you doing this? And of course, at that point I was 50 years old -- I'm not training for the Olympics anymore. People ask the same things now, “Why do you do what you're doing? Why even get up at 6:00 in the morning and thrash your body?” It's because I can. And that maybe, the defiance that I was expressing, that this thing was not going to get me, was not going to get me out of my comfort zone, and I had that attitude before. The day before I had surgery, I remember, I was running down the block, and one of my friends saw me and he rolls down his window, and he says, “Should you be doing that?” [shared laughter]. And I said, “I am not sick, why shouldn't I be doing this?” I kind of went into surgery with that attitude, and I thankfully came out with it.

Gus' leisure involvement included a passion and interest for golf. The side effects from treatment, however, have made a large impact. He said:

I still play golf, but that's, there's an area where prostate cancer has really messed things up for me...I lost all control of my bladder -- I became incontinent, and really seriously incontinent. For a while, I couldn't play golf. Because in this climate [Southeastern United States], depending on the time of year, you have to take in a lot of liquids and I couldn't take them, because I had no control. I couldn't wear khaki shorts -- I'd wear blue ones [we laughed]. So, I didn't want to play -- it was too embarrassing. I still have that problem. I haven't played seriously now for a month now, because I can't take in enough liquids. Between July and October, I don't play golf. That's a new thing for me. For five years, I played Monday through Friday all year long, I can't do that anymore. And I'm sure, it has something to do with my age, too, but I tend to blame it on the prostate.

Later in the interview he made a comment that incontinence interfered with attending events that otherwise had been participated in without restriction. He commented it was about:

Just not being able to feel comfortable going to functions, a lot of things that I might go to, or with people that I . . . because I was going to the bathroom, to the men's room probably every 20 minutes, and, you know, I never had to do that before.

When asked about the impact of incontinence now, Gus mentioned, "It's getting better and better all the time now -- whether it will completely go away, probably not." Trying to understand "getting better" and how much recovery remained, I asked, "How do you gauge? I'm trying to get a gauge...30%?" He answered, laughing, "Well, I can talk about it in terms of trees on the golf course." Sharing his laughter, I commented, "After so many holes?" and he said:

Yeah, okay. There is a bathroom facility at the end of the ninth hole, so, before I play, I don't do it before I leave home, but just before I play, I urinate. And then, I won't have any water for the first few holes, and then I'll have a drink on the fourth, and I can probably get to number 6 which has a place that you can kind of hide yourself in the bushes. And then I can go to [hole] 9, and take water. When I first started, I couldn't even do those first three holes, I wanted to go every hole.

Gus had also shared an interest in cooking, and I suggested, "I can't imagine that it [prostate cancer] impacted your ability to cook?" He laughed, and said, "No." I added, "Or watch TV, or do computer?" and he included, "Or read. There has been no effect on

that all.” Gus was then asked about any increased attention to his diet due to the prostate cancer. He joked, “I never have been concerned about it. But [my wife] goes on diets quite often, she is on one now. And I go on the same diet with her, but I just take larger portions” [shared laughter].

Harold’s experience with prostate cancer affected his leisure in a unique way. He commented, “Well, for somebody who has an unfulfilled need or desire for feminine companionship, I might be losing some opportunities to have feminine companionship that I might be able to have if I didn’t have enlarged breasts, because women like to be the ones with breasts, not their men.”

Irving shared the fact that he liked to travel – both as part of continued work and for pleasure. Due to the problems of incontinence, he stated, “I’m working like mad to now control it and contain. But that is my worry, because I travel.” When asked if the prostate cancer has affected his value of leisure, Irving answered:

No, not really. I have, we like very much going off and seeing the grandkids and so forth, and we like going to movies. But we have a different taste toward movies, but we accommodate each other. She’ll come to one that I like, and then [laughing] the next one I will suffer through.

When asked about leisure providing motivation or incentive for treatment and recovery, he answered:

Yeah, you might say, my wife, I went through a period, a short period when I wasn’t tremendously interested in things [interrupted by phone call]. . . . Yeah, I remember, I used to get, I mean, my wife, I like to read the papers . . . on-line and so forth, but there was a brief time I wasn’t overly interested in. I just relaxed here, and watched shows or something, not the same type of enthusiasm like I have now . . . but I have a hunch that there was a brief period of time, I’m not so sure what it was, but, my wife mentioned, eventually you’ll get back into the flow of things.

Like Irving, prostate cancer did not appear to have much of an impact on leisure for Jack, yet his notion of quality of life, which includes leisure pursuits, impacted his

decision of treatment. When asked about leisure and his decision about treatment, Jack stated:

Well, I think probably leisure was maybe somewhat instrumental in my final decision to have a radical, in the sense that I enjoy life. And I could have opted for maybe ten years of watchful waiting, and then die. I think it is possible that if I didn't enjoy life so much, I might have considered the ten years and out type thing. But, as far as leisure, I still do what I want to do, when I want to do it. Not everything, but almost everything.

