

**PERCEIVED SEXUAL CONCERNS AND SEXUAL ADJUSTMENT OF PATIENTS
UNDERGOING PROSTATIC CANCER THERAPY**

BY

PERIYAPATNA VENKATESH

**A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the degree of**

MASTER OF NURSING

**School of Nursing
University of Manitoba
Winnipeg, Manitoba.**

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ABSTRACT

The purpose of this study was to describe the perceived sexual concerns and adjustment of prostatic cancer patients undergoing treatment. The phenomenological approach was used to examine the perceptions of prostatic cancer patients regarding sexual matters surrounding their illness and its therapy. Dorothea Orem's theoretical perspective was used as a framework to gain insight into sexual self-care of the study patients, and to provide direction for implications emerging from the study findings.

A total of seven prostatic cancer patients, 40 to 70 years of age, were interviewed for approximately one and one-half hours, before and after treatment, using a semi-structured format with open-ended questions. Due to the sensitive nature of the subject matter, particular attention was paid to the ethical aspects of the study.

The respondents were primarily Caucasian, a majority of them being Protestant with at least high school education. While one patient experienced surgery, and another hormone therapy, the remaining five patients received radiotherapy. The interval between interviews was approximately two to three months.

Through Giorgi's method of phenomenological analysis, three major categories with their various properties were identified in the transcribed data--

Sexual Being, Sexual Coping, and Sexual Knowledge. These categories respectively described the sexual concerns and sexual adjustment of respondents, and the nature, amount and timing of sexual information desired by them.

All respondents identified sexuality as an important component of their lives, irrespective of the nature and degree of their sexual activity at the time. Although they had perceived numerous sexual concerns, the life-threatening nature of their illness had prompted them to focus their attention on matters of survival rather than sexuality. In their attempts to adjust to the sexual impact of their illness experience, the study patients adopted various coping behaviors.

The most significant finding of the study was that the patients, despite acknowledging many sexual concerns, did not see a need to deal with those concerns until after the completion of their treatment. The only information they expected to receive prior to deciding to undergo treatment was the sexual consequences of various treatment procedures.

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CHAPTER I

Introduction

Background to the Study

Although sexuality of patients has been identified as an essential part of nursing care, very little has been done to acquire related knowledge. In a survey conducted by Wilson and Williams (1988) to determine the oncology nurses' attitudes and behaviors related to sexuality of patients with cancer, lack of awareness of sexuality needs and lack of knowledge were cited as the reasons for not addressing sexuality concerns. The majority of the nursing literature related to sexuality is primarily anecdotal or theoretical, not based on scientific studies. Of the studies conducted to date, an overwhelming majority focus on sexuality of female patients.

One can only speculate on reasons for the scarcity of research related to sexuality of male patients. For many nurses, a problem does not exist if the patients do not express concerns regarding a matter. With such sensitive matters as sexuality, it is understandable that most male patients do not voice any questions or concerns with their nurses, who are usually female. According to Weisman (1979), "sterility, impotence, sexual inhibitions, and social restrictions are topics many patients accept without complaint (p.77)". Nurses are also guilty of not initiating sexuality related conversations with their patients. Wilson and

Williams (1988) studied a group of nurses, primarily female, regarding their attitudes and behaviors related to sexuality of patients with cancer. The investigators found that the nurses discussed sexual concerns with a patient only if the patient initiated the discussion. They also found that the nurses were quite liberal in their attitude toward sexuality-related matters and, quite conservative in sexuality-related nursing practices.

It is imperative that sexuality of male patients be well understood and addressed by nurses. This is even more the case when illness and therapy involve genital organs, and the sexual impact is more blatant. Research in this area is not only necessary, but crucial to fully understand and address sexuality concerns of prostatic cancer patients.

Statement of The Problem

Cancer, a group of malignant diseases, is a much feared entity with different meanings to different people. Whatever the type of cancer and the meaning one attaches to it, it is well understood that experiencing such an illness affects every facet of one's life.

Genitourinary carcinoma, including cancer of the prostate, bladder, and kidney, is the most frequently occurring cancer in men (Scott, Oberst, & Bookbinder, 1984). Among the three, cancer of the prostate is the most prevalent.

Carcinoma of the prostate is a common disease that occurs primarily in men over 50 years of age. An increased incidence of prostatic carcinoma over the past 50 years is partly a reflection of the longer life expectancy of men (Whitmore, 1984). The mortality rate from cancer of the prostate is quite high (Whitmore, 1984); however, the survival period for men with prostatic cancer ranges from one to ten years (Ahman, 1985b). Due to the complex system of compiling and reporting cancer statistics, actual up-to-date figures for Canada are not available. However, annual world health statistics, for the period between 1983 and 1986, reveal a 10% overall cancer mortality rate for males in Canada, 10% of which is directly attributable to prostatic carcinoma. The estimated rate of prostatic cancer for 1988 is 10% of all cancers, and 20% of all cancers occurring in men (Silverberg & Lubera, 1988).

Most reported statistics focus on morbidity, mortality, and survival rates. The survival period, that period from diagnosis to eventual demise of the patient, is of great importance to nursing. The quality of life during the survival period is what actually determines if there is any meaning to one's survival. Although survival is often the means by which we judge the effectiveness of cancer treatment, little attention has been given to the quality of that survival (Atwell, 1983). The survival period is characterized by the patients' need for optimal physical, psychological, social, and spiritual comfort. Meeting this need is an

integral part of nursing's attempt to improve the quality of life of all patients in general and, oncology patients in particular.

The survival periods for those experiencing prostatic morbidity vary in their range--anywhere from one to 5, 10, and 15 years. This expected survival period is dependent on the age of the patient at time of diagnosis, the stage of the disease, and the treatment regimen in place.

Cancer of the prostate is a disease of older adults. At diagnosis, the average age of prostatic cancer patients is 73 years (Karr & Murphy, 1984). Most bodily processes are known to become less efficient with aging. The decreased defensive ability of the body and reduced functional efficiency of the organs make it difficult to counter the disease and withstand the rigors of the treatment. These factors may shorten the patient's survival period and/or compromise their quality of life. Another factor that affects survival is the potential for prostatic cancer metastasis. Over 70% of newly diagnosed prostatic cancer patients have stage B disease or higher (Herr, 1986). It has been well documented in the medical literature that the higher the stage of prostatic cancer, the lower the rate of survival. However, the treatment procedures in use today, even with their tremendous potential to decrease the quality of life, are believed to increase survival periods of cancer patients.

Various treatment modalities are used in the management of patients with prostatic carcinoma. The most commonly used modalities include surgery,

radiation therapy, chemotherapy, and hormonal manipulation through pharmacotherapy and orchiectomy (Huben & Murphy, 1986). The treatment procedures are known to have many discomforting side effects. These invasive treatment procedures carry a certain potential for sexual dysfunction for its recipients, and hence adversely affect their quality of life. Commonly observed sexual dysfunctions include: diminished libido, retrograde ejaculation, and temporary or permanent impotence (Bergman, Damber, Littbrand, Sjogren, & Tomic, 1983; Swanson, 1981; Walsh, 1980). Regardless of the type and origin (psychogenic or organic) of sexual dysfunction experienced, its impact on the man's sexuality is considerable (Fisher, 1983). For cancer patients, life and death concerns are initially of high priority. However, as the illness trajectory lengthens, concerns regarding sexuality emerge (Wilson & Williams, 1988).

The events occurring in one's life after his or her gender is established have important effects on one's sexuality (Woods, 1987). The effects of prostatic cancer and its treatment on one's sexuality may be compounded by the individual's "sexual self-concept". The phenomenon of sexual self-concept includes such factors as gender identity, gender role, body image, and self-concept (Woods, 1987). The sexual self-concept is believed to influence the development and maintenance of one's sexuality. The patient's reaction to his perceived or real sexual dysfunction may be adversely affected by his altered sexual self-concept, and hence, may make the consequent sexual adjustment a difficult one.

Sexual adjustment is a necessary part of the total well being and quality of life of prostatic cancer patients. Hence, nurses have an important role in facilitating the sexual adjustment of their patients during the survival period (Frank-Stromberg, 1985). Teaching, counselling, and providing emotional support are important interventions to promote their patients' overall health. As a necessary component of health, sexuality is an important aspect of patient care, particularly of prostatic cancer patients.

Facilitating sexual adjustment of prostatic cancer patients demands that nurses understand the topic of sexuality and know about the intricate mechanisms involved in the adjustment process. However, few nursing research studies have examined the sexuality of patients. Between 1971 and 1981, only one study explored the sexuality of patients with cancer (Hott & Ryan-Merit, 1982). Recently, in nursing, there has been an increased interest in studying the impact of various illnesses on the sexual life of patients and their sexual partners.

Although as nurses we attempt to facilitate sexual adjustment of patients under our care, our knowledge base regarding sexuality of male patients is very limited. In order to provide quality, individualized care, nurses need to understand sexual behaviour in terms of its meaning to the individual patient (Zalar, 1982). Irrespective of the patients' age or health status, only when the sexual lives of prostatic cancer patients are enhanced can their quality of life be said to have been truly improved. To acquire the necessary scientific knowledge,

it is imperative to study rigorously, and describe accurately, the sexual concerns of prostatic cancer patients.

Therefore, the questions this study proposes to investigate are:

1. What are the perceived sexual concerns of prostatic cancer patients following diagnosis, before and after treatment?
2. What are the prostatic cancer patients' perceptions regarding altered sexuality and the consequent sexual adjustment process?
3. What do prostatic cancer patients perceive as the effect of their illness and its treatment on their family and family relationships?

Purposes of the Study

The purposes of this study were:

1. to understand the prostatic cancer patients' perceived sexual impact of their illness and its treatment.
2. to identify the prostatic cancer patients' perceived sexual concerns and the consequent sexual adjustment.
3. to determine the effect of prostatic cancer patients' illness experience on their family relationships.

Conceptual Perspective of the Study

A conceptual framework of Orem's self-care theories form a basis to help explain the sexuality needs of individuals, particularly prostatic cancer patients. For the purposes of this research study, the perspective of self-care is also intended to provide direction for recommendations based on the study's findings.

The theories of self-care, self-care deficit, and nursing system are based on the view that individuals are responsible for their own care (self-care) in relation to their health, and that it is nursing's responsibility to assist them when their ability to meet self-care requisites is diminished (Orem, 1985). Orem lists self-care requisites of individuals under three main categories--1. Universal Self-Care Requisites, 2. Developmental Self-Care Requisites, and 3. Health Deviation Self-Care Requisites. The universal self-care requisites include such requirements as air, water, food, elimination, rest and activity, social interaction, prevention of hazards, and promotion of human functioning and development within social groups. The developmental self-care requisites refer to the requirements through the stages of human development. The health deviation self-care requisites refer to those requirements of the individual during an illness or debilitation. Since prostatic cancer patients are experiencing the effects an illness and its treatment(s), those self-care requisites referred to as health deviation self-care requisites become central to the subject matter of this study.

The health deviation self-care requisites are associated with genetic and constitutional defects, human structural and functional deviations and their effects, and with medical, diagnostic and treatment measures. The individual is believed to require assistance to meet the therapeutic self-care demands necessitated by health deviation self-care requisites.

According to Orem's conceptualization, self-care is not forthcoming if the self-care agency, the patient, is unable to meet self-care demands. In this situation, a self-care deficit exists and is evidenced as health-deviation self-care requisite, with which the patient may require assistance.

Orem's theory would propose that the prostatic cancer patient is a self-care agent with therapeutic self-care demands to maintain his integrity and functioning. The sexual dysfunction(s) resulting from prostatic cancer and/or its treatment may render him unable to meet the self-care requisites of affection, love, friendship, social warmth, and closeness, that are essential for continuing development and adjustment (Orem, 1980). It may be particularly so if the self-care requisites in question are closely bound to his sexual relationship. According to Orem, in health-deviations, the nurse becomes the provider of self-care and uses the educative-supportive nursing system to facilitate health. This involves interventions such as teaching, counselling, and providing emotional support (Orem, 1985).

Orem (1980) stated that:

"human beings are distinguished from other living things by their capacity to: a. reflect upon themselves and their environment, b. symbolize what they experience, and c. use symbolic creations in thinking, in communicating and in guiding efforts to do and to make things that are beneficial to self and others" (p. 118).

Thus, in Orem's conceptualization of the client, the individual's perceptions of the world are an integral part of their "self". In order to intervene and provide self-care, Orem directed the nurse to understand the clients' viewpoint and the meaning they attach to various life events. Thus, knowledge about the subjective meaning patients attach to the entire illness experience of prostatic cancer is a prerequisite for effective care. Hence, if nurses can determine how clients perceive the effects of prostatic cancer and its treatment on sexuality, then their self-care can be enhanced.

Appendices A and B further explain the terms in Orem's theory, and the investigator's conceptualization of the prostatic cancer patient according to Orem's theory.

Methodological Perspective for the Study

The phenomenological method shares in the values and beliefs of nursing that the human phenomenon is holistic and meaningful (Omery, 1983), and that human beings are individual and their actions in some sense are free (Munhall,

1989). To understand a complex phenomenon, such as the sexuality of patients, is to discover its holistic meaning for patients, in the context of their illness.

Premises underlying phenomenology

Phenomenology is a philosophy, an approach and a method (Oiler, 1982). The term phenomenology is derived from two Greek words--"phainomenon", meaning an appearance, and "logos", meaning reason. Phenomenology is a reasoned enquiry aimed at discovering the essences of appearances (Stewart & Mickunas, 1974). The appearance is thought to be anything of which one is conscious.

Phenomenological philosophy came to light in the beginning of 20th century, and has been written about by many philosophers, such as Max Weber, Max Scheler, George Herbert Mead, Charles Cooley and John Dewey, to mention a few. The basic writings in this field, however, come from the German philosopher Edmund Husserl. His thesis is that consciousness constitutes the world--the thesis that the existence of the world and anything in it is an achievement of the consciousness (McKenna, 1982). A phenomenologist would say that a phenomenon exists when one is conscious of it, and for one to be conscious of any thing is to experience it.

"Phenomenology subsumes all positions that stress the primacy of consciousness and subjective meaning in the interpretation of social action" (Davis,

1978, p. 187). No assumptions are made regarding behavior; the action is defined through the meaning of an experience, or experiences, which are consciously apprehended and cognitively constituted (Schutz, 1967).

Alfred Schutz, a philosopher and a sociologist, has written a great deal explaining and clarifying Husserl's writings on phenomenological philosophy. His effort in life was primarily to establish phenomenological sociology. A major portion of his writings has been primarily in the area of phenomenology of the social world.

In discussing Schutz's work, Wagner (1970) has stated that "knowledge of another's mind is possible through the intermediary of events occurring on or produced by another's body" (p.164). Referring to Husserl's terminology, Schutz (1967) calls this "appresentation" of the other. That is to say that only the body of the other is originally presented for our perception. However, the mind, with its storehouse of experiences is given to us only in copresence, and hence, not original. The original perceptions of the other are his own, and can be learned only by interacting with the other. These original perceptions are dependent upon his time-space: his particular Here and Now (Wagner, 1970). Thus, the experience of prostatic cancer patients, and its meaning to them may be influenced by their past and present context.

Phenomenology and the study

One appropriate way to elicit the clients' perceptions of his concerns is the

methodologies, phenomenology is an inductive, descriptive research method designed to determine the cognitive and subjective meanings of the individual experiences from the participants' perspective (Omery, 1983). Phenomenological research methods enable the researcher to understand the clients' perceptions of their experiences as they are lived, from their viewpoint. The aim of a study using the phenomenological method is to describe lived experiences of its participants (Omery, 1983).

"As long as an experience has meaning, a potential is there for the phenomenological method to be utilized" (Omery, 1983). The illness experience surrounding prostatic cancer is believed to have differing meanings for each individual patient. In order that the clients receive holistic nursing care, it is necessary that the illness experience be understood in terms of its meaning to the individual client. Phenomenology is aligned with the client oriented, holistic approach to nursing care. Since sexual health is an integral part of holistic health care (Fisher, 1983), phenomenology offers an appropriate approach to understanding the sexual concerns of prostatic cancer patients.

Nursing, a human science, is concerned with human phenomena. Experiences of these phenomena and their effect on clients and nursing practice are of great importance to the nursing profession. The phenomenological approach can most effectively serve nursing's goal to understand experience (Oiler, 1982) since this approach is primarily concerned with lived experiences.

Orem's perspective of self-care is congruent with the phenomenological approach. Orem's basic assumption of man as a being capable of thinking, perceiving and experiencing life events, and as having the ability to communicate this experience for the benefit of self and others, is fundamental to phenomenological philosophy. Thus, it is believed that these philosophical and theoretical perspectives lend much support to the purposes of this study.

Phenomenology accepts the experience as it exists in the consciousness of the subject and does not expect duplicate behaviour from duplicate data (Omery, 1983). This is to say that experiences are individual and holistic. However, although the experiences of each prostatic cancer patient are expected to be unique, some common sexual concerns are believed to emerge. To this end, phenomenology is a very appropriate research method to answer this study's questions.

Definition of Terms

In this study, the following definitions apply:

1. Sexuality--a comprehensive term that encompasses physical, functional, psychosociocultural, and ethical attributes that are expressed by one's gender identity and sexual behaviour.
2. Sexual health--the integration of the somatic, emotional, intellectual, and social aspects of sexual being, in ways that are positively

enriching and enhance personality, communication and love (World Health Organization, 1975).