Ken, when asked what impact prostate cancer had on his leisure, struggled for an answer. He said, "I think that, you know, because one of those things, how has this affected your activity, the only thing that I can think of that my prostate has affected my activity, was that I missed my 55th college reunion." After a short time figuring out the time that reunion occurred, which was some seven years prior the interview, he continued. Later though, he shared, "I would like to get into some deep breathing exercises, and I want to get back some actual muscle stretching, and get back on the bike and start riding it again." He was then asked, if he had more strength, what type of activities he would be doing – bringing up the fact he had previously mentioned riding a stationary bike for exercise. He responded, "Well, it's something that I was doing ten years ago, very regularly, about 45 minutes a day. But somehow, between the prostate and everything else that has gone on, I've dropped out of the routine."

Leroy stated that much of his leisure time was taken by being involved with civic organizations, church activities, and watching television at home. Martin initially experienced concerns over incontinence. Of the days immediately after treatment, he said, "I'm at home, I'm not going no place. So, I did that. And, the next two, three days, and I'm still dry, I'm still dry. You know, I'm afraid to try walking outside, or go anyplace because I'm afraid I might, you know, relax [laughs]." He found, however, that

he was fairly successful at maintaining continence. He stated, "But I noticed that nothing happened. As of today, I have to be careful, you know, but, you know, it's great." This has allowed Martin to engage in activities during his free time that are important to him.

Norm was asked about leisure and what his attitudes toward leisure were since his prostate cancer experience. He stated, "I find myself not able to cut this whole yard at one time . . . but that is not my prostate cancer, that is just general overall." I inquired, "Yeah, getting older?" and he said, "Yeah, I refuse to admit it, but it's happening -- it happens to everybody."

As part of the process of interacting with different men at Man-to-Man meetings, other experiences were heard. Of note, one man mentioned that he enjoyed playing bridge. However, taking hormones, he was prone to hot flashes and recounted the first time it occurred at a bridge night -- he got red, began sweating, and it caused him considerable embarrassment, such that he questioned whether or not he would continue participation.

Leisure as a Condition of Coping and Adaptation

Chapter 2 included a review of the literature that suggested leisure is a means that people may use to help counter the negative effects of stress. Likewise, analysis of leisure behavior also helps in understanding the processes men go through to achieve and maintain life satisfaction.

Recreation and leisure is known to have a potential beneficial role for individuals coping with the daily ups and downs of life (Driver et al., 1991). Harold's use of his leisure time to write a book, Irving's and Alan's continuation of time spent in religious ministry, Eric's pursuit of love and companionship, Frank's running, and Norm's and Leroy's interest in civic involvement capture leisure time used to pursue activities that

have personal meaning. Other researchers support this notion. Iwasaki and Mannell (2000) stated that leisure can be utilized as a mechanism that promotes autonomy, facilitates relationships and friendships, and can enhance mood. Within this research and exploration, leisure was purported to promote coping strategies. For example, leisure activities are sometimes viewed as being escape-oriented, wherein they serve to keep people's minds occupied and their bodies busy. Recreational involvement also acts to develop and illustrate personality characteristics, in addition to helping create and enhance relationships between people. Social support also is received within the context of leisure (Coleman & Iso-Ahola, 1993), and research has shown that recreation results in a positive mood while at the same time reducing negative thoughts (Driver et al., 1991).

The word *meaning* is contrived as being designed or destined for a certain purpose, therefore placing some degree of importance on an activity, event, or idea (Mirriam-Webster, 2003). The meaning one attaches to leisure is personal, yet open to change and adaptation due to internal or external events or experiences (Watkins, 2000). As a person copes and adapts to a new situation (e.g., changes in one's body, alteration in routine) or experiences changes in oneself, leisure will also change to reflect a person's sense of the meaning of life and his priorities. As noted in this research, and supported by outside literature, leisure can either be positively or negatively affected as a result of this appraisal (D Kleiber et al., 1995).

When Charles was asked if his experience with prostate cancer produced any significant changes or helped to prioritize what was important to him, he replied:

It clarified it in that sense, you know, I want to see the kids graduate from college, the grandkids. But that's the only desire that I had, okay, I'm going to try to get as much as I can between now and then Yes, I have tried to be more understanding, and I've tried to be nicer to the grandkids.

Some researchers have examined the concept of development or growth following illness or the onset of a disabling condition. Another man, Ken, when asked about the significance of having cancer, stated:

Well, I had a grandfather die of cancer, and a cousin who I think had cancer. But I think, compared to all the other things that have happened to me, you know, it's that I can, when I'm up against a difficult situation, I have to do my best to survive.

Strauss (1997) theorized that crises (such as coping with cancer) combine many intrapersonal and interpersonal factors, therefore a critical event in a man's life might be considered or viewed as a "turning point." A turning point is a recognition wherein a person comes to the realization that he is not the same person he was before. Charles was asked if he felt his experience was a turning point in his life. He responded:

I think for most people in general, it certainly was for me. I think, if this had happened when I was 40 it would have been one thing, or if I were 50. But it happened when I was 62. That makes a difference, you have had a whole lot more life to live, and you've had many more experiences, good and bad, that you've gone through. This was not necessarily a turning point, I mean, it was not an epiphany.

Suggesting then that it was not a "complete turnaround" for him, he stated, "No, no, no-no. It was just one more facet to[paused]. I think meeting my wife was more important," and he went on to mention, "The birth of the kids was more important. And certainly, and their happy marriages are very important to my wife and I."

Jack added his thoughts that diminished the notion of the prostate cancer being a hugely influential one for some men. When asked if his experience had been a turning point, Jack said:

No, I think that if I had been diagnosed with serious cancer, and the chance of survival was just fair, and if I would have recovered from that, it would have been a very pivotal thing in my life. But from the minute that my PSA went up the second time, I said, well if I have cancer I will deal with it. It really never did bother me that much.

Another concept introduced in this examination is that of posttraumatic growth (Tedeschi & Calhoun, 1995; Tedeschi et al., 1998). These authors describe a phenomenon that occurs when people develop beyond their previous level of adaptation. In doing so, they also may obtain greater psychological or emotional functioning or awareness with life circumstances or priorities. According to Tedeschi, et al. (1998), several types of posttraumatic growth are possible. Changes in self-perception may be seen as viewing oneself as a survivor, enhanced self-reliance, and heightened awareness of mortality or vulnerability. Greater compassion or empathy for others might be evidenced, and changes in philosophy toward life as part of posttraumatic growth may involve a reassessment of priorities and appreciation of life, a heightened sense of meaning, potential spiritual development, and accumulation of wisdom.

Frank shared how a part of his life philosophy had changed. When asked how his experience had influenced his views toward life, he shared general feelings, along with some specific to sexuality and masculinity wherein he stated at one point in the interview that sexuality was tied into his spirituality. He later stated:

The first thing that I would say, and this comes from my own experience, in spite of the fact that I was a positive, and what most people would agree was a well adjusted adult male that I was, the first thing that I would say is there is life after prostate cancer. Not only is it not the kiss of death, that it is, it can be a positive, you know, spirituality - God can take the most negative things and turn them into extremely positive things. And whether you believe in a, and I hope everyone does, in a Creator, God, or not, still there are very positive things that can come out of this. And as I've shared already, the broadening of my, my attitudes about my own sexuality, the opening of my mind to be receptive to other things. And I really believe, although I have not personally achieved all of that, that even if I couldn't ever get an erection again like I used to, that I can still enjoy my sexuality with my wife, you know, with alternative ways. And I mean, there, there is more to being a man, I really believe this, there is more to being a man than getting an erection, it is something that if it doesn't happen I would dearly miss, but, there is a whole lot more to it. I, so in many ways, it really has really deepened my own personal sense

of man, I know that I am not a man because of the big erection I could get. There is a whole lot more to that.

Relative to sexuality and leisure, Frank also said, when asked if he felt sexuality is a form of leisure, “Yeah, definitely. And it certainly, as I said, the cancer, I probably wouldn’t have admitted that, four years ago. I don’t think would have thought that, even if I thought it, I wouldn’t have admitted it.”

Gus also shared comments that reflected a subtle change in his life philosophy. He shared:

It certainly, well, any kind of cancer would do this, but it made me realize that I am mortal, and that has been a very positive thing for me, because I hadn’t thought about it much. I had dealt with lots of other people, but never thought about it myself, and then I suddenly realized that it could be the end, but it wasn’t. So, I think that I am a much quieter person now about my own mortality than I was before.

Another man, Jack, was asked if he made it through his cancer experience as the same person he was before. He responded:

Well, of course I can’t answer to the subconsciously, because you just don’t know, but, I was much more aware of my wife’s needs and desires I don’t think I appreciated life anymore, I have always appreciated life. Life is a bitch, but it is the best we have, you know, there are a lot of bad things, but you take that with the good.

Martin was another man who discounted any significant changes to his life or outlook of it. When asked if there had been any changes because of having had prostate cancer, he said, “No, there hasn’t been any changes.” When then asked, “Was it important to you that there wasn’t any changes?” he replied, “Yeah, it is, it is important.”

Specifically focusing on prostate cancer, Curtis and Juhnke (2003) wrote that having a healthy *sense of coherence* (a dynamic feeling of confidence) is important for older men. Elaborating further, this coherence, or confidence, is “the degree to which one uses life events to learn more about oneself and others” (p. 164), thus one would

hopefully “remain open to the many lessons a cancer diagnosis can teach” (p.164).

Several comments from men speak to this occurrence. Darren remembered being told that he was likely going to be impotent and that despite being told about the variety of erectile aids that exist, he described that it “shook me up,” and that, “All of a sudden, that [erectile function] became very important to me.” Frank, who spoke openly about his sexuality, stated, “I took certain things for granted, like to be honest, like getting an erection,” and that the experience led to a “broadening of my attitudes about my own sexuality, the opening of my mind to be receptive to other things.”