3. Sexual dysfunction--an alteration in sexual structure or function of the body.
 - a. Impotence (erectile dysfunction)--the inability to achieve or maintain an erection sufficient for sexual intercourse.
 - b. Retrograde ejaculation--expulsion of ejaculate in the opposite direction to that which is considered normal.
4. Sexual adjustment--an ongoing process by which alterations in sexuality are accommodated into a person's lifestyle in ways promoting sexual health.

Assumptions

The following assumptions are recognized in this study:

1. All human beings are sexual beings.
2. Prostatic cancer is a health-deviation of individuals which affects self-care ability.
3. Health-deviations have meaning to individuals.
4. Individuals can communicate this meaning to others.

Limitations

The following are recognized as limitations of the study:

1. A disparity may occur between what people say and what they mean (Schwartz & Jacobs, 1979). However, this disparity may be reduced by clarification and validation during the interview.
2. Considering the sensitive nature of the subject matter, a sampling bias may occur. Those who have more liberal attitudes toward matters of sexuality may be more willing to participate, and hence, may be over represented.
3. Any particularities of the health care facility where from the participants are recruited may influence their perception of the illness experience.

Organization of the Thesis

In the forthcoming chapters, the events leading to presentation of discussion of findings will be addressed. In the next chapter, relevant literature related to the study topic will be thoroughly discussed. Chapter 3 deals with the details of the study's research design. In this chapter, along with specifics of data collection and analysis procedures, ethical considerations relating to participants will be discussed. Chapters 4 and 5 will respectively present and discuss findings analyzed and synthesized from the data. Lastly, the discussion in chapter 5 will

be followed by the investigator's recommendations for nursing practice, education and research, emerging from the study findings.

Summary

The quality of nursing care of prostatic cancer patients could be greatly enhanced by understanding the sexual impact of their illness and its treatment. The concerns of prostatic cancer patients' have not been addressed systematically through research. In this chapter, the statement of the problem and its significance to nursing were presented. Also, the theoretical and methodological perspectives providing direction for the study were established.

For a research study to be scientifically sound, that is, for it to answer the research questions accurately, adequately and appropriately, there must exist a proper triangular fit between the study's purpose, conceptual perspective, and methodological perspective. Such a triangular fit is evident in this study. Orem's Self-care theory proposes that the client's perceptions of his life events are an integral part of his "self", and hence directs the nurse to understand the client's "self" in order to intervene and provide self-care. The research questions proposed to be answered by this study seek to understand the prostatic cancer patient's perceptions of his illness experience from his perspective. The philosophical tenet of the phenomenological method not only subsumes such a view regarding the nature of human beings, but also provides an approach to collecting data. Hence

the questions, and the conceptual and methodological perspectives of the study are congruent in their focus directed toward understanding patients' perceptions of their illness experience. This triangular fit is believed to considerably enhance the content validity of the study.

CHAPTER II

Review of the Literature

Introduction

The impact of prostatic cancer and its treatment on one's sexuality is a complex matter. Although it has been identified that one's sexuality is affected by the experience of a chronic illness such as cancer (Williams, Wilson, Hongladarom, & McDonell, 1986), the patient's own perspective is not well established. It may be that the perceptions of such an experience are unique to individual patients. However, at a time when individualized nursing care is so strongly emphasized, it is imperative that patients' own perceptions of their concerns, and reactions to their illness and its treatment, be thoroughly understood and precisely documented. No where is this more true than with such a sensitive and personal topic as sexuality.

A review of the literature from 1975 to the present suggested that research related to the sexuality aspect of prostatic cancer patients is very limited. Fisher and Levin (1983), referring to sexual knowledge and attitude, stated:

"it must be emphasized that there has been no research to specifically address either the nurses' attitude toward the significant sexual adjustments often necessary for the cancer patients, or the nurses' ability to assist the cancer patients with these adjustments" (p. 59).

The preceding statement is reflective of the paucity of nursing research studies in the area of sexual adjustment, especially of prostatic cancer patients. According to Fisher (1985b), research into the sexual problems and adjustment of patients with cancer is vital to the quality of future care nurses can offer. Knowledge development in this area is a prerequisite if nurses are to facilitate optimal sexual adjustment of their patients.

Lately, more sexuality related nursing research has been conducted but the focus has been primarily on nurses' knowledge, attitude and behavior rather than patient concerns. Moreover, a majority of these studies relate to female sexuality, and the topic of sexuality of prostatic cancer patients is rarely addressed. The available medical literature in this area refers to the effects of prostatic cancer and its treatment on the integrity of sexual structure and function; not sexuality as a whole, or the whole person's responses to these changes.

Sexuality of prostatic cancer patients and their consequent sexual adjustment are complex phenomena which need to be addressed by taking all related factors into consideration. The following is a discussion of the reviewed literature encompassing all such factors.

Cancer of the Prostate

The prostate gland, about the size of a chestnut, is located just below the urinary bladder and surrounds the proximal urethra. The normal prostate is a

mass of glandular tissue enclosed in a capsule composed of fibromuscular connective tissue, blood vessels, lymphatics, and nerves (Catalona, 1984). According to the physiologists, the exact purpose of the prostate gland in the human body is unclear. However, the gland is known to contribute prostatic fluid to the male ejaculate. Although this fluid is known to aid in the composition and passage of the ejaculate, the gland alone does not possess any reproductive or sexual function.

However, surgical and radiation treatments to the prostate gland can be potentially hazardous to one's sexual function because of the proximity of the gland to the vascular and neural supply of the penis. It is believed that the penis receives its neural innervation from the cavernous nerves, located just outside the prostatic capsule (Walsh, 1987), and the blood supply from the internal pudendal artery, which lies adjacent to the prostate gland (Langman & Woerdeman, 1982). Sexual dysfunctions, especially erectile dysfunctions, are believed to be a result of injury to the neurovascular bundle in the prostatic plexus (Walsh, 1987). Since excision of all tumor and preservation of life are primary goals of any cancer surgery (Walsh, 1987), sexual consequences command only secondary importance.

The prostate gland is an important organ, not so much for its useful functions, but rather for its tendency toward inflammation, hypertrophy, and cancer (Langman & Woerdeman, 1982). Prostate cancer is the most common malignancy among elderly men in North America, and adenocarcinoma accounts

for 98% of the primary malignancies of the prostate (Guthrie & Watson, 1987). Most affected males are over 50 years of age, the peak incidence occurring at age 70 (Herr, 1986). If the Manitoba population is considered to be representative of Canada, it is estimated that over 7000 new cases of prostatic cancer will be diagnosed nationally, each year (Singer, 1984). As with any illness, early detection and treatment enhances the survival rate of prostatic cancer patients (Ahman, 1985a; Andriole & Catalona, 1987).

Treatment of prostatic cancer is a very controversial topic. There is no one definitive mode of treatment for prostatic cancer. The decision to treat by any one or more methods is known to be based on the stage of the disease (Herr, 1986). When cancer is confined to the prostate gland, the higher the stage, the more rigorous the treatment. In those cases where the disease has metastasized beyond the prostatic capsule, the choice of treatment may be restricted to just palliative therapy--conservative management of the disease and associated symptoms (Table 1).

The advent of modern treatment methods has increased the survival rate of cancer patients, and the quality of life of their extended longevity has become a major issue in cancer care (Sachin, 1982). However long the survival, staying alive may not be desired by patients if life has too much suffering and too little meaning (Golden & Golden, 1980).

Table 1

| Stage and Treatment of Cancer of the Prostate | | |
|---|---|---|
| STAGE | DESCRIPTION | TREATMENT |
| Stage A | <ul style="list-style-type: none"> - incidentally discovered carcinoma. - generally detected after prostatic surgery performed to relieve urinary obstruction from clinically benign prostatic enlargement (BPH). | <ul style="list-style-type: none"> - Observation (70+ years) - Prostatectomy - Radiation |
| Stage B | <ul style="list-style-type: none"> - a nodule confined to the prostatic capsule. | <ul style="list-style-type: none"> - Observation (70+ years) - Prostatectomy - Radiation |
| Stage C | <ul style="list-style-type: none"> - locally advanced cancer invading prostatic capsule or seminal vesicles. | <ul style="list-style-type: none"> - Observation (70+ years) - Prostatectomy - Hormonal (with obstructive urinary symptoms) - Medication - Orchiectomy - Chemotherapy |
| Stage D | <ul style="list-style-type: none"> - pelvic nodal or systemic metastases, most commonly detected in bone. | <ul style="list-style-type: none"> - Palliation - Hormonal - Medication - Orchiectomy |

Cancer of the Prostate and its Meaning to the Patient

Different people attach different meanings to an illness. In explaining this human phenomenon, Susan Sontag (1978) suggested that the most healthy way of experiencing an illness is to be completely void of metaphoric thinking. She explained that, in reality, it is seldom possible to divorce oneself from the lurid metaphors conjured up by an illness. This is very true with the experience of an illness such as cancer. Cancer, like many other events, evokes symbolic or metaphoric meanings. For the majority of people, cancer becomes the act of being close to death, or death itself (Sontag, 1978).

According to Lakoff and Johnson (1980), "the essence of metaphor is understanding and experiencing one kind of thing in terms of another (p. 5)". They asserted that a conceptual system guides both human action and thought, and is fundamentally metaphorical in nature. Thus the use of metaphors is pervasive and evident in the way people think, perceive, and act. Metaphorically speaking, cancer is referred to as something that is invading, burning, spreading, consuming, blocking, agonizing, debilitating, and one leading to death (Sontag, 1978). With reference to illness, all of the above words have negative connotations. Patients, upon being diagnosed as having cancer, attempt to understand their disease with such a built-in metaphoric conceptual system. For prostatic cancer patients, having a disease of the urogenital organ that is directly associated with their sexual self (Atwell, 1983), the metaphoric meanings may

indeed surround their sexual being.

For many, sexuality and sexual expression convey being human, and being alive (Lamb & Woods, 1981). For prostatic cancer patients, alterations in sexual function as a result of disease or its treatment may have tremendous implications for meaning, purpose and hope in life. It may indeed affect their sexual-self. For prostatic cancer patients, reduced sexual life may mean loss of quality of life, or life itself.

The Sexual-Self and the Prostatic Cancer Patient

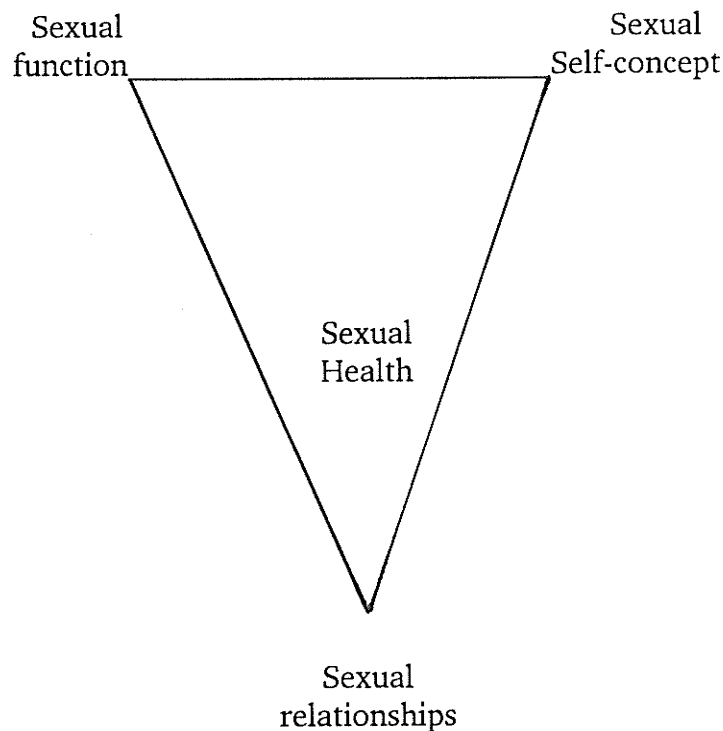
Sexual function, sexual self-concept, and sexual roles and relationships constitute important dimensions of human sexuality (Woods, 1987). All human beings are believed to be sexual from conception to death. However, one's sexual interest and activity may decrease with aging (Kolodny, Masters, Johnson, & Biggs, 1979). Kolodny et al. (1979) and Woods (1987) suggested that one's sexual function changes gradually throughout the lifespan. Although there is no evidence to suggest that sexual function ceases at any one particular point in life (Melman & Leiter, 1983; Woods, 1987), a prevalent societal myth has been to view loss of sexual function as a natural phenomenon of aging (Sviland, 1978; Tallmer, 1984).

Considering that the overwhelming majority of prostatic cancer patients are older adults, over the age of 60, it is safe to assume that they are already adjusting to certain changes in their sexual life. The additional changes caused by

their illness and its treatment may compound the difficulties of their sexual adjustment process. Adjusting to changes in sexual response requires the integration of functional changes into one's sexual self (Woods, 1987).

Woods (1987) defines sexual-self or sexual self-concept as "the image one has of oneself as a man or a woman and the evaluation of one's adequacy in masculine or feminine roles (p. 1)". Sexual self-concept is a term used to collectively refer to one's gender identity, gender role, body image, and self-concept. The nature of the interrelationship of one's sexual function, sexual relationships, and sexual self-concept is a measure of one's overall sexual health (Woods, 1987, Figure 1).

Figure 2. Sexual Health and its Various Components.



Sexual health comprises much more than just sexual function. Therefore, sexual dysfunctions by themselves do not constitute lack of sexual health. It is the impact of sexual dysfunctions on one's sexual self-concept and relationships that determines a person's sexual health status.

According to Woods (1987), "gender identity is the feeling one is male, female, or ambivalent (p. 2)". Woods points out that gender identity is believed to be well established very early in life, whereas the gender role, the sense of maleness or femaleness, is known to be assigned by parents and, learned and expressed by the child in early childhood. Western society has long identified certain emotional and physical behaviors as uniquely feminine or masculine. The pressure to adhere to these societal role expectations is both overt and covert. A major portion of these expected role behaviors, especially for a man, pertain to the area of sexuality. Shipes and Lehr (1982) stated: "an area saturated with stereotyped male role expectations is that of sexual expression (p. 377)". Most pervasive of these male sexual role expectations appear to have stemmed from the association of maleness with insatiable appetite for sexual intimacy, ability to engage in sexual acts for long duration, exaggerated penis size, and power and physical strength. One's body image and self-concept are built on one's ability to fulfil such role expectations. Any injury or illness that is perceived by men to compromise their sexual role performance can be a severe threat to their body image and sexual self-concept (Shipes & Lehr, 1982). The authors also point out

that when the injury or illness affects their sexual function the impact may be even greater. Not only are sexual dysfunctions a consequence of such expectations, but these dysfunctions are also viewed catastrophically (Shipes & Lehr, 1982).

Prostatic Cancer and Sexual Dysfunction

When examining the effects of prostatic cancer and its treatment on one's sexual function, the effect of the disease alone is not well understood. It is estimated that erectile and ejaculatory dysfunctions may be present in up to 40% and 23% of prostatic cancer patients respectively prior to any treatment (Schover, von Eschenbach, Smith, & Gonzalez, 1984). It is, however, well documented that sexual function is affected by all of the main forms of treatment for prostatic cancer--surgery, radiotherapy, chemotherapy, and androgen manipulation through orchiectomy and/or pharmacotherapy (Bachers, 1985; Bergman et al., 1983; Eggleston & Walsh, 1985; Fowler et al., 1988; Goldstein, Feldman, Deckers, Babyan, & Krane, 1984; Heinrich-Ryning, 1987; Rowan, 1986; Schover et al., 1984; Swanson, 1981; Vikram & Vikram, 1988).

The sexual dysfunctions as a result of prostatic cancer treatment may range anywhere from changes in sexual interest to erectile impotence (Krane, 1986). The type and degree of dysfunction is believed to be dependent upon the mode of treatment and the age of the patient (Heinrich-Rynning, 1987; Walsh, 1987).

The untoward effects on sexual function that may be encountered as a result of prostatic cancer treatment can be classified into four major problem areas--problems of sexual expression, problems of sexual response, problems of ejaculation, and problems of erection. Problems of sexual expression include altered perception of self as a sexual being and feelings of diminished masculinity; problems of sexual response include decreased or absent sexual interest, sexual desire, and sexual pleasure; problems of ejaculation include decreased ejaculation (force and amount), absent ejaculation, and retrograde ejaculation; and problems of erection include temporary or permanent, partial and complete impotence.

Problems of Sexual Expression

According to Lamb and Woods (1981), "for many, sexuality and sexual expression convey being human, and being alive (p. 137)". Fisher (1983) asserted that an "ample evidence exists to confirm the fact that a loss of femininity or masculinity is a major effect of today's cancer treatments" (p. 64). Not only do prostatic cancer patients experience physiologic effects from therapy, but also effects on their sexual identity. Besides damaging sexual function, prostatic cancer treatments may also trigger psychological responses, including diminished self-image and depression (Rowan, 1986).

Upon examining the literature on sexuality, it is abundantly clear that one's sexuality is greatly influenced by such psychosociocultural factors as sexual beliefs

and attitudes, sexual experience, family mores, body image, and self-concept (Fisher, 1985a; MacElveen-Hoen & McCorkle, 1985). Human sexuality is a complex phenomenon that encompasses our biological being, our sense of self, and our ways of relating to others (Lamb & Woods, 1981). These factors are important considerations for prostatic cancer patients, whatever the degree of sexual dysfunction.