Jack, when asked where his sense of purpose and strength lies, stated, “Sense of purpose. I just like to live. Ah, share, I like sharing, I like sharing the wealth.” Having gone through prostate cancer, Leroy stated he came away with a sense of purpose. He stated, “It helps morale.” When it was suggested that this type of experience helps people know what others are going through, he replied with a simple, “Yes.” Martin, sitting next to Leroy, added, “You know, people try, they are so secretive about it, they don’t want nobody to know, that, that you got cancer, or you had cancer. But, you know, I think they should come out of the closet.” He later elaborated on his views:

I’m still active, but, not quite as active as I used to be. Because, you get older, you have a tendency to slow down a little bit, you’re not speedy like you used to be. It has changed, and you just have to go with the flow.

When asked if his experience with prostate cancer had helped him to appreciate things, he replied, “It did, yes,” but explained that the side effects of treatment, coupled with getting older, had interfered with his daily routine. He explained, “I used to be able to move around a little faster, you know. The pace is slowing down somewhat, you know.” Norm also spoke to the effects of getting older. When asked if things that can still be done were taking on a greater importance because of things which cannot be done, he

said, “Ah, yeah, I can see that working, I hadn’t thought about it. I can begin to see it working in me when there is going to be that time when I’m going to want to do more things than I can physically do. Norm also spoke about how his belief in religion helped shape his recollection of this experience with prostate cancer. He stated:

I think there is an overall sense of calming that one’s religion can bring, can bring to the matter. I mean, if we learn to live with what you’ve been diagnosed, you pray that it will be successful, radiation. I couldn’t conceive not having a religion to help you with these things. I’m sure there are people out there, and it must be very frustrating for them, but, ah, I’ve always, I’m not an overly religious person, but there are certain pieces of it that I find very meaningful to me.

Perception of self was another area seemingly addressed by men within their experience with prostate cancer. Darren recounted walking out to his car after being diagnosed. He stated, “I sat there for awhile, and I said, ‘Alright boy, what are you going to do about this, you can’t walk around like this the rest of your life.’” He then recalled praying to God saying, “I’m not strong enough to handle this, and I’m going to put it in your hands.” He then phoned his wife and said he never really worried about it, believing that one of the reasons he had been successful in coping with the whole experience was because of his attitude.

Frank also spoke about perception. He had stated, “That word cancer sticks in people’s minds; and people around us hear cancer, and think ‘restricted’ – you can do this, you can’t do that, you know, it’s a perception on their part.” He shared another thought that implies posttraumatic growth:

Certainly, it has brought home, not a sense of mortality, I mean I know I am not immortal, and there will come a time, and I’m not ready for it yet, but it certainly has given me an appreciation for what I do have and what I can do. And God willing, I will do it as long as I can.

For Irving, this sort of realization was also spoken of within a spiritual realm. He stated, “Maybe I have had some sort of spiritual connection in that way. That had to be,

and just not about cancer, I am ready to face anything based on my own personal relationship with my God.” For him, enjoyment was being able to continue his work, to continue taking trips, being able “to do the work that I do.” For Ken, his perception of reality had become such that, laughing, he stated, “I think death is just the end of life. You live it while you’re alive.”

Leroy’s comment that, “I still classify myself as a cancer survivor,” was followed up with a question asking if being a survivor added to a sense of who he is, if he was a different person. He replied, “It speaks to what my health is, my general health is. And it gives me confidence that, uh, maybe I had some years added to my life, if I hadn’t gone through this procedure.” Martin also replied affirmatively that there was pride in being able to identify oneself as a survivor, in addition to the fact that it added a certain quality to his life.

Changes in relationships are another area in which posttraumatic growth can occur. Gus, who stated having a good relationship with his wife before his experience with prostate cancer, stated:

I felt that [my wife] was an integral part of me, and the whole process with me. It was almost as though she had it too, and we’d talk. And I think I got through it because of that. So, in a way it was very positive.

When it was reflected that it sounded as if he had enjoyed a good marriage up to that point, but that it had gotten better since then, he affirmed, “Oh yeah, no question about that.” Frank was asked if his experience with erectile dysfunction caused trouble within his relationship. Being one to view sexuality as a form of recreation, he replied:

Yes it has, yes it has. I mean, leisure activity, that definitely impacted that. Again, couples deal with that in different ways. You know my wife is very accepting, and she certainly placed no pressure on me. In fact [he chuckled], I wish that she would place more pressure on me.