The meaning of sexuality for a prostatic cancer patient may depend on his individual experience, and his perception of that experience. Hence, for the prostatic cancer patient, sexual expression may take on a whole new dimension.

"Sexual expression is a means of knowing oneself and then sharing that self with others" (Ver Steeg, 1981, p. 268). Sexual expression is a multipurpose tool (Ver Steeg, 1981), that in part serves to give and receive comfort, love, and affection, and to convey one's masculinity or femininity (Zilbergeld, 1978).

Sexual expression has to do with activities involving the genitalia and much more. Any resulting loss of sexual function due to disease or therapy should be examined in the context of patient's own perceptions of his sexuality and its importance to his personhood (von Eschenbach, 1981).

Appropriate adjustment to any sexual change is a prerequisite to healthful sexual expression--an integral part of one's total well being. McRae and Henderson (1975) described sexual adjustment as the process of exploring alternatives in expressing sexuality. Waterhouse and Metcalfe (1986) defined

sexual adjustment as "the clients' sexual feelings and functioning after treatment for cancer, relative to sexual feelings and function before diagnosis of the cancer" (p. 54). In their attempts to develop a tool to measure sexual adjustment, Waterhouse and Metcalfe (1986) studied eight head and neck cancer patients and 84 healthy individuals. They found cancer subjects to have lower sexual adjustment.

Many patients after a prostatectomy or an orchiectomy have "feelings of grief and loss similar to those that women may have after a hysterectomy or mastectomy" (Bachers, 1985, p. 19). Most available medical literature in the area of male sexuality refer strictly to physical sexual dysfunction. However, some research studies have considered the impact of therapy on patients' perception of self as a sexual being. One such study by Bergman et al. (1984) explored the impact of radiotherapy, estrogen therapy and orchiectomy on overall sexuality of prostatic cancer patients. The patients treated with estrogen were found to have felt changed, or more feminine, and had high scores for depression. Almost all patients who underwent either orchiectomy or estrogen therapy believed that their partners' sexual attitude toward them had changed. The investigators described these feelings as having a basis in obvious physical changes and concluded that these changes induced by therapy may be frustrating experiences that attack the male role. It was also observed by the investigators that the group receiving orchiectomy seemed to cease all types of sexual expression more often than the

group on estrogen therapy.

Blackmore (1988), in her study of unilaterally orchiectomised patients, noted that the study subjects had significant body image problems. This was found to be more prevalent in those men where orchiectomy was performed for removal of cancer. The same group of patients were also found to have significantly decreased sexual interaction. Most men desired intercourse more frequently than they attained it. These findings may very well explain how difficult it is for men with body image changes to express themselves sexually.

Nurses have an important role in facilitating sexual adjustment of patients, and promoting optimal sexual expression. Healthy sexual expression may indeed signify quality of life, not just survival.

Problems of Sexual Response

One's inability to express the self as a sexual being may in fact affect one's sexual response, that is, the experience of sexual interest, sexual desire, and sexual pleasure. "Cancer is a thief. It steals from its victims the precious possessions of their personhood" (von Eschenbach, Pamphilis, & Kean, 1981, p. 217). This statement exemplifies the impact of cancer on its hosts. Sexuality is only one aspect, but an important aspect of personhood. When the loss of any dimension of a cancer patient's sexual self can be prevented or alleviated, it becomes even more important to understand the sexual concerns of prostatic cancer patients.

Sexual response concerns in themselves may lead to more severe sexual problems in prostatic cancer patients. Almost all forms of cancer therapy have been implicated to some degree in the loss of sexual interest, orgasm, and satisfaction (Bergman et al., 1984; Goldstein et al., 1984; Krane, 1986; Rowan, 1986; Schover et al., 1984; Swanson, 1981). Healthy sexual response of any degree during the post therapy period may indicate how well the patient is adjusting to the sexual effects of the disease and its therapy. Any coital and relational difficulties experienced by the patient may be a result of sexual response problems.

The study by Bergan et al. (1984) of 36 prostatic cancer patients, 12 from each of the radiotherapy, orchiectomy, and estrogen therapy groups, found that overall sexual desire either diminished or completely disappeared in 58% of the 36 patients. In addition, significant decreases in coitus and orgasm, and a high degree of dissatisfaction with their sexual life were noted. The second most common reason given for decreased sexual activity, after erectile capacity, was decreased interest. Men treated with estrogen reported feelings of various body image changes. Those men who were depressed experienced decreased sexual satisfaction.

In the report of a sexual activity survey of 34 post therapy prostatic cancer patients (von Eschenbach, Pamphilis, & Kean, 1981), the authors pointed out that 39 percent from the radiotherapy group and 54 per cent from the orchiectomy

and/or hormonal therapy group failed to experience orgasm during sexual activity. A 90 per cent rate of loss of libido in patients undergoing Buserilin therapy (androgen suppression) has been reported (Presant et al., 1987).

Reports of the rate of retention of libido with all forms of therapy have been varied and controversial. Goldstein et al. (1984) reported that in their study of 23 patients, libido was preserved in 80 per cent of the patients following external beam radiation therapy. Ahman (1985b) noted that almost all androgen suppression therapies (estrogen, orchiectomy, and LHRH analogues) decreased libido, and considered this to be a reversible complication.

Any degree of problem with sexual response is a serious concern. What is evident from the review of the literature is that there appears to be a definite relationship between occurrences of sexual activity and the quality of sexual response. These can be viewed as cyclical events, where success in one is necessary for success in the other.

Problems of Sexual Function

Problems of ejaculation.

One common problem encountered by patients with prostatic carcinoma relates to the ejaculate and the act of ejaculation. The literature supports the notion that ejaculatory problems in prostatic cancer patients may be organic in nature, and caused by the disease process itself or its treatment (Krane, 1986;

Swanson, 1981). Normally, the act of ejaculation entails "passage of ejaculate through the urethra and its expulsion out of the urethral meatus" (Benson, Lipshultz, & McConnell, 1981). The most common ejaculatory problems for prostatic cancer patients are retrograde, painful, and diminished or absent ejaculation.

Schover et al. (1984) referring to their 1978 study of 22 prostatic cancer patients, stated that 23% of the patients experienced painful ejaculation prior to any treatment. These authors also found that radiation therapy caused painful ejaculation due to irritation of the posterior urethra, and permanent reduction in semen volume.

Krane (1986) pointed out that 62 per cent of patients experienced retrograde ejaculation (the semen travelling in the direction opposite to what is normal) following prostatectomy. This may be due to the bladder neck being rendered incompetent by the surgical procedure (Rowan, 1986). According to Swanson (1981), absence of ejaculation occurs in every patient following prostatectomy. Of the 36 prostatic cancer patients examined for post therapy sexual function, 25 per cent of radiotherapy, 8 percent of orchiectomy, and 25 per cent of estrogen therapy patients complained of ejaculatory problems in the study conducted by Bergman et al. (1984).

Both vascular and neurophysiological changes have been implicated as the underlying mechanisms responsible for ejaculatory problems. Whatever the cause,

changes in the characteristics of ejaculation and the ejaculate are alarming and stressful to the patient. Since many patients see ejaculation as successful completion of sexual intercourse, absent or diminished ejaculation may discourage them from attempting future sexual activity.

Problems of erection.

Erectile dysfunctions that were dismissed as merely psychogenic in their origin are now increasingly considered to have an organic basis. In the recent past, 90 per cent of the erectile problems were assumed to be psychogenic (Ahman, 1985a). Such an assumption has limited the research done about erectile problems, their incidence and management. Of late, an increasing number of studies are being carried out to assess the impact of disease and its treatment on patients' sexuality.

Erectile problems that occur in prostatic cancer patients as a result of treatment are believed to be caused by such complications as damage to the nerves innervating the penis, fibrosis of the pelvic vasculature, or decreased levels of circulating androgen (Bachers, 1985). Prostatectomy, radiation therapy and androgen manipulation (orchiectomy and/or estrogen therapy) employed in the management of prostatic cancer are known to involve one or more of the above complications.

An incidence of erectile impotence approaching 100 per cent with conventional radical prostatectomy has been mentioned in the medical literature (Reznicek & Williams, 1986). Impotence is known to occur in 80 to 90% of the patients undergoing radical prostatectomy (Eggleston & Walsh, 1985; Walsh, 1980). Swanson (1981) found that 85% of his patient sample experienced erectile dysfunction following radical prostatectomy. According to Schover and Fife (1985), men under 60 years of age were more likely to retain erectile potency after a recovery period of six months following this procedure.

Transurethral prostatectomy, which involves removal of prostatic tissue through the urethra, is more commonly performed for relief of urethral obstructive symptoms as a result of benign prostatic hypertrophy or as a staging procedure for cancer of the prostate. This procedure, by far, is the least rigorous of all forms of prostate surgery which involve direct surgical excision of prostatic tissue. However, the incidence of impotence following transurethral resection of the prostate (TURP) is noted to be anywhere between 5% and 65% (Collins, 1987). The report of actual rates of impotence following TURP is varied and controversial. Fowler et al. (1988) documented a self-reported absence of penile erections in 5 per cent of the patients undergoing TURP (n=263). According to Guevera and Sethney (1986), the postoperative impotence with TURP is low. They concluded that although most incidents of post TURP impotence should be attributed to psychologic factors, sufficient objective data in this field is lacking. Their advice

to patients undergoing TURP is that "uncomplicated TURP will neither diminish nor enhance their sexuality" (p. 546). As the meaning of sexuality is quite personal and individual, the use of the term sexuality by these authors may be too general and erroneous.

Recently, nerve sparing techniques in the field of prostatic surgery have been shown to retain erectile potency in most patients undergoing prostatectomy (Walsh, 1987). Walsh and Donker (1982) reported a high potency retention rate in their follow up study of 250 patients whose cancerous prostate glands were excised using a nerve sparing radical surgery. The investigators found that 149 of the 206 patients who were potent pre-operatively remained potent post-operatively. The return of potency in most of the 149 patients was found to be gradual over a period of one to two years following surgery. Although it may be possible to preserve erectile potency, adoption of new nerve sparing surgical techniques appears to be very limited. The fear of leaving behind some cancerous tissue when attempting to avoid injuring or removing the pelvic nerve plexus has been noted as the most frequent reason for not using the nerve sparing techniques. Where the goal of surgery is cure by removal of all cancerous tissue, the fear of leaving behind some cancerous tissue may be justified and widespread.

Eggleston and Walsh (1985) believed that this fear was unfounded and unnecessary. According to these investigators, it was possible to preserve erectile potency in most patients undergoing radical prostatectomy by adopting the nerve

sparing technique, without compromising the adequacy of the removal of the cancer. In their two year study (1982 to 1984) of 100 patients who underwent modified nerve sparing radical retropubic prostatectomy for complete resection of localized prostatic carcinoma, Eggleston and Walsh (1985) found that of the 60 patients who were potent preoperatively 84 per cent remained potent one year postoperatively.

In a similar study of 52 patients, Catalona & Dresner (1985) reported that they obtained comparable results. Of 42 patients who were sexually potent preoperatively, 98 per cent were found to have partial erections postoperatively. Of these 41 patients, 52 per cent were found to have erections sufficient for vaginal penetration. Although no correlation between pathological stage and postoperative potency could be established, it was reported that erections sufficient for vaginal penetration returned in 67 per cent of the patients less than 60 years of age and 43 per cent of those over 60 years of age.

Walsh, Epstein, & Lowe (1987) studied 312 patients for their erectile potency following radical retropubic prostatectomy with wide unilateral excision of the neurovascular bundle, a nerve sparing technique for preservation of sexual function. The investigators found that of the 29 patients who were potent preoperatively, 31 per cent experienced impotence postoperatively. Of the 20 patients who retained potency, age was found to have a significant influence. They included 100 per cent of those between the ages of 40 and 49, 80 per cent

of those between the ages of 50 and 59, and 50 per cent of those between the ages of 60 and 69. Despite the return of partial erectile capacity with nerve sparing techniques, the quality of erections in some patients may not be sufficient for satisfactory intercourse (Bahnson & Catalona, 1988).

In the treatment of prostatic cancer, one treatment that is frequently chosen over surgery is radiation therapy. The reason for choosing radiation over radical surgery is based on many factors--age of the patient, stage of the disease at the time of treatment, expected survival period, and probable sexual dysfunctions (Huben & Murphy, 1986; Swanson, 1981). Even though it is not documented, physicians' choice and comfort with the treatment method is believed to play an important part in selecting treatment. It has been noted in the medical literature that radiation therapy is chosen over radical prostatectomy since impotence and other complications are less significant with radiation therapy (Huben & Murphy, 1986; Reznicek & Williams, 1986; Rowan, 1986). However, it was reported by Paulson, Lin, & Hinshaw (1982) that disease control and survival rates were significantly better with radical surgery at 90 per cent than with radiation therapy at 62 per cent.

Radiation therapy is administered in one of two ways-- external beam or internal implantation of a radioisotope (Gold 198 or Iodine 125). The incidence of erectile impotence following external beam radiation was reported to be higher than that following interstitial radiation (Swanson, 1981). According to von

Eschenbach (1980), impotence occurred in 41 to 84 per cent of the patients undergoing radiation therapy. The loss of erectile function experienced by prostatic cancer patients as a result of radiation therapy during the first year after treatment is believed to be gradual and permanent (Schover et al., 1984; Vikram & Vikram, 1988).

In an attempt to understand to what extent prostatic cancer patients were sexually active post radiotherapy, von Eschenbach et al. (1981) surveyed 66 patients, of which 23 had had radiotherapy. All of the 23 patients had reported having been involved in various levels of sexual activity prior to therapy. Post therapy (5 months to 9 years), almost 52 per cent stated that they were unable to achieve erections. Almost 40 per cent had suspended all types of sexual activity. Although this survey was not intended to measure sexual dysfunction, the impact of radiotherapy on sexual function was certainly apparent.

In a study of 36 prostatic cancer patients, 12 from each of the radiotherapy, orchiectomy and estrogen therapy groups, Bergman et al. (1984) found that 25 per cent of radiotherapy patients experienced impotence. It was also found that with those nine patients (75%) who had retained potency, the frequency of coitus had decreased considerably. However, no explanation was given for such a decline in their coital frequency. Goldstein et al. (1984) reported in their study of 23 prostatic cancer patients that radiation associated impotence was evidenced in 79 per cent of the 19 patients who were potent prior to radiation therapy. The

erectile potency of the other four patients was found to remain unchanged. Contrary to the belief that loss of erection occurs as a result of radiation injury to the parasympathetic pelvic plexus (von Eschenbach, 1980), these investigators concluded that the results of the study overwhelmingly supported the notion that radiation associated impotence has a vasculogenic cause, and that it is dose dependent. All of the subjects were found to have normal or near normal levels of androgen, which clearly excluded any suggestion of a hormonal cause for radiation associated impotence.

Significant changes in sex hormone levels in humans are known to affect their sexual function. Since it was established in the 1940's that prostatic cancer may be androgen dependent, androgen manipulation in the treatment of prostatic cancer either by pharmacotherapy (estrogen, LHRH analogues, or antiandrogen therapy) or surgical castration (bilateral orchiectomy) has been extensively used to prolong the survival periods of patients with advanced cancer of the prostate (Trachtenberg, 1987). However, the use of this treatment has had deleterious effects on sexual health of its recipients.

Hormonal manipulation by means of surgical castration, although quite effective for androgen suppression, has been found to be somewhat psychologically unacceptable for many physicians and patients (Trachtenberg, 1987). Orchiectomy is believed to grossly affect sexual ability. The incidence of erectile dysfunction with orchiectomy is quite high (O'Brien & Lynch, 1988; Schover et al., 1984;

Swanson, 1981), while other side effects, those associated with estrogens, are considered to be significantly low (Trachtenberg, 1987). With estrogen therapy, although the untoward effects on sexual function are not considered to be any less, the other side effects of nausea, vomiting, headaches, fluid retention, gynecomastia and cardiovascular problems are found to be quite pronounced (Trachtenberg, 1987). Schover et. al. (1984) also suggested that patients on hormonal therapy fear that they will become fat, effeminate, and asexual.

Although this fear is considered by some experts to be unfounded, many sexual effects of hormonal therapy are real. Mellman, Tiefer, & Pederson (1988) evaluated 406 patients who in general complained of erectile dysfunction. Those patients (27.3 per cent) who exhibited either organic or psychogenic erectile dysfunction were diagnosed as having either very low levels of testosterone, very high levels of prolactin (hormone capable of inducing impotence), or very high levels of estradiol. Although this was not a study involving prostatic cancer patients, the results showed a direct hormonal influence on sexual function.

Bergman et al. (1984) studied sexual function in 36 patients with prostatic cancer, 12 patients from each of three treatment groups--radiotherapy, orchiectomy and estrogen treatment. During the following 24 months, of all 36 patients who were known to have had successful intercourse prior to treatment, the investigators found that 83 per cent on estrogen and 75 per cent who had orchiectomy experienced considerable erectile problems. Impaired erectile capacity

was the most commonly cited reason by all groups for decreased sexual activity. Patients from both estrogen and orchiectomy groups were also found to have testosterone levels that were significantly low. Although 70 to 90 per cent of the patients responded positively to hormonal manipulation (Heinrich-Rynning, 1987), the quality of their sexual life was severely compromised.