Leroy was asked about how cancer had impacted his relationships with family, friends, and loved ones. He responded, "If it had any effect, it was positive," and went on to explain how he had gained the friendship of a woman from his church who had taken him to his daily radiation appointments and that it "helped her morale" the day he gave her a hug and "told her that I was cured." He explained that, "She had spent a lot of her time and effort helping me, and she saw something good come of it." Martin experienced the opportunity to encourage his brother to be checked for prostate cancer. When his brother was also diagnosed positively for prostate cancer, Martin said, "He found out that he did have it. And he was thanking me, you know, he said, 'I really thank you for doing this for me.'" He said that this made "me feel good too, you know."

Settlage, et al. (1988) theorized that having a serious illness (such as prostate cancer) might incite new development and a renewed exploration of self. Leisure has also been theorized as activities that are self-protective and restorative. Charles mentioned he liked to read because it served as a distraction, Alan's involvement in tractor restoration, and Frank's running all indicated a personal intent to maintain participation in activities that were valued. This coincides with reports that, during negative life events, leisure has been conceptualized to: (a) be a distraction, (b) generate optimism for the future, and (c) preserve a sense of self (D. Kleiber et al., 2002). Other researchers have also demonstrated that leisure can and often does serve important functions in times of illness. The finding that leisure serves as a mechanism for providing structure and keeping active and busy, particularly for men who were at or near the retirement phase of their life, is an outcome supported by other studies (e.g. Hutchinson, Kleiber, Loy, & Datillo, 2002).

This chapter has provided details from men's lives about their reaction to the news of their diagnosis, how they selected treatment and the experiences they had when coping from the physical and psychosocial side effects of treatment. Varied emotional responses were noted as men recollected how they reacted to being diagnosed with prostate cancer – ranging from shock and denial to relative calm and acceptance. Selection of treatment embodied a process of seeking and gathering information and then making a decision thought best for each man and his circumstances. In some instances, this included varying levels of involvement from his spouse. Dealing with physical and psychosocial side effects of treatment involved many different manifestations of maladies that invoked specific methods of coping in order to move on with life and important activities. This includes those attitudes and behaviors that relate to choices and experiences that lay within the context of leisure.

CHAPTER 7 SUMMARY AND RECOMMENDATIONS

Summary

Men who encounter the diagnosis of prostate cancer face the difficult decisions surrounding treatment, and while coping with side effects carry on with their lives using the resources, knowledge, and supports available to them. Those in this study represent a cross section of men who are of different races, had varied vocational backgrounds, were diagnosed with prostate cancer at different ages, selected different treatment approaches, and, while similarities existed, were challenged and coped with the side effects they experienced in unique ways. While common threads existed about what quality of life was about for them, certain differences existed in their presentation of what it meant to be a man or fulfill masculine roles, and many added varying facets for the meanings and description of what leisure was in their lives.

Each man who participated in this study faced prostate cancer and dealt with the consequences of treatment. Most encountered physical side effects resulting from treatment. Most shared having to cope, consciously or not, with psychosocial and emotional side effects that temporarily or permanently altered the way they viewed and went about their daily lives. Being problem- and solution-oriented, a gender trait shared by most men, participants spoke of how the processes they went through were about overcoming or coping with whatever was unpleasant and moving on with life -- being the person and doing the things deemed important to them and their families.

Leisure, as a central part of their lives, also consisted of participation in activities and behavior deemed important enough that efforts were made to seek out, try, and use a range of products or strategies to continue doing what brought enjoyment and satisfaction to their lives. Though modification of certain activities was evident, or the timing of when or how often participation could occur, men still eagerly shared what was important in their lives and, by and large, were seeing themselves as successful throughout the process of moving on with their lives.

Limitations

This research and the findings produced should be considered in light of several limitations. These limitations include several aspects of the research design, as well as the unique nature of this research as part of a Ph.D. course of study. Recruitment of participants occurred through identification and contact of volunteers at Man-to-Man meetings sponsored by the American Cancer Society. Therefore, only those men seeking the advice and support available at those meetings came into contact with this research opportunity. Men with prostate cancer who never heard of these meetings or had reasons not to attend were not part of the potential participant pool. Also, those who volunteered to be a part of this research may be considered to be of a certain personality type, or had particular life experiences that influenced their desire to share their experience. Men who were more reluctant to share, perhaps because of a difficult or troublesome experience, may have been hesitant to participate. Because the length of the interview was advertised as approximately one hour, some with busy schedules at home or work may have been discouraged from participating.

Also, twelve of the fourteen participants had experienced their treatment several years before being interviewed. The passage of time and the nuances of memory may

have distorted perception and the recollection of their experience. Casting a wide net -- seeking men of different backgrounds who had experienced varied forms of treatment -- allowed the broader picture to be understood, but at the expense of more specified knowledge about a particular group of men who had all received a similar treatment method (e.g., low-income Caucasian men having received external beam radiation). Finally, given the logistics and timelines often part of academic study, the ideal practice of incorporating research participants into the analysis of data was not able to be completed. Thus, verification of data results and discussion of interpretation was done utilizing the expertise of faculty who made up the supervisory committee.