A sexual activity survey conducted by von Eschenbach et al. (1981) revealed that, of the 11 prostatic cancer patients treated with orchiectomy and/or hormonal therapy and who were sexually active pretherapy, approximately 54 per cent were unable to achieve an erection and only 36 per cent were involved in any type of sexual activity post therapy. It is, therefore, likely that hormonal manipulation affects sexual function.

Recently, analogues of luteinizing hormone-releasing hormone (LHRH) have been gaining widespread popularity as an alternate form of hormone manipulation (Huben & Murphy, 1986). These LHRH analogues are believed to be as effective as estrogen in their ability to suppress androgen while being considerably less cytotoxic (O'Brien & Lynch, 1988). However, their effect on sexual function may be as devastating as any of the other forms of hormone manipulation. A test conducted by Presant and colleagues (1987) on 33 stage C or D prostatic cancer patients to determine the safety and efficacy of Buserilin (LHRH) showed that although overall quality of life for 50 per cent of the patients improved, 85 per cent of the patients experienced impotence. In a similar study with LHRH

analogue Zoladex (N=27) by Murphy et al. (1987), the effect of the drug on overall sexual function was not reported. The only mention was with regards to the drug causing decreased libido. In addition, LHRH analogues are believed to also induce the physiologic flare (a transient increase in serum androgens and disease related effects such as bone pain) (Trachtenberg, 1987).

There are many reported instances of retained erectile potency after hormonal treatment of prostatic cancer. Fisher (1987), citing accounts of his own experience with hormonal therapy, stated that after six years of continuous therapy it was still possible to enjoy a healthy sexual life. According to many experts in the field, the chances of retaining erectile potency is dependent upon the patient's age and other concomitant disease conditions. That is, the older the patient and the poorer the health status, the greater the chances of experiencing erectile dysfunction.

Schlegel and Walsh (1987) evaluated 25 preoperatively potent patients for erectile potency following radical cysto-prostatectomy using a nerve sparing technique to preserve sexual function. These investigators found that age had a significant effect on postoperative potency. Of the 8 patients less than 60 years old, 88 per cent were potent compared to 40 per cent between 61 and 70 years old. The investigators also found that the advanced pathological stage did not appear to adversely affect postoperative potency. The influence of age on post

treatment sexual function is also supported by other similar studies (Schover et al., 1984; Walsh et al., 1987).

Of late, nonsteroidal antiandrogens such as flutamide have been increasingly used when preservation of sexual potency is desired (Trachtenberg, 1987). Trachtenberg suggested that drugs such as flutamide preserve sexual potency since they induce hormonal remission through competitive inhibition rather than by suppression of circulating androgens. These antiandrogen agents, when used in combination with LHRH analogues, have been found to achieve immediate androgen blockade and prevent the physiologic flare associated with LHRH analogues (Labrie, Dupont, Belanger, & Lachance, 1987; Trachtenberg, 1987). However, sexual effects of this type of combination therapy have not been described clearly.

Whereas androgen deprivation is the main treatment method used in the management of hormone dependent prostatic cancer (deKernion & Lindner, 1984), cytotoxic chemotherapy alone has been used primarily in patients with endocrine-resistant tumors (Chodak, Eisenberger, Scardino & Torti, 1987). Various combinations of hormonal and cytotoxic agents have also been used in patients with heterogenous tumors with the hope of ablating androgen-dependent cells and destroying androgen-independent cells (Elder & Catalona, 1984). Some of the more commonly used cytotoxic agents such as cyclophosphamide, 5-fluorouracil, methotrexate, doxorubicin and mitomycin (Catalona, 1990) are believed to cause

severe side effects, and directly or indirectly affect the patient's sexuality (Guthrie & Watson, 1987).

Besides the fact that prostatic cancer therapies affect patients' sexual function, it is important to understand that erectile problems may in themselves cause the prostatic cancer patient to doubt his ability to function as a man since sexual ability is often equated with masculinity (or manliness). It is equally important to also understand the feelings and behaviors such a sensitive matter may evoke.

Summary

It was evident from a review of the literature that the sexuality of patients experiencing prostate cancer is not well researched. Both medical and nursing literature in the area of sexuality of prostatic cancer patients was scant. Whatever literature that has been published focused primarily on sexual function and activity, not on the impact of disease and its therapy on the total person. The nursing literature was found to be primarily anecdotal rather than research based.

Research studies describing the sexual experiences of prostatic cancer patients from the patients' perspective were almost nonexistent. This not only raises questions regarding the nature of health care for prostatic cancer patients, but more fundamentally, what is understood about the sexual concerns prostatic cancer patients may have.

It is true that concerns regarding sexuality are a sensitive and personal matter. It is also true that our mandate as health care professionals is to view and address patients as total human beings. To this end, it is crucial that patients be understood and treated holistically. Upon reviewing the literature it was apparent that there is much to be learned about prostatic cancer patients and their sexuality. It is possible that, despite the sensitive nature of sexuality, a thorough understanding of patients' sexual concerns could contribute to the development of much needed knowledge in this area.

CHAPTER III

Research Design

Introduction

The design of a research study includes protocols for sample selection, data collection, and data analysis (Wilson, 1985). In order to obtain valid and reliable answers to the research questions, it was imperative that an appropriate design be selected. The selection of a research design was greatly influenced by the study's purpose and the questions it purported to answer.

The main purpose of this study was to understand the sexual concerns and the sexual adjustment of prostatic cancer patients undergoing therapy. In essence, it was to sense the lived sexual experiences of prostatic cancer patients in the context of their illness and its therapy.

Given the personal, sensitive and subjective nature of the topic of sexuality, the qualitative method was deemed ideal for the study. According to Giorgi (1975), to understand one's lived experiences is to begin with naive descriptions and, for the researcher to let the situation, as it exists for the subject, to reveal itself through the descriptions in an unbiased way. The notion of capturing the meaning of situations as they exist for the subjects is the phenomenological approach. Hence, this study adopted the qualitative method of phenomenology.

In this chapter, details regarding the study's sample selection, data collection and data analysis procedures will be discussed. Where necessary, statements will be supported by appropriate literature.

Study Sample

Study Population

The target population was identified as patients recently diagnosed as having prostatic cancer and scheduled for either prostatic surgery, radiotherapy, chemotherapy, or hormonal therapy. At the time of first interview, the treatment protocol had been just decided or had just begun for the majority of patients.

Criteria for Selection

The criteria for inclusion of patients into the study were:

1. diagnosis of prostatic cancer;
2. ability to understand and speak English;
3. oriented to time, place, and person;
4. under 70 years of age;
5. scheduled for medical or surgical treatment;
6. has a sexual partner;
7. is sexually active; and
8. absence of a diagnosis of diabetes.

The criteria were used to select those individuals who represented the most valid viewpoint of prostatic cancer patients. In order to minimize the concerns of sexuality associated with other biological factors, the criteria regarding age and diabetes were included. According to Harmatz and Novak (1983), erectile potency diminishes considerably after age 70. Diabetes is also known to cause organic impotence (Silber, 1981).

Selection Procedure

Urologists at three different clinics in Winnipeg were approached and requested to ask those patients who met the selection criteria if they would be interested to enrol in the study. Phone numbers of those prospective participants who met criteria, were interested in the study, and agreed to talk to the investigator were obtained from the urologists. The patients were then called to set up an appointment to describe the study and obtain consent for participation in the study. During this initial interview verbal and written descriptions regarding the purpose of the study, the number and length of interviews, the nature and subject matter of the study, and patients' rights and responsibilities for participating in the study were given. The content of the consent form was read aloud, and each participant was allowed to read the consent form prior to signing. The wives of those participants who were present during the explanation of the study were requested to witness their spouse's consent. Once the consent was

obtained, this initial contact with the participants was utilized to build rapport, to establish investigator's credibility, to answer questions regarding the study, and to set up the first of two interviews for data collection.

Profile of the Participants

A total of seven prostatic cancer patients, whose therapy had just begun or was scheduled to begin within a week's time, consented to participate in the study. All but one patient remained in the study until its completion. This one patient refused the post-therapy interview, but consented to inclusion of the data provided at the pre-therapy interview.

The participants' ages ranged from 45 to 70 years--one at 45, four between 60 and 67, and two at 70 years of age. Their educational background was varied; while one had university education, four had some high school and two had less than high school education. All but two participants had retired from the work force. All of the patients were Caucasian and of Protestant affiliation with the exception of two patients who were of Catholic affiliation. All participants were married, anywhere from eight to 46 years, and living with their spouses at the time of data collection. All participants consumed alcohol only occasionally. Of the seven patients, while one patient continued to smoke tobacco, five had quit either smoking or chewing tobacco six to 15 years ago, and one had never smoked.

All of the participants had been diagnosed as having prostatic cancer in the last six months. Of the seven patients, five had radiotherapy, one had radical prostatectomy, and the other, bilateral orchiectomy followed by hormone therapy. Five of seven patients had undergone transurethral prostatectomy prior to their cancer treatment. While three patients did not have any coexisting medical conditions of consequence, four had been at one time diagnosed as having some cardiovascular illness, for which three were on medication. None of the participants were severely restricted in their everyday activities due to their illness(es).

Data Collection Technique

Indepth, semi-structured interviews were conducted with each participant, before and after treatment. All participants were interviewed privately in their own homes. These interviews were conducted alone with respondents, in the absence of their wives. All interviews were tape recorded for transcription at a later time.

Each interview averaged approximately one and one-half hours in duration. The first of two interviews occurred shortly after recruitment and, the second, eight to ten weeks after completion of the patient's therapy. The lag time of six to eight weeks before the second interview after completion of therapy was allowed to accommodate patients' recuperation from the stress of hospitalization and/or therapy, and for the return of their interest in sexual activity.

During the interviews, the respondents' feelings and concerns regarding sexuality and the sexual adjustment process surrounding prostatic cancer were explored. The questions during the first interview focused on anticipatory and/or real concerns, and during the second, actual and/or expected concerns. In addition, during the first interview, pertinent demographic data and a brief sexual history were obtained. An interview guide with Open-ended questions was used to direct the conversation and collect data relevant to the research questions (Appendix C). The interviewer's questions followed Orem's theoretical perspective and phenomenological thought (Giorgi, 1975; Orem, 1985).

The open-ended interview technique was selected since the researcher was investigating a relatively unexplored area (Field & Morse, 1985). The phenomenological method also required the researcher to let the experience unfold as it existed for the participants (Omery, 1983). The interview typically proceeded from superficial to increasing depth, from more general to less general questions, and from less sensitive to more sensitive issues concerning the subject matter under study. Participants' were frequently and appropriately asked to clarify their responses and to validate the investigator's understanding.

Investigator's Role

Nursing's primary concern being human responses, "the researcher becomes oriented toward discovering and uncovering insights, meanings, and understanding

of those responses" (Munhall, 1989, p. 26). Mindful of such an orientation, the investigator was cognizant of the need to avoid imposition of the interviewer's own insights and beliefs regarding the topic, while collecting and analyzing participants' responses. According to Munhall (1989), the phenomenological method requires the practice of "suspension or bracketing out of what the researcher has already come to believe, suspect, or assume" regarding the topic being investigated (p. 27). "Bracketing" refers to the researcher forsaking, temporarily, all presumptions and prior conceptions, and to view the data with an open and clear mind. The practice of bracketing was exercised rigorously by the investigator during data collection and analysis.

Ethical and Human Rights Considerations

The research proposal for this study was approved by the Ethics Committee of the University of Manitoba School of Nursing.

Polit and Hungler (1988) stated, "When human beings are used as subjects of research investigations, as is generally the case in nursing research, great care must be exercised in ensuring that the rights of those human beings are protected" (p. 22). To this end, many safeguards were built into the study. Considering the highly sensitive nature of the topic of sexuality, prior to, during, and after all interactions with the participants, much attention was given to matters of ethics. Archbold (1986) suggested that the risk-benefit ratio of qualitative research should

be assessed continually through the study. The study participants themselves expressed that the study was useful and they were happy to contribute to it. At no time during the study did they express any concerns about participation.

Prior to Data Collection

Human subjects have the right to know what is involved if they decide to participate (Archbold, 1986). In light of this it was important to clearly explain the details of the study to all prospective participants approached by the investigator.

The participants for the study were sought from three urology clinics in Winnipeg. The urologists were requested to approach the newly diagnosed prostatic cancer patients at their respective clinics and to ask if they would be interested in participating in the study. The prospective participants were contacted only after they expressed interest to participate. The researcher personally introduced himself and explained the study's purpose, use of tape-recorded interviews, and maintenance of confidentiality. The researcher then explained that the confidentiality would be maintained in the following manner.

1. The participant's name would not appear on transcripts. Each participant would be assigned a code number.

2. The list of participants' names and code numbers, as well as the consent forms, would be kept separate from the data in a safe place and would be accessible only to the researcher.
3. Any information that might identify the participants would not be revealed to any one.
4. At the completion of the project, all related material would be destroyed.
5. With regards to the identification of the source of data, no specific references would be made in presentations or publications.

The introduction of the study to clients occurred only when they were judged by the clinic's medical and/or nursing staff as physically, emotionally and mentally able to tolerate an information-sharing meeting. An explanatory letter and the consent form were read aloud and shared with the clients (Appendix D). The researcher informed the clients that they were not obligated to participate and that refusing to participate would in no way jeopardize their future care. They were also informed that if they agreed to participate, they could refuse to answer any questions or withdraw from the study at any time without any effect on their care. In each case, clear explanation was provided for excluding the spouse from participating in the interviews. The participants were asked to sign the consent form only after they repeated in essence what the researcher had explained.

During Data Collection

Participants were seen for the first interview approximately one week after consenting to participate in the study. This one week period was allowed for the participants to reconsider and withdraw from the study if they chose to do so. One participant withdrew after the first interview, but consented to the data obtained in the first interview. At the outset of each interview, the participants were reminded not to utter names and other information that could be identifiable.

During data collection ethical issues relate to the relationship between, and the roles of, nurse/investigator and participant/patient (Archbold, 1986). In some instances, the acquisition of information serves the interest of participants (Polit & Hungler, 1988). Some participants in the study indicated that the interviews were therapeutic because they were allowed to express their feelings. In most instances, the participants expected the investigator to provide information regarding their concerns. This role expectation was overcome by clearly explaining the researcher's role and encouraging them to consult their urologists. However, while they addressed the matter of death, emotional support was provided and the interviewing was suspended momentarily until they agreed to continue. They were periodically asked to take short breaks during the interview. The participants did not appear to find the general nature of interview questions as stressful.

After Data Collection

The audio recordings of interviews were placed in a safe place after each interview. During transcription of the recorded interviews, all responses deemed to identify the participants were omitted or changed to unidentifiable terms or letters. At the conclusion of the second interview, the participants were reminded that they had consented to the presentation and/or publication of the study findings, and that their identity would not be revealed in any manner.

Data Analysis Technique

Parse, Coyne, & Smith (1985) stated that:

"the data analysis of phenomenological method is rigorous, adhering strictly to a systematic approach, which compel the researcher to abide by the spirit and intent of the guiding principles of phenomenological analysis. The strict adherence is in the contemplative dwelling of the data. The contemplative dwelling is the undistracted reading and re-reading of the descriptions with the intent to uncover the meaning of the lived experience for the subject. The contemplative dwelling frees the researcher to be open to both the tacit and the explicit messages in the data" (p. 19).

To this end, Giorgi's (1975 & 1985) procedure for phenomenological analysis was adopted in this study. The five steps contained in Giorgi's procedure required this type of rigorous contemplative dwelling.

Upon completion of data collection, the tape recorded interviews were transcribed and coded to protect the participants' identity. The transcribed data were initially read to sense the whole and delineate constituents, the meaning units. These two steps of data analysis were carried out as each interview was completed. This practice allowed for more focused questions in subsequent interviews in order to procure quality data regarding the emerging constituents. Then the content of each interview was analyzed following the five steps outlined by Amedeo Giorgi (1975 & 1985).

Step 1. Sensing the whole:

The entire description is read straight through to get a sense of the whole. The researcher experiences the situation described by the participant rather than merely viewing the words on a page.

Step 2. Delineating constituents:

The same description is again read more slowly to sense transitions in meaning in the experience. These are called meaning units--the constituents. The differentiating parts are identified in this process while being mindful of the whole.

Step 3. Eliminating redundancy:

The researcher identifies and discards redundancies while keeping all units. Then the meaning of constituents are clarified and elaborated by relating them to each other and the whole.

Step 4. Transforming meaning:

In this process, the researcher examines each constituent and transforms the meaning from the naive language of the participant to the language of concerned science. Here, the researcher interprets the relevancy to the discipline of interest.

Step 5. Forming structure:

Insights are integrated and synthesized into a descriptive structure of the meaning of that experience (Omery, 1983). The structure is then communicated to colleagues for criticism.

Steps two and three, described above, were carried out with the assistance of a computer using the Ethnograph software program. This program assisted the researcher in identifying and categorizing the constituents--the meaning units of the content.

Validity and Reliability

Validity and Reliability are much contested terms in the arena of qualitative research. The suggestions are that these criteria are misnomers for judging the methodological rigor of a qualitative study, as qualitative research is based entirely on a different set of assumptions from that of quantitative research (Burns, 1989; Guba, 1981; Sandelowski, 1986; Younge & Stewin, 1988). Various alternate criteria have been suggested by which to assess the rigor of qualitative studies

(Lincon & Guba, 1985). Sandelowski (1986) (relating to the criteria suggested by Guba and Lincon) describes four measures of rigor--1. truth value/internal validity, 2. applicability/external validity, 3. consistency/reliability, and 4. neutrality/objectivity. These criteria will be considered in the following discussion regarding the rigor of this study.

Interviews conducted in the participants' natural settings enhance the reliability of the data because it minimizes some of the environmental constraints and allows the participants to feel comfortable and in control (Field & Morse, 1985).

The content of the interview guide emerged from clinical practice. As a graduate student in an earlier clinical course, the investigator's primary objective was to encourage and assist prostatic cancer patients to express their sexual concerns. During this time a set of questions generated from the investigator's discussions with prostatic cancer patients under his care proved facilitative, and were used to formulate the study's interview guide. The interview guide was then piloted to ensure high validity and reliability.

According to Field and Morse (1985), both validity and reliability can be increased through rigorous training of the interviewer, as s/he is the instrument. Since the investigator interviewed all participants and was experienced with this type of interviewing, the interrater reliability and internal consistency were greatly enhanced.

During an interview, the informants often have a tendency to wander off the topic and provide irrelevant information. The amount of irrelevant information in an interview is known as the "dross rate" (Field & Morse, 1985). This was minimized by guiding the interview and keeping the informant on topic, reducing the proportion data not germane to the research questions.

Too much familiarity with participants may prove detrimental to the data collection process (Schwartz & Jacob, 1979). The necessary rapport and trust were established by visiting the participant in their homes once prior to conducting the interviews, thus adding to the truth value of the data. Establishment of rapport and trust are known to aid persons to more fully reveal themselves. Prostatic cancer patients as key informants, being the true source of data, also enhanced the truth value (internal validity). That is, those undergoing the reality of the experience were the ones asked to provide information for research.

Threats to internal reliability and validity were also reduced by the use of participants' verbatim accounts of their experience (Field & Morse, 1985). The verbatim accounts minimized subjective interpretation of the data.

Also, according to Field and Morse (1985), a high degree of congruency between the investigator's and other nurse-peers's identified categories and properties enhances the internal validity of a study. To this end, a small group of nurse peers were asked to examine the transcripts of two interviews to ascertain

if they could identify the same meaning units (or properties) in the data. The resulting congruency of over 90% supported a high internal validity.

In terms of applicability/external validity, the findings of the study is contextual, as intended. Limited generalizability is not a concern since the study was intended to understand the true experience of a small number of patients.

The personal nature of the subject matter of sexuality, however, may have prompted the participants not to be candid with their responses and as a result could have decreased the truth value of the responses. This is recognized as one of the limitations of the study.

Limitations of the Study

The following are recognized as limitations of the study:

1. A disparity may occur between what people say and what they mean (Schwartz & Jacobs, 1979). However, this disparity may be reduced by clarification and validation during the interview.
2. Considering the sensitive nature of the subject matter, a sampling bias may occur. Those who have more liberal attitudes toward matters of sexuality may be more willing to participate, and hence, may be over represented.
3. Any particularities of the health care facility where from the participants are recruited may influence their perception of the illness experience.

CHAPTER IV

Findings

Introduction

Upon analyzing the contents of all interviews with the respondents, three major categories emerged--Sexual Being, Sexual Coping, and Sexual Knowledge. Each category was then found to contain several interrelated themes (Table 2).

The category of Sexual Being pertained to the sexual experiences of patients before and after the diagnosis of their prostatic cancer. Their sexual history revealed that the evolution of their sexual-self was uneventful. Although their sexual practices varied, all respondents were found to have led an active sexual life until the investigation and eventual diagnosis of their prostatic cancer. The sexual impact of their illness experience was evidenced not only by perceived changes in their sexual function and ability, but also in the way they viewed sexuality matters in the context of their illness. The illness experience had altered their sexual meaning--their sexual need, and the value they ascribed to such needs. Their sexual meaning, through the illness experience, was found to be strongly influenced by their "life-death" notions regarding cancer.

The category of Sexual Coping included a set of behavior patterns evidenced by patients in their attempts to cope with the sexual consequences of prostatic cancer and/or its therapy. They were found to incessantly compare their sexual

predicaments with those of other similarly ill patients to ascertain their relative sexual health. Whatever the outcome of these comparisons, they proceeded to ascribe their conclusions to factors other than their diagnosis and therapy. Also, whether or not they perceived their sexual alterations were related to their prostatic cancer illness experience, the respondents felt that it was necessary to make certain adjustments in their sexual life. In their attempts to make those adjustment that were deemed necessary, patients were found to first prioritize their life events. The reordering of their life events was primarily based upon what they perceived to be the eventual result of their illness experience--sexual, spiritual, or physical death. When patients realized that living was possible even in the face of their illness, and perhaps death, they began to exist on a new plane of life and acquired a renewed perspective on all that mattered to them in life. In their opinion, this was a growing experience.

The category of Sexual Knowledge pertained to patients' understanding of illness related sexuality matters, and/or obtaining such information from health professionals. It was apparent that sexuality related interactions among all concerned were rare, and if any, the information received by patients was scant, untimely and often incidental.

Each of the above categories and their properties will be addressed separately and examples of patients' verbatim comments will be presented to further describe, clarify and support the findings. The investigator's view is that

most comments made by individual patients deserve to be presented. However, only a few representative quotes will be used owing to their quality and depth of meaning.

Table 2

Definitions of Categories and Properties

| Categories and properties | Operational Definitions |
|---------------------------|---|
| Sexual Being | Lived sexual experiences, and meanings attached to such experiences. |
| Sexual History | Accounts of sexual experiences prior to the diagnosis and treatment of prostatic cancer. |
| Sexual Meaning | Sexual need and valuing of such needs as a sexual being, in the context of prostatic cancer illness experience. |
| Sexual Impact | Changes perceived in the sexual self as a result of prostatic cancer and its therapy. |
| Sexual Coping | Adopting and enacting those behaviors which are perceived as helpful to minimize the effects of prostatic cancer and its therapy--comparing, justifying, prioritizing, adjusting, supporting and growing. |
| Comparing | Relative definition of self in comparison with others--relatives and/or other patients with cancer or similar diagnosis and situation. |
| Justifying | Speculation of behaviors, events, or situations as reasons for physical or sexual disability. |
| Priorizing | Redefining and reordering of life events, situations and relationships in the context of probable death. |
| Adjusting | Compensating for, or substituting, decreased or lack of sexual intercourse with sexual activities other than intercourse, or non-sexual activities. |
| Supporting | Offering encouragement and hope to spouse and family through words and action. |
| Growing | Acquiring renewed perspective on life and life events that is considered to be positive, realistic, and reasonable. |

Sexual Knowledge

Patients' gathering and learning of sexual information, and their perception of health professionals and their role in providing necessary information regarding sexuality.

Findings - Sexual Being

Introduction

The category of Sexual Being emerged as its various interrelated properties were identified--Sexual History, Sexual Impact, and Sexual Meaning. This category contained data regarding respondents' evolution as sexual beings and their past and present sexual practices. The sexual impact of prostatic cancer illness experience was evidenced by patients' perceived changes in their sexuality since diagnosis and therapy. Patients' illness experience had affected not only their sexual functioning, but also their sexual meaning--their sexual need and sexual value.

Sexual History

All respondents were noted to have led a very active sexual life in the first few years after their marriage. Three of the respondents stated that their sexual activity began in their teenage years, with more than one sexual partner. One respondent reported having several sexual partners prior to marriage. All respondents, however, asserted that since their marriage they had been loyal to only one sexual partner, their respective wives.

Most respondents were of the opinion that, in their lives, sexual activity was natural, important and purposeful. Some patients believed that, in their younger days, sexual experience was more personal and restrained, and that they lacked opportunities for sexual fantasizing and experimenting.

"Well, like out in the country you were never as free in those days. There was no free love or anything else, those days. Well, you had one girlfriend, maybe, that's it. And there was no sex before marriage or anything else. After marriage, we both worked and, sex wasn't fantasized as much. You didn't read books, see TV shows, or anything else. You didn't have any sex education, none at all. Just what you picked up from your brothers or boyfriends. And after we got married, we had three children. Wife's health wasn't the best after. I would say sexual activity was normal. It was nothing the way you hear some of these guys talk."

For most patients, over a period of 20 to 40 years, frequency of sexual intercourse had decreased anywhere from six to eight times a week soon after marriage to approximately once or twice a month at the time of prostatic cancer diagnosis. During this period of decreasing sexual activity, it was noted by some patients that while the frequency declined drastically, sexual performance and satisfaction decreased only slightly. A majority of patients stated that their need for sexual activity prior to diagnosis and treatment of prostatic cancer was fairly strong. A 68 year old patient described his pre-therapy sexual activity in the following manner.

"Well, it started maybe a little before marriage, but not very much before. And then after I was married, intercourse was very often. I really enjoyed it and, ...it was very important in my life. But, I have always stayed with the same woman, and I have always had sex with the same woman. From then on, around age 50, it started to decrease some. Even at 60, I would say we were having sex once a week--more often on holidays. My sexual life has been pretty active. Over the years, my desire to have sex has stayed the same. Since age 55, the erections started to taper down some. But, I can still complete sex effectively, and the satisfaction is still the same."

Overall, patients reported a fairly active sexual life prior to prostatic cancer therapy. However, sexual activity of all patients was found to decline gradually since the time they initially began sexual activity. Most patients felt that their sexual function was further affected by prostatic cancer and/or its therapy.

Sexual Impact

Patients exhibited a clear awareness of sexual changes that had occurred around and after the diagnosis and therapy of their prostatic cancer. Their perception of these sexual alterations were conveyed by patients through direct and indirect verbalizations. All messages inferred by the investigator from indirect explanations were verified by the respondents.

Patients' experience of various sexual alterations pertained to either their sexual function, expression or response. Sexual function changes were related to erection and ejaculation. Sexual expression changes were related primarily to matters of sexual self-concept. Changes in sexual response included such factors as sexual interest, sexual desire, and sexual pleasure. It was clearly evident that patients' experiences of sexual impact were in fact a result of the interaction among all three aspects of their sexuality--function, expression, and response. A change in any one aspect influenced a change in one or both of the other two aspects. The order of occurrence of a change any one aspect, or its magnitude of influence on others, was not clearly visible. However, sexual function changes

were the first to be recognized and were considered by patients to be most significant.

All respondents were found to have experienced one or more of a variety of sexual function changes. Most apparent of these were erection and ejaculation changes. Of the seven respondents, 6 (86%) reported erectile changes and 7 (100%) reported ejaculatory changes. Of the 6 patients with erectile changes, 3 (50%) were found to have experienced complete impotence and 2 (33%), intermittent impotence. These two patients were found to achieve erections approximately 50% of the time, and even then, only partially. One other patient reported no difficulty obtaining erections, but stated that he experienced occasional spontaneous loss of erection during coitus. The same problem was noted to have occurred at times with one other patient whose potency was known to be intermittent. Some patients also reported that the time they required to obtain an erection had increased considerably. It should however be noted that at least three of the six patients with erection problems had undergone transurethral resection of the prostate for diagnostic purposes, or for purposes of relieving severe urinary retention, prior to beginning any form of therapy.

Without exception, all respondents reported some sort of ejaculatory change. While only three patients reported complete absence of ejaculation, others noted a general decrease in the amount, force and/or consistency of their ejaculate. One patient who received radiotherapy complained of burning pain

upon ejaculation. All patients regarded these obvious sexual function changes to have affected their sexual expression and response. One patient related his experience of sexual function changes and its influence on his sexual expression in the following manner.

Interviewer: What has been your experience with obtaining an erection?

Patient: Never had any problem. It (erection problem) started...., my problem started with the prostate. The prostate started it. It (prostate) got large and I had a hard time passing water. It just started, something like, strange.

Interviewer: What are you referring to?

Patient: Well, erection.

Interviewer: Would you please describe it?

Patient: Well, sort of a half erection. Not total. And sometimes, I get a fairly good erection and maybe start having sex, and then, it would peter out. That's very disappointing. And it hurts the ego. See, then it makes one feel that you better not, just in case. So, you don't start it.

Interviewer: But, you both still attempt intercourse?

Patient: Oh yes, if I said let's have intercourse, well, she would go along with it. But, I'm still a little afraid that it may not work out. I don't want to start unless I can do the job. Well, you have an erection, you start and then it quits on you. Not very good.

Most patients related fear and embarrassment of not being able to perform as reasons for changes in their sexual expression. Some patients expressed that they felt obliged, and expected, to end all sexual activity with coitus and eventual ejaculation. When they perceived that it was not possible to do so, they tended to avoid situations of a sexual nature. The uncertainty of being able to obtain and/or maintain an erection was viewed as an obstacle to initiating any sort of sexual activity. Some patients felt that most sexual encounters were not worth pursuing since they lacked spontaneity. Although patients felt sexually inadequate, they were not found to severely doubt their masculinity in terms of their sexual self-identity.

While most patients denied that their impotence or any other sexual dysfunction had in any way affected their sexual identity, some patients openly expressed feelings of decreased masculinity.

Interviewer: What did you mean when you said it hurts your ego when you cannot perform sexually?

Patient: Well, you have an erection, you start and then it quits on you. Not very good. You feel it degrades you. It, you know, it costs your pride. Good for nothing. Not a man anymore. That thought comes to your mind. If my wife was more aggressive and said let's have it to night, something like that, then I guess it would affect my life. She doesn't bother me, so, that helps me. It sure does.

In the opinion of most patients, since their sexual activity was not a major concern at this point, matters of masculinity were not focused upon. However, some patients admitted that their feelings and opinions regarding their masculinity might change if their wives desired sexual activity and they couldn't perform, or vice-versa. For example:

Interviewer: How do you feel your erection problem (impotence) has affected your masculinity?

Patient: Well, I don't think it bothers me in terms of masculinity at all. Ah, I suppose it might affect me more if my wife was eager and I couldn't do anything about it. So that hasn't been a great problem. I don't feel any less of a man that I can't get an erection. I suppose if it doesn't improve, I imagine I'll just have to live with it. It's not likely to become a big factor. Maybe there would be more problems if it does improve and I'm eager and my wife isn't.

Despite their somewhat compromised feelings of masculinity, these patients appeared to maintain a fairly healthy opinion of their sexual-self by assigning little or no importance to coital aspects of their existence. They openly admitted that it was possible for them to maintain their sexual self-identity by demanding less of themselves sexually. Most patients had no difficulty perceiving themselves as sexual persons since they believed that their ability to express and respond

sexually had not totally ceased. For example, one of the patients who could occasionally experience partial erections responded in the following manner.

Interviewer: How about your desire for sexual intercourse?

Patient: Desire is always there. Like I said, the spirit is willing, but the flesh is weak.

Interviewer: How does that make you feel?

Patient: I don't feel that badly about it. Really, because, I feel I don't want it that badly anymore as I used to. If I want it that badly, I think it wouldn't work. I get a part of an erection, but I don't bother with it. I don't want it to go any further. But, my mind is always there.

Sexual expression changes were also a result of fear related to perceived untoward consequences of prostatic cancer therapy. Lack of knowledge and/or information regarding his therapy was apparent with one patient who was capable of, but did not attempt, sexual intercourse during or after his therapy. However, he admitted that he had resorted to daily masturbation to ensure intact sexual function. This 39 year old patient, the youngest of all respondents, related his fears about sexual consequences of his radiation therapy in the following manner.

Interviewer: What (sexual) changes have you noticed since the beginning of your radiation treatment?

Patient: No, no change at all. The only change would be on ejaculation. There is that same burning sensation like you get when you urinate. That's the only difference.

Interviewer: Have you then been having sexual intercourse as usual?

Patient: Ah, sexual intercourse, no. Because, I had in the back of my head; okay, these treatments are going on, there is something happening at a cellular level. If my wife gets pregnant, what's happening with the cells? That, kind of turned me right off.

Interviewer: How did that bother you?

Patient: I was worried about a "mutated type of baby" or whatever. Because, genes and cells are all tied up together, eh. So, if they (x-rays) are zapping the cells, they are zapping the genes at the same time.

In terms of sexual response, most patients experiencing sexual function problems were found to lack sexual interest. They stated that they had neither

sincerely attempted sexual intercourse nor had any motivation do so. It was noted that they had for the time being suspended all such notions. According to them, their life and health superseded all other matters. When asked how important matters of sexuality were as a total person, one patient responded:

"Well, I suppose, the main thing as far as I am concerned is that the cancer be cleared up. Ah, side effects, you hope they can be cleared up too. But that is something you can live with. And certainly the urinary problems that I started with were a very troublesome thing that I'm glad to be rid of. It would be desirable to have the other (sexual function) problem cleared up too, but it is not a life and death thing. I can live with it. It's not nearly as important as it would have been at one time. It is desirable but not essential".

While all patients reported that they had still retained their desire to have sex, most admitted that it had somewhat diminished. Of the four patients who were able to obtain any degree of erection, only two patients had experienced no change in their desire to have sexual intercourse, or in their sexual satisfaction. The two other patients had noted a considerable decrease in the satisfaction derived from sexual intercourse. For example:

".....Well, I always ejaculate. Once in a while, my erection, I pretty near lose it when I ejaculate. I mean, that makes a difference. Well, as if the feeling isn't quite there. Like, that usually is the biggest part; point of sex is when you ejaculate. And if your erection is going back, it isn't quite....., pleasurable".

The sexual impact experienced by most patients as a result of diagnosis and therapy of their prostatic cancer was evidenced by sexual function, expression or response changes, or a combination of such changes. Whatever the change, the impact on patients appeared to be one of diminished or lack of sexual interaction. Although matters of sexuality were not deemed important by patients, their desire for sexual activity was found to still exist.