Although efforts were made to obtain a racially balanced sample and, in fact, four of the fourteen participants identified themselves as African-American, the reality that nearly half of the American men diagnosed are Black would suggest that a similar percentage of participants be of that racial category. The availability of participants of different racial (and socioeconomic) groups may reside in factors that lead members of certain groups to or away from participation in discussion groups like Man-to-Man.

Implications for Practice and Research

The themes that evolved from this study, along with information about the conditions and properties present in men's lives when coping with prostate cancer, can lead to better services and support for men and their families. Additional studies can be designed to expand our depth of understanding about significant themes pertaining to prostate cancer, quality of life, and the role and place of leisure to enhance health and well-being.

The World Health Organization (1948) defined health as the "state of complete physical, mental and social well-being and not merely the absence of disease or

infirmity.” Recreation and leisure professionals are interested in facilitating quality participation to enable people to attain this definition of health. More specifically, recreation therapists, often in concert with other health care professionals, work with persons with illnesses or disabling conditions. The aim of recreational therapy (RT), also commonly referred to as therapeutic recreation (TR), is to “restore, remediate or rehabilitate in order to improve functioning and independence” (American Therapeutic Recreation Association, 1998), in addition to acting so the effects of illness or disability are reduced or eliminated. Recreational opportunities, resources, and services are provided to “improve health and well-being” (American Therapeutic Recreation Association, 1998).

As noted in Chapter 2, the World Health Organization (WHO) has recently published a new conceptualization to better interpret and view health conditions. This study of the impact of prostate cancer on leisure attitudes and behaviors, in addition to other aspects of quality of life, offers an opportunity to share this knowledge in a broader rehabilitation arena. In fact, almost a decade ago, Shank, et al. (1996) stated:

If TR research is going to impact the lives of people with disabilities, it is very important that it does not occur in a vacuum and that it is shared and articulated in the language of the broader rehabilitation sciences . . . thereby extending the researcher’s relevance beyond the TR discipline to the broader rehabilitative science arena (p. 182).

The latest WHO conceptualization, the *International Classification of Functioning, Disability and Health* (ICF), depicts the relationship between an individual’s health condition and its effect on body structures and systems, along with his or her level of activity and participation and other personal and environmental factors. Having identified and discussed the many facets of men’s experience with prostate cancer, the ICF provides

a framework for a non-directional blend of medical and social factors as a biopsychosocial model (Bickenbach et al., 1999).

The health condition of men who have experienced prostate cancer may vary, due to side effects of treatment received, the results of aging, or any variety of other illnesses or conditions. It is known, as described in this research and supported in literature, that the physical and psychosocial side effects of prostate cancer are the result of changes to particular body structures (e.g., the prostate gland, urethra, urinary sphincters, and nerves) and body systems and functions (e.g., urination or penile erections).

Psychological stresses, such as anxiety, uncertainty, or depression, may also interact with other conditions, such as high blood pressure. There is a need for support, counseling, and information about how to best cope with psychosocial and physical ailments (Lintz et al., 2003).

Understanding personal attributes, such as personality, one's sense of masculinity, religiosity, and attitudes toward social and leisure involvement also factor into what comprises health. Environmental factors, such as familial support, access to health care, health care products, and technology (e.g., new medical procedures or enhanced pharmacological aids to facilitate erections) also play into the health enjoyed by men and their loved ones. With or without prostate cancer, most older men go on through life performing expected activities and participating in normal life events. Some men with prostate cancer, however, face certain challenges in doing so. As a component of health, the ICF conceptualization stresses the importance of having both the opportunity and the ability to engage in activities and participate in important life events as a necessary component of health (World Health Organization, 2001). However, being diagnosed with

prostate cancer or receiving treatment does not necessarily mean a man will have a disabling condition, viewed as one that lessens his health or diminishes his quality of life.

The ICF model describes *activity* as being able to execute and complete tasks. *Participation* is defined as completing tasks or duties as a necessary part of being involved in larger life situations. *Activity limitations* are difficulties, such as those mentioned above relative to body structures or systems affected by prostate cancer, which are experienced by a man when attempting to perform an activity, such as using the restroom or having sex. *Participation restrictions* for men with prostate cancer are situations that, when wishing to be involved in important life situations, interfere with the motivation, actual experience, or recollection of the event. For example, Alan's incontinence has interfered with bike riding and swimming, and he mentioned knowing others who curtailed their interest in going to movies for fear of accidents. Gus' incontinence limited his involvement with golf and the interpersonal relationships that go along with it. He also provided evidence that he had to deal with feeling comfortable in going to functions until he had overcome incontinence or found an acceptable way to protect against embarrassing situations. Another example is Jack, who stated he had adapted to the threat of incontinence by using pads that allowed the resumption of participation in important activities like mowing the lawn, fishing, and boating. Charles and Irving both spoke of making decisions and taking actions so that side effects did not adversely curtail their interest in traveling.

The relevance of *environmental factors* has been discussed as social aspects of the culture in which one lives (e.g., friendships, family relationships, co-workers, religious peers). *Personal factors* have also been seen as an important part of the larger health

puzzle and can include things such as economic welfare, habitual behavior when dealing with anxiety or uncertainty, and ways men deal with perceived threats to masculinity or identity.

As leisure held a central focus within this study, the reader is reminded that recreation and leisure holds an important place within the conceptualization of the activity and participation domain within the ICF. Men with prostate cancer who were part of this study spoke of recreation and leisure as a positive and growth-producing element within their lives. As literature states, positive leisure activity and involvement results not only in the facilitation of physical health, but enhances social, psychological, emotional, and spiritual health (Driver et al., 1991; Godbey, 1999; McGuire et al., 1999). The quality of one's leisure participation is a key component of satisfaction for older adults (McGuire et al., 1999). As health-related quality of life has been studied pertaining to prostate cancer (Penson et al., 1998), variables related to leisure choices and behaviors should be included.

Practitioners should be mindful of men's unique personalities and circumstances that are affected and brought to bear when prostate cancer is experienced. Screening for depression or other emotional disorders is recommended. Given most men's desire for information about the disease and treatment considerations, effective methods for the delivery of this information should be evaluated and promulgated. Help, when needed and requested, should be given to ascertain and follow through with the decisions considered in the best interest of those involved. Recommendations to attend support groups and other informative enclaves should be made based on the individual circumstances of the man and his family.

Implications and recommendations stemming from this research are many. Identifying and isolating salient variables that may have a possible relationship and impact on a man's experience is very important, and these variables deserve careful examination. Because this study sought to establish preliminary data, numerous research questions can be asked to further this important line of inquiry. Several examples are now offered.

One research question of interest, when noting the prevalence of incontinence experienced by men and the potential impact on restricting activity following treatment, would be, "Do the meanings prescribed to leisure serve as a motivation for men to overcome barriers to allow continued participation?" Another question is, "Does literature found within the field of leisure studies regarding the nature of constraints provide a framework for consideration of coping mechanisms used to overcome various degrees of incontinence or erectile dysfunction?" A third interesting research question is, "Do models of human sexuality fit possible research designs that study the impact of erectile dysfunction wherein sexuality is defined as a leisure behavior?"

Yet another question may be, "Does the determination to cope with side effects of prostate cancer (as a negative life event) fit with other theories that suggest that human development results from leisure experience?" These types of questions serve as examples of the depth and breadth of approaches remaining to be explored that, when accomplished, will aide in understanding men's experience with prostate cancer.

Participant's Advice to Other Men

In the course of this study, typically near the end of the initial interviews, a question was often asked of the participant to the effect of, "If you were to meet a man who was newly diagnosed with prostate cancer, what words of encouragement or advice

would you offer him?” How participants answered this question is worth noting here because it offers support for the types of things health care providers need to consider when taking into account prevention strategies or interventions to alleviate emotional distress and advance positive coping strategies. The following comments are samples of narrative that capture the participants’ most salient words of advice – what went well for them as well as what they would do or wish to try over again.

Alan shared the importance of being able to talk to someone who had been through the experience. His work, which had been in a hospital setting, provided many such opportunities He stated:

I see our guys after surgery here and they say, “Oh my goodness, I’m hurting, and I’ve got this hose [catheter] here, and I don’t know if I’ll ever pee right again,” and I say, “Look, you know I went through that operation and, uh, I take my wife dancing, I ride bicycle, I do what I want to do, you know.” And they say, “Gee, you don’t look too bad either, you know.” One guy says, “Hey, look at him,” you know. And back when I was wearing pads, I told them, “I’m wearing pads, and well, that’s not so bad.” So, one guy [said] that he wouldn’t be able to go out of the house until he can hold his urine, see. And there are some guys, you know, that stop going to church, they stop going to movies, those are things where you do have to watch out, because you sit for a long time.

Gus expressed his opinion by simply stating, “I would tell him to read a lot about it, and study a lot about it.” Charles gave more detail to the idea of reading and studying. He said:

Becoming proactive, absolutely proactive. Proactive, I mean, getting knowledge, and some people are not the type that are interested in knowledge, it depends on the doctor. Becoming proactive, and becoming a partner in the treatment. Don’t let the doctor just tell you or dictate to [you] what you want done, ask him. Get second opinions, that’s the main thing....

Jack’s advice was similar. He stated:

I think the first thing that I would say, pre-surgery, would be to become your own advocate. Get at least three, if not four or five opinions. And you make the decision, nobody else. And then, when you make it, live with it.

Ken's suggestion was simple. He said, "About all I could say is to look hard, and consider very carefully." Irving, who is Black, stated he had, on occasion, gone with the local facilitator of the Man-to-Man group to speak to men, particularly when the audience was made up of African-Americans. He stated, "They are much more reluctant to talk about it, and men are being diagnosed much later." He was then asked if he had a sense that people listened to him, and he said, "Oh yeah, and I talked to individuals, I talk to my kids about that, because they are more liable for this to happen to them." Leroy stated, "I would ask him to, I would suggest that he attend these [Man-to-Man] meetings. We told men in our church." Martin stated, " That's right," and Leroy again mentioned his church leader. He said, "I even told my minister, and my minister went to one of the meetings."