Sexual Meaning

The prostatic cancer patients' sexual meaning, a composite of their sexual need and its relative importance to them, was deemed to be grounded in their perception of the illness experience. The patients in the study were found to view their illness upon diagnosis as a severe threat to their longevity and/or life. This notion of their impending demise had consequently influenced the perception of their sexuality needs and the value they ascribed to gratifying such needs.

Referring to his choices, one patient commented:

"My doctor told me that there is a 30% chance of being impotent after treatment. I figure, I'm gonna go with impotency. At least, you are still alive, eh. There is more to life than sexual intercourse. And, as far as the relationship goes, sexual intercourse, on a scale of 1 to 100, it's way down at the bottom."

A majority of patients reported that, prior to the diagnosis of prostatic cancer, they considered sexuality in general, and sexual intercourse in particular, as an important basic need. They not only viewed it as a necessary part of life but also as having an intrinsic value in their relationship with their spouse. For example, one patient related a situation to illustrate the usefulness and importance of sex in his life.

"Well, to me and my wife sex is, it's not the act of having intercourse. Seems to me, you are closer while you are doing it than any other time. I mean that's the way it is. Sexuality is much more than intercourse, way more. Mind you, sex, intercourse is important. But, I mean, what goes with it is just as important, or more so. Let's put it this way. My wife and I too, no matter who you are and when you were married, don't get along all the time. We have arguments. That (sex) is what we'd do when we make up. We'd go to bed. See, if I couldn't do that, that would be one way gone. I would have to think of something else. I kinda worry about that."

Most patients expressed that their illness had affected their sexual lives. Although they admitted to having a desire for sexual intercourse at times, they said that they neither felt they needed it nor that it was important at this point in their lives. They also insisted that their wives felt the same way. For example, following are some patients' comments regarding their illness and sexuality prior to therapy.

Patient 1:

"Right now, that (sexual intercourse) is not the biggest thing on my mind. And, neither my wife's mind. Well, my first question is, what are my chances of making it (surgery)? According to my doctor, the chances are good. And, of course, my second question is, will it affect my sex life? The answer is, it possibly will. But, like I said, it is only second now. That is not the first thing on my mind. First thing is to make it through the operation without too much problems".

Patient 2:

"No, it (sexual intercourse) is only a small part of your life. Ah, people, in Canada anyway, put too much importance or emphasis on something strictly a biological fact of life. Way too much importance on it. There is hell of a lot more to life than sexual intercourse. You know, sometimes a good shit feels better than a piece of tail. Depends how bunged up you are."

Patient 3:

"Well, my wife told me, when you are older, sex isn't that important. It is the fondness towards one another, what you can do for one another. And, the things you have in common that you can talk about. She says, sometimes it outweighs sex. That's what she told me, so. So, I guess it is not that important at this point in time."

Patient 4:

"Well, my wife and I talked about this (sex). My doctor told me, the prostate treatment that's coming up now, he said, in some cases it is quite bad. If it goes into my testicles, the best treatment is to remove them. And, he says, you know what that means? Then you are getting to the zero mark of sexual intercourse. We discussed it when we got home. And, we decided, well, if it gets to that, that's what it is. We'll be sorry, mind you, but... what can you do? You are better alive than..... The priority is life."

The overall illness experience of patients had a significant effect on the way they viewed and valued their sexuality as a whole. Their sexual needs and values had changed since the diagnosis of their prostatic cancer. Through their entire illness experience, pronounced changes were noted in the way they perceived their sexual need and its importance to them. The nature of these changes was determined primarily by the extent of their perceived threat to life. For a majority of patients, their sexual need and its importance to them were least significant soon after diagnosis and during therapy, the period when their perceived threat to life was greatest. In the face of death, sexuality matters were regarded as not even worth considering. After, or toward the end of their therapy, when death was no longer viewed as imminent, sexuality matters were reconsidered. At that point, sexuality was regarded as a need and was assigned renewed value. However, having experienced some sexual dysfunctions, the act of sexual intercourse itself was neither given any importance nor considered of any value to them. Other aspects of sexuality were not only considered important, but were accorded greater value. These patients were found to have acquired increased interest and importance for all aspects of sexuality other than actual sexual intercourse.

The changing sexual needs and values followed a definite pattern as the patients moved from the pre-diagnostic stage to post-treatment stage in their illness experience. In all instances, their choices were based on the order in which

they valued all matters in life. The following illustration from one respondent represents the progressive changes in sexual meaning experienced by most patients, through their illness experience.

Prior to diagnosis:

"Well (sex) first started maybe a little bit before marriage, but not very much. After I was married, sex was very often. We raised seven children so we had sex very often. I really enjoyed it and it was very important in my life. But, I have always stayed with the same woman, and I have always had sex with the same woman. My sex life has been pretty active."

Before treatment:

"Right now, sex is not the biggest thing on my mind. And, neither my wife's mind. Well, my first question is, what are my chances of making it (surgery)? According to my doctor, the chances are good. And, of course, my second question is, will it affect my sex life? The answer is, it possibly will. But, like I said, it's only second now. It is not the first thing on my mind. First thing is to make it through the operation without too many problems."

After treatment:

"I'm so glad I got over the operation. Sex is secondary. My wife agreed with me on that. Since the operation I have changed my mind about sex. I went through a big operation and I don't think it is important as I thought it was. It would be nice to be back to normal, but it is secondary now. I think I can have sex without having an erection or without penetration. We hug and kiss pretty often. We spend the time together. We go to the city to shop. We both do a little bit of gardening. Things like that."

In summary, the category of Sexual Being included three important properties--Sexual History, Sexual Impact, and Sexual Meaning. All respondents believed that sexuality was an important aspect of their lives. They had led a fairly active sexual life prior to the diagnosis and treatment of their prostatic cancer. The patients perceived their prostatic cancer illness and its treatment as negatively impacting on their sexuality. The meaning they attached to the illness

experience in general, and its sexual impact in particular, primarily determined their sexual coping and adjustment.

Findings - Sexual Coping

Introduction

The notion that patients may be attempting to manage and contend with the sexual impact of their experience of prostatic cancer and/or its treatment surfaced after an initial analysis of the first few interviews. Upon completion of data collection, it was abundantly clear that all patients were attempting to cope with alterations in their overall sexual function and ability by various means. These coping behaviors, although somewhat unique to each patient, were found to have certain common elements.

Upon final analysis of all interviews, the category of "Sexual Coping" with its various inherent properties was evident. The properties of comparing, justifying, adjusting, prioritizing, supporting and growing were then clearly identified as distinct sets of coping behavior patterns.

Comparing

The respondents, while describing their personal experiences, consistently compared their circumstances with those of other patients, relatives and/or family members whom they believed or knew to have had similar diagnoses and therapy.

This was particularly evident when they were describing experiences of a sexual nature. These comparisons, however, were not exclusively sexual in nature and, at times, were not limited to the experience of prostatic cancer.

Comparing themselves to other persons occurred in two different ways--one in terms of their own relative status, and the other, in terms of their knowledge of the others' status and nature of being. The patients' comparative descriptions most often pertained to their relative status in terms of what they perceived the other individual(s) had said or experienced. For instance, during the discussion with a patient regarding his sexual history, the following ensued.

Interviewer: So, would you say then that your sexual activity was quite active in the beginning?

Patient: Oh, I would say normal, maybe.

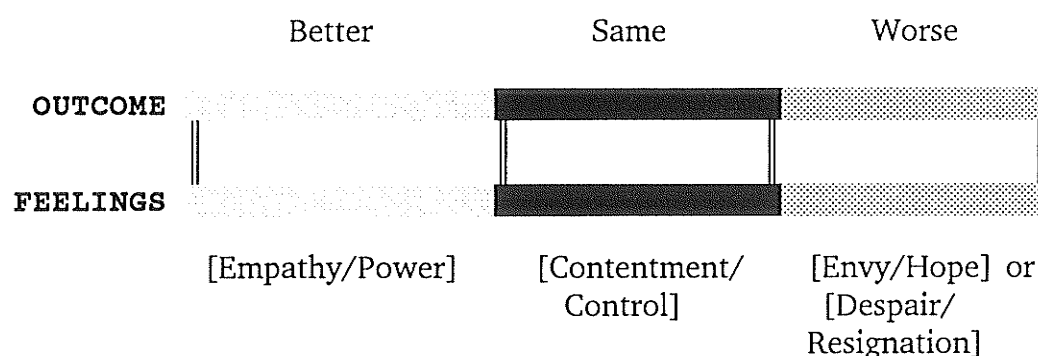
Interviewer: Normal?

Patient: It was nothing the way you hear some of these guys talk.

The comparisons, or descriptions of relative experiences, were related to various aspects of their illness experience--the manifestations of prostatic cancer, positive and negative effects and/or outcomes of prostatic cancer and therapy, past and present sexual ability and/or activity, and age-related sexuality. The non-comparative talking about others was focused on those individuals' status and their nature of sharing pertinent information. These non-comparative descriptions of others' experiences pertained to issues of obtaining and giving information regarding the illness experience of prostatic cancer and soliciting emotional and psychological support. Discussions in this regard were, in the main, based on their knowledge and perception of the others' experience.

The patients' comparing of themselves with other patients was made primarily to determine their relative status within the realm of their illness experience. These determinant comparisons were found to have three outcomes: 1. better than the other; 2. same as the other; and 3. worse than the other. In the opinion of the respondents, each of the three outcomes conveyed specific meanings to them. These meanings were basically reflected in their general feelings of empathy/power, contentment/control, and envy/hope or despair/resignation depending on the comparison outcome (Figure 2).

Figure 2. Comparison Outcomes and Related Feelings.



One patient, while describing his general feelings about his illness experience in relative terms, best exemplified the reason for comparing own experience with that of others in the following manner.

"Five years ago my neighbour had surgery for valve replacement in his heart. The doctors couldn't guarantee whether it would work or not. Now it is exactly the same with me and my cancer. If doctors got it all that's fine. But, there is a chance it often comes back. It is the same with heart attacks and stroke. So, really, I'm not an exception at all. There are many people in the same predicament. If you start thinking that there are other people as bad off or worse off than you, it helps a lot. That self pity is a terrible thing".

Comparisons resulting in similarity were described in a manner to ensure normalcy within the context of patient's own situation. The idea of normalcy provided the patients with feelings of contentment, and a sense of control. In some instances, comparisons were made to identify and establish negative or positive differences in the experience of their illness. Those comparisons that resulted in positive differences were made in a manner that was reassuring to themselves--either that their experiences were less threatening in nature, or were less severe. In those instances where the patients concluded that they were relatively better off, they expressed feelings of empathy for others whom they felt were worse off, and experienced a sense of power. However, in those instances where comparisons resulted in negative differences, that is, where respondents found themselves in a relatively worse situation, feelings of despair and a sense of resignation, or feelings of envy and a sense of hope prevailed.

Although the comparisons occurred frequently in all of the above three modes, all modes were not consistently used in every area of comparison. However, every mode of comparison was adopted by the respondents while discussing various situations.

With regards to manifestations of the disease, urinary problems were the main focus of comparison. These comparisons were both in terms of similarities and differences. The following quotes are three examples of comparison that illustrate each of the three modes of outcome--better, similar, and worse.

Example 1 (Better):

Interviewer: What changes, if any, did you notice around the time you were diagnosed as having prostate cancer?

Patient: Well, actually I didn't notice what other people would tell me-- getting up at night (to urinate) all the time and everything else. I slept right through from ten o'clock till six in the morning. I could go until noon without going to the bathroom.

Example 2 (Similar):

Patient: Well I suppose it (urinary problems) started with frequent urination and pressure there (bladder). Well, from talking to other people with the same problem, they described it as not emptying the bladder. When I thought about it, that's the way it appeared to me too.

Example 3 (Worse):

Patient: Even after urination, I still had some pressure there (bladder). I suppose I delayed a bit. I suppose I expected it to be routine prostate. Oh, a number of people of my acquaintance have had the operation; it wasn't that way. Well, the biopsy brought on problems because the water works cut off altogether. Then the doctor got to the operation quickly. I guess it had to be that way.

Effects of therapy were found to be one of the major concerns of prostatic cancer patients. This was another aspect of the illness experience where patients tended to compare their perceptible consequences from therapy with those of other patients. Such comparisons were possible since therapy occurred at a common place and the respondents were able to interact with other patients who received similar therapy.

The study patients received either radiotherapy, surgery or hormone therapy, in order of frequency. The patients perceived the sexual effects and other physiological effects as two distinct and separate factors. They reported that it was much easier to share and compare, and that the other patients were more

receptive, when non-sexual consequences of therapy were the focus of conversation among patients.

It was evident that the comparisons centred mainly around non-sexual effects of therapy and were carried out primarily to ensure normalcy. One of the patients, referring to radiotherapy, stated.....

"They (radiotherapy personnel) told me I may have diarrhea. I didn't have any diarrhea. Like, some of them (other patients) had diarrhea real bad. And another thing, my rectum was sore. One of the other guys (patients) I talked to, he said he had a problem with his rectum too. He had to sit in a tub all day long. I had to do that a couple of times too."

To most patients, similarity in experience also meant that the therapy was working. Most equated experience of side effects with effectiveness of treatment. One of the respondents accounted his fears regarding non-similarity with other patients undergoing comparable therapy in the following manner.

"They (radiotherapy personnel) told me that I would experience some nausea, maybe a little diarrhea, burning sensation when I urinate, and stuff like that. I didn't feel anything. I was worried if the machine (radiation) was working or not. I would walk out of there five minutes later, like. Is it done, or is somebody pulling the wool over my eye. With some diarrhea and burning sensation by Friday, you knew there is something going on."

Along with physiological effects of therapy, psychological and sexual effects of therapy were also compared. Comparative discussions in these areas, however, were infrequent, and in some instances, non-existent. In instances where comparison of psychological effects occurred, information for comparison was obtained primarily through observation. One respondent, while discussing the psychological effects of therapy, presented the following comparative description.

"I don't think there was one day I walked in there (treatment centre) depressed. But you see some guys going in there, I don't think you can squeeze a word out of them. I can understand why some people facing cancer and cancer

treatment commit suicide. Because, you occasionally get very depressed. Very depressed. I'm probably lucky in one aspect that during the treatments it didn't drag me down to the point, physically, where all I did was lay or sit around and do nothing but think about the treatments. During the treatment period I was active, and since the end of the treatments I have probably been over-working to keep busy. That's probably what is keeping me from getting depressed or thinking about it".

As infrequent as comparisons of a sexual nature were, the information for such comparisons was, at times, obtained directly from patients and, at other times, from a third party. Many explanations were given for infrequent discussions regarding sexual matters among prostatic cancer patients. Overall, in order of importance, the study patients offered the following reasons: 1. sexual things were not important at the time; 2. patients shied away from talking about such things; 3. it was a personal matter so they didn't feel comfortable talking about it.

The sparse nature of discussions among patients regarding their sexual function and ability was clearly evidenced in the following excerpts from interviews.

Excerpt 1:

Interviewer: Considering the proximity of your prostate to the genitals, what are your feelings?

Patient: Like, I thought I would be losing my testicles too in a whole operation, if it gets bad or something. I often thought of that. Would I be like a cat after, get big and fat. Get lazy. I was wondering if it will happen that way because, nobody ever says whether they have it or not. A lot of them say they had a double hernia or something. That might be it. They don't talk about it, no.

Excerpt 2:

Interviewer: You seem to know some of your friends who have had prostate cancer. Have they ever opened up to you about sex?

Patient: No, the last..... No, not about sexual. We'd never talk about sex. The only time you'd ever talk about sex was at work. Some of these guys brag or complain, one or the other.

Interviewer: I see. Not the ones who have had prostate cancer?

Patient: No, not them, no.

Excerpt 3:

Interviewer: Do you know people who have had this kind of operation (TUR)?

Patient: Yes.

Interviewer: Have they talked to you about their sexual experience?

Patient: No, no. Whether the operation was a success as far as urination was concerned, yes. I haven't discussed with them, sexually.

Excerpt 4:

Patient: Even when I was young and going out (with girls), fellows would say, "how did you make out with her?". I would say, oh, nice girl. Some like to advertise. I never did. That's none of their business. Ah, no way, that's private.

In instances where sexual information was sought from other patients for comparison, it was done so only when they felt assured that they were better off. Some respondents admitted that their curiosity was sometimes more the reason for gathering sexual information, not comparing. This type of non-comparative information gathering was not limited to sexual matters and usually not without some purpose. The information thus gathered was used to reassure themselves that they were not in real jeopardy, to speculate what future held for them, to assist them in making treatment decisions, and to gain psychological and emotional support.

For certain respondents, mere awareness of those prostatic cancer patients who had survived the ordeal of the illness and its treatment was an encouragement. It provided them with hope, reassurance and psychological

support. Upon talking to these patients, some respondents also obtained emotional support by their consoling and encouraging words. This sort of vicarious gratification was apparent in one of the respondent's responses.

Interviewer: What are your thoughts about your treatment that is coming up?

Patient: I have no idea you know. I didn't hear too much about it or anything else. I try not to worry about it.

Interviewer: Worry about it?

Patient: No, I ain't that worried about it. Not that worried. I always forget that I was pretty healthy all the time 'til now and, there's a lot of people I know had prostate operations and stuff and they were good for quite a few years after. Like, they were mobile and everything, so.... Actually, I ain't worrying about it that much. It doesn't bother me that much.

Some respondents, while speculating about their own treatment plans, spoke in light of other patients' progressive treatment trajectories. For example:

"We read books. Most of them (prostate cancer patients) come out good. Like, some patients there (cancer treatment centre), you get talking to them. They had the operation before the therapy, radiation therapy. So, I may still have to look forward to the operation someday."

Information about other patients' treatment and its outcome was not only used to speculate on their own treatment but, in some instances, also to either make their own treatment decisions or to reassure themselves that they had made the right choice. In one respondent's opinion, learning the fact that a patient with treatment similar to his own had lived for many years, was very comforting and reassuring.

"Another thing helped me, I forgot to tell you. When I had my bone scan, there was this patient ahead of me; he was putting his clothes on, I was taking mine off. He asked me what I was there for. And I said, well darn, like all men get, I got prostate cancer. Well, he said, if you'd come out of it like I did, I had mine 10 years ago and never had a fall since. So, that perked me up a lot, you better believe it did. If somebody that's involved with it (radiation therapy) tells you that he had good results, oh that helps a lot. If you saw a guy and he had been whimpering and that, it would have been a very bad, sad thing for me".

Overall, respondents' comparing of their own illness experience with that of others seemed to serve many purposes. In almost all instances, such comparing was carried out to primarily gain self-satisfaction and feel reassured of positive prognosis.

Justifying

The respondents were found to readily attribute any perceived or real sexual changes to factors other than prostatic disease and/or its treatment. Although they admitted to having noted various changes in their sexual function or in their overall sexual being, they were reluctant to relate those changes to their illness experience. They frequently attributed their sexual changes to such physical, psychological, chemical, natural and situational factors as age, fatigue, drugs, weather, and physical separation from wife.

Those patients who considered themselves to be old were between the ages of 60 and 70 years. These patients were found to consistently refer to their age as "old age". They readily attributed their many perceived physical changes to their "old age" as if they considered these changes to be a natural and expected consequence of aging.

Decreased or absent sexual activity was one of the physical changes most frequently attributed to their increasing age. Although they agreed that sexual activity should not cease because of their increasing age, they definitely tended to

draw a direct relationship between their increasing age and decreasing sexual activity.

" Yeah, that's what I say. I mean when you get my age..... I mean, we had a good sexual life, we still have. Now I'm 67 years old, so, if we should get to a point where there is no (sex), it won't be all that bad. I don't think it will, not for a while yet."

Two patients were found to have ceased sexual activity, whether or not they were capable of sexual function. In fact, they admitted to still possessing sexual desire and ability to some degree. These patients, however, conveyed the notion that sexual inactivity is a given when one is into old age, and that absence of sexual activity is natural and inevitable. In fact, one patient conveyed in no uncertain terms that sexuality matters were not of any consequence to him at his age, and did not exhibit any interest in sexuality related information.

Interviewer: So, did they (the health professionals) say anything about sexual activity prior to your treatment?

Patient: No, no they didn't.

Interviewer: Did you ask them?

Patient: No, I didn't ask them. At my age I'm finished with that anyway.

The patients were not alarmed by any sexual change that occurred either before or after treatment of their prostatic cancer. Also, contrary to the notion that one may be alarmed by sexual change(s) in the absence of any disease, the patients were found to be in fact less concerned with any such change prior to the diagnosis of prostatic cancer. Pre-diagnosis sexual changes were attributed to increasing age even more readily and without reservation.

Interviewer: Did you notice any (sexual) changes even before you went to the doctor for your urinary problem?

Patient: Well, I suppose, ah...., perhaps some changes which I attributed to changing age.

"Old age" was also blamed by patients for its indirect diminishing influence on their sexual activity. The patients considered that their accumulated age caused them to be easily fatigued, and hence did not have any desire for sex or, were not able to perform. In response to why his sexual activity had considerably decreased, one patient stated...

"But, at our age, well, I guess we need the rest, though".

Another factor that was related to decreased sexual activity and ability was their psychological status. According to some respondents, the worry and stress brought on by their illness definitely affected their sexual life. The following is an account by a patient with reference to his altered sexual activity since the diagnosis of his prostatic cancer.

Interviewer: What are your thoughts about any changes you may have experienced in your sexuality, as a whole?

Patient: Ah, the sex is a little different now. It seems, we still have sex, may be once every two weeks. But, I seem to have, once in a while, as if it's hard for me to finish. As if you lose your erection. Not always, just once in a while. But, that maybe just in my mind, what I have in my mind. But, see, that never used to be before. That's just since.... (my cancer).

With almost an equal frequency, medications they have been taking, or they have taken at some time, were also described as having had some effect on their sexual life. One respondent insisted that the pills he had been taking for some years were more to blame than anything else, although he admitted to further decrease in sexual function after prostatic cancer therapy.

Interviewer: Has your sexual activity changed in any way?

Patient: Well it decreased as soon as I started taking those pills. It decreased quite a bit. Maybe once a month, maybe six weeks, maybe two months. It's gradually going down.

Interviewer: How long have you been taking these pills?

Patient: I think fifteen years, around fifteen years.

Interviewer: What about since your prostate problem?

Patient: I would say it has decreased more. Lately, last few years, I have problem with erection. It has become slower and slower.

At least on three different occasions the respondent referred to these pills as high blood pressure pills. The notion that antihypertensive drugs may cause sexual impotence has been well supported by medical literature. However, this patient admitted that he was capable of intercourse prior to radiotherapy. It is uncertain whether the sexual alterations experienced by this respondent were due, as he perceived, to antihypertensive drugs or to prostatic cancer and/or its therapy.

The practice of not sleeping in the same bed as the spouse was also implied as a reason for decreased sexual activity. One of the respondents noted that sexual activity was not possible because he was in a separate bed when the urge occurred.

"After we got twin beds we quit sleeping together. In the last few years, we got twin rooms, even. So, that has something to do. When you have the urge in the middle of the night or something, she isn't there. And I think that may have a lot to do with it....Now, it's got to be by appointment".

Respondents seemed to have some difficulty in being able to differentiate between decrease in sexual activity and decrease in sexual ability. They tended to view both as one and the same since they believed the outcome for both was identical--absence of sexual intercourse. They attributed absence or decrease in sexual activity to many causes other than factors related to their prostatic cancer. They appeared to be more comfortable speculating on these other causes than to

relate their sexual alterations to prostate cancer and/or its therapy. Justifying their sexual alterations in terms of those factors they were already living with may have helped them view the experience of prostatic cancer as less threatening and easier to cope with.

Priorizing

All respondents appeared to attach various meanings to the term "Cancer". In all instances, these meanings related to some event or experience they feared or could not bear the thought of happening to them. Although they were concerned for their own being, they seemed even more concerned with the effects that their illness might impose on their families, relatives and friends.

With regards to the metaphorical meanings of cancer, suffering and death were the two main notions expressed consistently by most respondents. However, they were not resigned to the belief that these events were inevitable results of their illness. In their opinion, since suffering and death were most often the experience of others with cancer, they felt obliged to view their own illness experience in that light. The respondents stated that this mode of thinking was purposeful, and that it helped them reorganize and reorder their life priorities in light of their impending death.

For the purpose of this study, it was imperative to identify what order of priority was assigned by prostatic cancer patients to matters of sexuality in

general, and sexuality concerns in particular. Patients' beliefs in this regard were considered to be crucial for recommending further research and/or determining suggestions for nursing interventions; particularly to determine the optimal timing for teaching and counselling of prostatic cancer patients with respect to sexuality.

All respondents were found to practice three different types of reordering of priorities--1. Situational; 2. Personal; and 3. Global. Situational reordering of priorities pertained to those basic human needs that had to be met in order to remove an immediate threat to comfort, and possibly life. Situational reordering of priorities occurred on a here-and-now basis and involved a particular need, or two inseparable needs, without any consideration of other needs. This type of prioritizing was found to be short term and temporary in nature. Situational prioritizing was evident in patients' description of events occurring around the time of their prostatic cancer diagnosis. One patient succinctly exemplified the concept of situational prioritizing when he gave an account of his feelings prior to undergoing Trans-Urethral Resection (TUR).

Patient: Well, I had to be catheterized because of the pressure in the bladder. I had the catheter from that day till the operation. In my case there was no choice. TUR was the only way.

Interviewer: How did having this procedure make you feel? Did it raise in your mind any question about sexual function?

Patient: I don't know whether that was the uppermost in my mind at the time. When you have a full bladder, you don't think of much else.

When patients were found to be faced with situational reordering, sexuality matters were not found to be even a consideration, let alone a priority. When

situational reordering of priorities was not called for, the patients entered the next phase of prioritizing--personal reordering of priorities.

Personal reordering of priorities required considerable investment of thought and time on the part of the respondents. It involved such considerations as disease and therapy, spouse and family, and life and death. Such matters were regarded as personal and important by the patients, and were considered concurrently in reordering their priorities. This type of reordering of priorities was found to be long term and more permanent in nature. Here, the list of priorities tended to be longer than the one in situational prioritizing and some consideration was given to those items not on their list.

In the face of a terminal illness, the respondents' first priority was to preserve life, no matter how extensive the therapy. With some patients the reason was, of course, personal, and with others, it was more altruistic--they wanted to survive for the sake of their family. Those patients who related altruistic reasons for wanting to preserve life exhibited fatalistic attitudes toward their own probable death.

Some patients appeared to accept death as a probable result of their illness, but exhibited a sincere concern for the welfare of their families. They viewed their self preservation as having more to do with providing the family with a nominal head, maintaining the family unit and its cohesiveness, and sparing the family the grief of losing their most significant other. The following interviewer

patient interaction clearly demonstrated that patients with terminal illness may hold priorities that are self preserving, not necessarily self serving.

Interviewer: How does having cancer make you feel?

Patient: The first day it bugged me. It still does once in a while. When I can't fall asleep I start thinking. It always seems to end up that galdarn cancer; will I be around to do that or what, you know. You get used to it.

Interviewer: It bothers you?

Patient: Yea, oh yea. It does, definitely.

Interviewer: Does it make you afraid?

Patient: Not really. I'm not afraid for myself. I have had so much in common with my children and grandchildren. They all like me so much. I'm worried about them. When I go, if I should go, that they will all miss me. I mean, I'm gone. I'm out of it. Once in a while it bugs me.

Interviewer: I understand.

Patient: I mean, we all got to go sooner or later. Better me than one of the boys who have wife and small kids. I mean, they are needed here to make a living for their kids and their wife.

The second priority expressed by the respondents in their personal reordering was their responsibility to spouse and family, and relationship among them. Spouse and family were considered to be of great importance in their lives. They stated that they had started to spend more time with spouse and family, and that they had gained a renewed perspective on family and its importance. In this regard, the potentially lethal nature of their illness caused them to refocus their energies on their family. In addition to gaining emotional support from their families, patients were found to have involved the family extensively in their treatment decisions. The therapy of their prostatic cancer was deemed by patients as their third priority in their personal reordering.

In the personal reordering of their priorities, sexuality matters were not considered to be important. Although patients regarded sexual matters as a concern, they did not perceive it to be crucial enough to either influence their

treatment decisions or to be a factor in the reassessment of their spousal and family relationships. According to patients, their spouses also concurred that sexuality matters were of little importance while struggling to cope with matters of life and survival.

Interviewer: What would you say your greatest fear is at this time?

Patient: Well, I guess right now, the most fear would be trying to get rid of that cancer, more than anything else. If it was straight prostate (without cancer), a person wouldn't worry that much. When you hear the word cancer, I don't know how bad it is or anything else. Getting rid of the cancer first; that is a priority I would say.

Interviewer: How did your wife react to your diagnosis of prostate cancer?

Patient: Oh well, she is more medically inclined. She reads a lot more. I guess she was expecting that, for men, it (prostate cancer) usually comes along with old age pension cheques.

Interviewer: How does prostate cancer make you feel in totality?

Patient: I suppose personally a bit worried. I try to put it out of my mind, worried or not. But, I think, it's still in the back of your mind. And you wonder what's gonna happen; whether they are going to cure or not. I guess the worst part of it is waiting for your treatment. Otherwise, I'm fairly active. I would like to be active. If it makes me inactive with sex it wouldn't bother me at all, I don't think. Not me or the wife.

Interviewer: What makes you say that?

Patient: What makes me say that? Like, sex isn't the first thing on our priority, at all. As long as you're together, okay, it doesn't matter.

In the above interaction it was evident that sexuality matters commanded much less attention from the patient as compared to other matters of priority in his personal reordering of life events. Similar views were expressed by other respondents. In their opinion, their spouses were quite undemanding of sexual attention and attached very little importance to sexuality matters in their spousal relationship.

For example:

Interviewer: What do you think your wife's concerns are at this time?

Patient: Well, right now, she told me she didn't care if we ever had sex again as long as I didn't leave her. Like, dying or something. Because, she said it

would be hard for her to face. So, I tell you, she is very good that way. I don't think it makes much difference to her whether we have sex or not.

In fact, the respondents believed that they and their wives had, to some extent, become more philosophical about many overall practices, events and issues in their lives. This belief was evident in patients' global reordering of their priorities.

Global reordering of priorities involved very broad and encompassing matters that related to actualization of the self. In the patients' opinion, as they internalized the reality of their probable death they felt compelled to reassess their own being--social, sexual, and spiritual. To them, living meant renewed and reordered life, their second chance at actualizing a more meaningful existence.

Upon global reordering of their priorities, prompted by their illness experience, it was apparent that patients' religious beliefs had strengthened, their family relationships had been considered more important, and their sexual intimacy had taken on a whole new meaning. In fact, they viewed all of humanity itself with humility and more empathy. This sort of transformation was quite evident in a discussion with one of the respondents.

Interviewer: In the last interview you had said to me that sex was very important to you as a man. What are your feelings now, after the operation?

Patient: That's right. I've changed my mind since. Yes, I think I did because I went through a big operation and I don't think it is as important as I thought it was. I think I have changed on that part, yes. But, it would be nice to be back to normal. But, it is secondary now. I'm ready to accept it. My health is more (important) than that, you know. Especially my wife agrees with me on that, so it is comforting to know that we both agree on that.

Interviewer: What did your wife say?

Patient: She said, I will go along with whatever comes as long as you feel the same way. She has helped me very much through the operation and it's very important to have a woman by your side when you go through something like this.

Interviewer: As I understand it, you had said to me that being manly was having the ability to have sex. What are your feelings now?

Patient: Well, it's different altogether. I think, maybe I was wrong. I don't feel you are manly only by having sex. So, I have changed my mind on that.

Interviewer: Last time, we also talked about your role in the family. You had said you were the boss. What are your feelings now?

Patient: Well, there again, there is a little bit of change on that too. I think the whole, the operation changed my whole life, you know. I don't feel as important a man as I was before. Although I like to say I'm the man of the house, but not as important as I thought I was.

Interviewer: You said your life has changed. What things have changed for you?

Patient: Well, I was laying there (hospital) on my back for three weeks, you know. There is a number of things that go through your mind. And, for one thing, I'm a Christian. So, I spoke to the boss, and I asked him for help. I got to follow what I spoke to the boss. I mean, God. So, that part, I think, has changed life a little bit. I think I'll be more involved in Christianity than I was before. And, because when you, you look at yourself and, you know that your life is in danger, I think it makes you think of what's gonna happen if you stay alive, you know. So, that part has changed my life to a certain extent....

Interviewer: How about family?

Patient: My wife and I, right now, do a lot of travelling to the city. Just going shopping, eye-shopping mostly. We both do a bit of gardening, some activity around the house. We want to travel to Europe a month later. My daughter lives in Europe. So, while we can still do it together, we're gonna do it together.

Sexuality matters were seriously considered by patients in their global reordering of priorities. However, their sexuality concerns were occult, and were incorporated along with their concerns for wife and family. The patients admitted that their need for closeness and companionship had increased. Blatant discussions about sexual function itself were regarded as something for the distant future, if all other things went smoothly.

Interviewer: Did you talk to any of the other patients having the same operation at the hospital?

Patient: This gentleman was talking very openly and we discussed the thing (sex), a couple of days before the operation. But, after the operation, that was the last thing on our mind. We were just so happy we had pulled through. Before leaving the hospital we exchanged phone numbers so we can talk someday.

Interviewer: When do you think you will go ahead and do that?

Patient: Well it could be months before it happens. But I expect to give this gentleman a call in the fall and find out a little more about his operation and sex after.

It was clear that in all types of prioritizing sexuality matters were not of high priority. Although sexuality was viewed as a concern by prostatic cancer patients undergoing therapy, it was not considered important enough to be even discussed. Their prioritizing involved those needs which were imperative for survival and necessary for maintenance of life. In the context of an illness that may cause death, sexuality need was not considered by prostatic cancer patients as deserving of overwhelming attention. However, patients considered that sexuality matters were of adequate concern to be seriously considered at a later time, once the storm had settled.

Adjusting

Respondents were found to have substituted their decreased or lack of sexual intercourse with nonsexual or other sexual activities. In examining respondents' adjustment behavior, it was discovered that all patients had made certain sexual adjustments, whether or not they were capable of intercourse. These sexual adjustments occurred for various reasons. Those who were not capable of sexual intercourse felt obliged to make adjustments in their sexual activities. Of those who were still capable, some made adjustments because they feared that their therapy might affect their spouses, and because they had gained

a new perspective on life in which sexual intercourse was no longer regarded as important or necessary.