Conclusion

A large number of men in this country and throughout the world are told they have prostate cancer and then face the uncertainty and worry about the potential effects of the illness and treatment. Regardless of the decisions made about treatment or the actual course of treatment, participation in meaningful leisure and recreation activities continues to be an important part of a man's life and the lives of his family and friends. Having prostate cancer does not change that. In fact, like encounters with other potentially serious circumstances or events, coping with cancer can often add greater meaning to life and the activities and experiences participated in.

Health care professionals can and should be aware and promote healthy recreation and leisure in the lives of those with whom they work. Understanding the likely psychological, social, and emotional reactions and experiences of men will allow for better services to be developed and provided to men and their families. Realizing that physical side effects and the feelings which accompany them will likely effect how men

go about their lives is important for post-treatment adjustment and continuation of a lifestyle that is self-determined and judged to be satisfying. The attitudes and behaviors that make up leisure for men who experience prostate cancer deserve greater exploration and understanding. Hopefully, the information and insight that stems from this study will fuel ideas and research designs that eventually will provide additional knowledge which will allow for more men to experience greater health and a successful adaptation.

APPENDIX A
FLYER

Your participation is requested to take part in a study exploring the impact of prostate cancer and its treatment on quality-of-life, specifically those aspects related to leisure

Men who have been diagnosed with prostate cancer in the past five years and have received treatment are eligible to participate.

Participation consists of being interviewed, which will take approximately one hour. There is no compensation for participation in this study and there are not any direct risks or benefits to you as a participant.

If interested in participating, please inform the facilitator of your Man-to-Man discussion group, or contact the research investigator listed below:

David Howard
206-I Florida Gym
P.O.B. 118208
Gainesville, FL 32611-8208
(352) 392-4042 ext. 1386
dkhoward@ufl.edu

THANK YOU!

APPENDIX B
INFORMED CONSENT

Please read this consent document carefully before you decide to participate in this study.

Purpose of the research study: This study is being conducted to explore the impact of prostate cancer and treatment for prostate cancer on your leisure and subsequent quality-of-life.

What you will be asked to do in the study: You will take part in a face-to-face interview that will be audio-recorded and transcribed (typed word-for-word). You may refuse to answer any question you do not want to answer. You may request that the tape recording be stopped at any time.

Time required: 1 hour.

Risks and Benefits: There are no anticipated risks associated with this study. Potential benefits include insights into understanding the role of leisure in their lives. It is possible that you may actually gain some psychological or emotional benefit from talking about difficult issues associated with prostate cancer and treatment.

Compensation: There is no compensation for participating in this study. However, you may request a copy of the results once the study is completed.

Confidentiality: Your name will not be associated with any information that you provide. Instead, you will be assigned a code number. There will be a master list of code numbers and names during the study period. The list will be destroyed when the study is over. The list will be kept in a locked file cabinet in the office of a research investigator in the Department of Rehabilitation Counseling. The only people who will have access to the list are the researcher and the faculty supervisor for this project. Audio-tapes and transcripts will be numbered with your ID number and kept in a different locked file cabinet also in my office in the Department of Rehabilitation Counseling. When the study is completed and the data have been analyzed, the tapes will be erased and lists and transcripts will be shredded. Your name will not be used in any report.

Voluntary participation:

Your participation in this study is completely voluntary. There is no penalty for not participating.

Right to withdraw from the study:

You have the right to withdraw from the study at anytime without consequence.

Whom to contact if you have questions about the study:

David Howard, Ph.D.c, M.S.W., C.T.R.S., (352) 265-0745
Elizabeth Swett, Ph.D., (352) 265-0745 (Faculty Supervisor)

Whom to contact about your rights as a research participant in the study:

UFIRB Office, Box 112250, University of Florida, Gainesville, FL 32611-2250; (352) 392-0433.

Agreement:

I have read the procedure described above. I voluntarily agree to participate in the procedure and I have received a copy of this description.

Participant: _____ Date: _____

Principal Investigator: _____ Date: _____

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BIOGRAPHICAL SKETCH

David Howard received his undergraduate degree from the University of Utah in 1995 in Recreation and Leisure Studies, with a specialization in recreational therapy. In 1998, he was awarded a Masters degree in Clinical Social Work (also from the University of Utah), with an integrative emphasis in corrections and juvenile justice. His doctoral degree was completed in 2004 from the University of Florida's Rehabilitation Science Ph.D. program (within the College of Public Health and Health Professions). Throughout these years, Mr. Howard gained valuable practical experience working in mental health settings, substance abuse treatment and prevention programs, and adult correctional institutions.