Primary adjustment noted in a majority of patients was that they suspended all attempts at intercourse and substituted nonsexual or other sexual activities. Those activities, which they considered nonsexual, were designed to spend more time with their spouses and families--going to movies, watching television, gardening, shopping, and travelling. One of the respondents who had experienced intermittent impotence, but who was considering the possibility of complete impotence, stated:

"I mean, if it (erections) should happen to be completely gone, we'll have to substitute something. We'd probably have to go to more shows or something, you know. I would sooner watch a T.V. show, if it's a good one. But, my wife loves shows. We used to go to parties when we were young. I can have fun with some other ladies and so can she. I mean that's what it is. We'll have to do something else, I mean."

Patients who had suspended all attempts at intercourse either physically removed themselves from intimate situations by sleeping in a separate bed and/or room, or had come to an understanding with their spouses not to engage in sexual intercourse. However, one patient with such an arrangement insisted that it was to ensure rest and sleep. For example:

Interviewer: How about your sexual activity at present?

Patient: After we got twin beds, we quit sleeping together. Now, we've got twin rooms. So, this way I shut my door and I don't hear her and I don't bother her when I snore.

Interviewer: So, these days, when you want sexual activity, what do you do?

Patient: Well, it is before we go to bed, then. It has got to be by appointment, now. Well, you could always do petting and all that, you know. That's the way I feel about it and I think the wife feels about it the same way.

Those patients who were not capable of sexual intercourse, but desired intimate contact, had substituted other sexual activities. These other sexual activities included holding hands, hugging, kissing, fondling, and petting. One of the respondents, who had experienced complete impotence, stated:

"We can sit and hold hands and talk about different things, not necessarily sex. A lot of other things. And (we) still sit and hold hands. Being fond of one another I think. The closeness. I think, as one grows older, sex is not that important as it was at one time. When you are young, sex is important. But, as one grows older, it's a little less. But, the love and fondness towards one another, I think is greater."

One of the respondents who had suspended sexual intercourse for fear of transmitting radiation to his wife, and not wanting to disturb therapy, had resorted to daily masturbation. One other patient, who also masturbated occasionally prior to becoming completely impotent, had elected to do so for reasons of noncooperation from his wife.

Except for one respondent, all respondents were of the opinion that their spouses cooperated extensively in their attempts to cope with their altered sexual ability. All patients conveyed that spousal support was crucial in their struggle to maintain their sexuality and remain a sexual being.

Supporting

Support of their spouses and family members was deemed crucial by all respondents in their struggle to cope with the illness. According to them, without such support it would have been almost impossible to survive the onslaught of

their illness. However, it was apparent that patients also consoled and supported their spouses and family members in return. Also, the respondents tended to put on a brave front in order to minimize their own fears and to allay the anxiety of others. Ultimately, whatever the dynamics, supporting each other was a meaningful and effective coping strategy.

Offers of encouragement, hope and comfort were viewed as support by all concerned. The exchange of support was frequent and abundant. Spousal support was considered imperative in all areas, especially concerning matters of sexuality. Patients perceived their spouses and children as helpful in alleviating their fear of cancer and death. The following conversation clearly illustrated one patient's feelings in this regard.

Interviewer: In what ways has your family been helpful to you?

Patient: Very, very helpful. That's what I say. My wife is worth her weight in gold. As far as helping me, you know, dark hours, these are kinda dark hours and you have cancer on your mind....., and she has been very good. And the kids, too. Our daughter that goes to university, she is just twenty now. It hit her pretty hard when I told her. And, I mean there is no easy way to tell anybody, because..... The other daughter is a medical secretary. When I had the barium x-ray about my stomach, she helped me a lot, too. She said, Dad, if that was cancer, CT scan would have picked it up. Your treatment is going on just on your prostate. And she said, if they picked up some cancer elsewhere, there would be some more treatment. It wouldn't be just at..... That's true. But, I mean, me, having the pain, you don't think that way, you know. I mean, that helped a lot. And it was true, the doctor told me the same thing.

In addition to cancer, the sexual relationship with their spouse was also a matter of worry for patients. In this regard, the spouse's acceptance of their sexual disability and sexual inactivity was deemed vital for maintaining their sexual identity. Except for one patient, all patients perceived that they obtained

such acceptance. They expressed feelings of relief that the spouse's sexual demands were one less thing they had to contend with. Hence, it was possible for them not to consider sexual activity as a must and were relieved of any untoward influence on their sexual identity. In fact, most patients felt commended for their hitherto sexual ability and reassured of their masculinity. For instance:

Patient:

"That's what I say. My wife and I had a very good sex life. Just super, I mean. Right now when we get fooling around in bed and I just can't perform, it doesn't make her miserable or mean at all. (She) says, God what's the matter, we'll do it some other time..... My wife, she has told me that she has nothing to wish for better than me, as for as her sex life is concerned."

Patient:

"Like I say, I was fortunate. My wife was no longer aggressive in sex. If I wanted it, fine. If not, it didn't matter. And, she is still the same. So I'm fortunate that way. At one time, she was the aggressor. Oh, yeah. After we got married she was the aggressor. She was always going, oh, let's have it now, you know. So, it was good. And, in the last few years, she has slowed down. Even before the prostate problems. And I became the aggressor then. She never said no or anything like that. And until the prostate problem started,.... and then I slowed down. So, now we're both slowed down. See if my wife was more aggressive and she says, let's have to night or something like that, then I guess it would bother me. But, she doesn't bother me, which is good. That helps me. Sure does."

Supporting of each other by patients and their spouses was also evidenced in many other day to day matters of living. To many patients it meant acknowledgement of their illness and their attempts at coping with that illness. For example:

Interviewer: How do you see your wife being supportive through your experience?

Patient: Ah, her? I'm probably using it to my advantage, too. She is more responsive to what I want. Like, I can see, I have been looking back on it, last couple of weeks now. I have been trying to quit smoking for four years. And, I was watching the television the other night and my cigarettes were out in the truck. She went out and got them for me. Before, she was trying to throw them in the garbage. That kind of thing. She is definitely more than a hundred

percent supportive as far as that goes. In the type of job I do where you are gone two three days at a stretch. Ah, you don't want to go on the highway thinking about somebody at home. You want to concentrate on what you are doing at the time. And in that way, she is a hundred percent supportive. When I leave her, I don't have to worry about what's going on down around here or nothing or how she is making out or how she is coping or something like that. That is the feeling I've got.

Some respondents felt that the whole nature of supporting had brought the family closer together. This in turn, they believed, had allowed them the opportunity to be even more supportive of each other. In response to a question regarding his perception of the spouse's role in his illness experience, one patient commented:

"I think my wife and I are a little closer now than we were before. Because we had this thing now, galdarn it, you know, maybe, it would be worse and I could go sooner than we expected. That kinda brings you a little closer in every day living, I mean. You know, when you are all well and everything, you get irritable and you tell each other off and stuff. I think, we kinda mellowed in that. That we keep it and think about it and forget it. Because, we saw what could happen. Yeah, maybe that's it."

Patients viewed the dynamics of supporting as not only comforting and encouraging, but also as growth producing. It was not only received when offered, but also actively sought.

Growing

The patients' thoughts and actions, through the illness experience, were to an extent guided by the metaphorical meanings ascribed by them to events in their experience. All patients echoed the feeling that, to them, cancer meant debilitation and/or death. Any alteration in their sexual ability, or the potential for such a consequence, was interpreted as the beginning of their sexual and

spiritual demise. Cancer was viewed by some patients as punishment decreed by God. While describing their illness experience, they tended to use terms that had metaphorical meaning to them. Death and uncontrollable destruction were two metaphors that were clearly projected while describing their illness experience. In their descriptions, the shock and fear that accompanies a negative image of an uncontrollable, unexpected destruction and perhaps, personal annihilation, were evident. For instance:

Patient:

"Well, like I say, it kinda hit me that first minute. Right after the doctor told me, I thought, oh no, not me. That happens only to others. But, you know, I said to myself,.... in fact I was preparing for a will and all that. Then, later I thought what for? Cancer can be beaten. That's when I decided to tell my wife. I didn't want to worry her before. When I told her, her jaw kinda dropped. She says, I thought we share our secrets. I said, I wouldn't do that again."

Patient:

"My wife was quite shocked that I had cancer and, it hit her pretty hard for a while. Well, she has got over that pretty well, now. I mean, we both realize it could be worse. Well, if it gets worse, I guess that's it, I'm finished."

Patient:

"Before the radiation treatment started, I had such a sore stomach, I thought I had cancer through my whole body. What would you think? You know you have got it. So, maybe, holey Moses, so I thought. That, kinda scared me. We were all on edge, here. Gee willikers, you know."

All patients felt that going through their illness experience had given them a new perspective on life. They believed that their basic philosophy of life had changed. They viewed themselves as having changed for the better. They stated that they felt more generous, more caring, more loving, and more accepting. Their priorities in life had been reordered. They were more interested in the here-

and-now. Their actions were more purposeful, and they had started to spend more time with their families. One patient even believed that his illness experience had actually helped him to accept the reality of having cancer and the possibility of an earlier death. For example:

Interviewer: Is there anything you feel now that you didn't before, or anything that you don't now but did before?

Patient: Well, I guess maybe, this feeling that I accept it now. You know it has smartened me up. Because, you know, I worried quite a bit there at Christmas time about this. It drives you berserk pretty near because you think, really, the worst all the time--now, what will the doctor tell me? how long do I have to get my things in order? Now, I don't do that. I mean, I don't care if I started to have pain and they diagnosed it as cancer elsewhere. It will never be that way again. I will be able to handle it.

Even though some respondents sounded fatalistic about their illness at times, they mostly showed courage and hoped for a better life and quality time with their families before their death. They spoke extensively regarding their concern for their families, if they should die.

In summary, the respondents employed various coping behaviors in their attempts to adjust to the perceived sexual impact of their illness experience. In the face of probable death, the respondents reordered and redefined their life events with a changed perspective on personal priorities. In this changed existence, sexual matters were accorded little or no importance. Their interest and need for sexual knowledge was reflective of this modified valuing of sexual matters in life.

Findings - Sexual Knowledge

Introduction

Two major components of sexual knowledge were identified among the respondents--sexual information and sexual learning. While sexual information referred to the type, source, and availability of illness related sexuality information, sexual learning involved the process of gathering, internalizing and utilizing such information.

Sexual knowledge pertained mainly to matters of sexual alteration and adjustment necessitated by their illness. Through the patients' illness experience, the degree of their perceived threat to life greatly influenced their interest for sexual knowledge, or lack of it. While facing life-death issues, sexual knowledge was regarded as neither essential nor important. Surviving the onslaught of illness and its therapy was foremost on the minds of patients during their illness experience.

Sexual Information

All respondents were found to be interested in receiving general information regarding their treatment procedures and their effects. Some respondents also desired more specific and in-depth explanations about procedures they were undergoing. For example:

"Like, they say, you're gonna hear the ding-dong, the machine is gonna wind up, but it's not gonna hurt. But, what's happening? You know, that type of deal. I guess, a more specific description of what's going on rather than the fact, well, it's not gonna hurt. I would say a pamphlet with diagrams, pictures or whatever.... and a discussion would be good".

A majority of respondents were generally aware that sexual alterations were a possible consequence of prostatic cancer and/or its therapy. However, prior to therapy, they were not cognizant of all probable sexual consequences of their diagnostic and therapeutic procedures. In assessing what type of sexual information patients would like to receive from health professionals, one patient stated the following.

"Well, they should explain about what's going to happen to your sex life. Whether it's going to be better or worse or, you know, a few things about that. I think they should, that's about it. And also, whatever you have is serious, or not so serious".

Patients generally conveyed the notion that they were not greatly interested in any sort of sexual information. They stated that they were more interested in knowing about their prognosis and life expectancy. Sexual information was not deemed important enough to be actively sought on their own initiative. In fact, all sexual information was regarded unimportant while struggling with their illness, and possibly death. However, whenever sexual information was volunteered by someone, they gladly accepted it.

Patients identified urologists, radiologists, nurses, and other prostatic cancer patients as their sources of whatever little sexual information they had received. Patients themselves seldom initiated sexuality focused discussions with any of their identified sources. Most respondents expected health care professionals to provide

sexual information without their having to ask for it. Although patients exhibited a need to learn about their sexual concerns, they reasoned that they either did not know what pertinent questions to ask, or were embarrassed to ask anyone. Also, they expressed that the health professionals rarely discussed sexual issues with them, or addressed such issues only superficially. The following excerpt from one of the interviews clearly exemplifies the nature of sexual discussions between patients and health professionals.

Interviewer: You said, very many of the health professionals that you have come in contact with did not adequately address your sexual concerns. What information would you have liked to receive?

Patient: Well, I could have been informed a little more on the possibilities of this might happen or that might happen. Actually, I think that of the doctors. I have dealt with, both Dr. Y and Dr. Z, for instance. Dr. Y didn't discuss a great deal. He talked a little more about the treatment and side effects that I could expect. Dr. Z didn't seem to volunteer a great deal of information. He would answer questions, yes. But, ah.....

Interviewer: You said they invited questions. Were they specific?

Patient: No, no. This was general.

Interviewer: Would you have felt more comfortable if they had asked specific questions?

Patient: I don't know if it would have made a great deal of difference. Like, at the time I wasn't aware what the problems might be. I would say the only way they could have improved things might have been to warn me that this might happen or that might happen as they did with some other side effects of the treatment. I would say more the urologist's problem rather than the radiologist's problem. As far I see, the radiation didn't make any difference, one way or another.

Interviewer: You mean, your urologist didn't talk about it, either?

Patient: No, not in relation to TUR. He did say this (impotence) could happen with removal of the bulk of the prostate, which was the alternative operation. So, I assumed that it wouldn't happen with the TUR. But, I didn't ask it.

Interviewer: Well, how do you feel now, after your radiotherapy?

Patient: Well, I hope for some improvement, whether there has to be treatment or something, or whether they are talking about doing it. I have read that treatment for impotence is available. I haven't seen Dr. Y since the treatments. I don't know whether he is going to initiate an interview or whether he is waiting for me to. I suppose that he would sometime want to examine me and see whether the whole thing did the job. But, maybe Dr. Z comes first to check on radiation. I suppose Dr. Y has the urine flowing properly, so, I suppose he considers he has done his job.

When explanations from health professionals were not forthcoming, patients tended to be silent and make assumptions based on whatever sexual knowledge they possessed, or found themselves reading whatever literature they came across and listened to other patients' stories. The information obtained from other prostatic cancer patients, although rare, was solely based on those patients' own experience or what they had heard from yet another patient. For example:

Interviewer: When you had your surgery (orchiectomy), did any one talk to you about sexual matters?

Patient: No, they didn't say nothing about that at all. He told me I had to have the operation. I really don't know why to take the pills. I guess, they are like hormones.

Interviewer: Did you ask your doctor or nurses any questions?

Patient: No, I didn't really. I asked him how long I had. May be two years, maybe ten years. If it gets worse, they will try treatments then I guess. But, they didn't say anything much about it, no.

Interviewer: If you could ask about sex, what would you have liked to hear from them?

Patient: I really don't know. Because, I knew sex was out of the question after I had the operation, see. I guess, I figured that. They didn't tell me a whole lot. I knew a guy who had the same kind of an operation. So, I just assumed that. So, I guess we had to assume it. Well, I guess if they cut your testicles out, then I can't see how you could have sex! I just assumed that you couldn't. It was a bit of a shock. But, I figured, I guess people can live without it, we will.

Most respondents felt that nurses were silent about sexuality related matters. Patients admitted that it was difficult for them to initiate discussions of a sexual nature with female nurses. They believed that it would be embarrassing to female nurses if they were asked questions regarding male sexuality. Also, they perceived that nurses were uncomfortable with the subject since they jokingly dismissed any opening offered by patients to discuss such matters. None of the

study patients had ever come in contact with male nurses, and hence, were reluctant to speculate how they would have reacted with male nurses.

Example 1:

Interviewer: Do you think nurses would initiate conversations about sexual concerns, or would you?

Patient: No, the nurses didn't say anything to me. Not about the sex end of it. I would if it were a little bit older nurse. I wouldn't with a young girl. Because they are apt to be embarrassed. They were kidding all the time.... These lines where the treatment is, right at your penis, the nurse would say, well, gee whiz, we will have to sharpen up those marks, you know. Sometimes she would take this red felt pencil, grrrr, like this you know. And they laugh like heck.....

Example 2:

Interviewer: What do you think are sexual consequences of the TUR procedure?

Patient: Some place I was reading that the ejaculate could go the wrong way. I read it somewhere.

Interviewer: None of the doctors or nurses told you that?

Patient: In my experience with nurses... I wouldn't expect this. I found the nurses, maybe I shouldn't use too broad a brush, some of them seemed somewhat embarrassed. Like, for instance, I had to have a catheter several times. And, well, the first nurse explained that we don't have an orderly on duty that's trained to do this. But then I encountered some others I felt were embarrassed to do the procedure. In one case, they called an orderly from another hospital.

A majority of patients felt they received more sexual information from doctors than nurses. One respondent recounted that, during his hospitalization, he was surprised by a nurse who thoroughly addressed sexual consequences of his prostatic surgery.

"There was one nurse, girl, that came and was very open on the whole subject. And, she told me, approximately what my doctor had told me, or something similar, you know. And very open terms. But, I was surprised to see a nurse talk openly about sex life".

Although some respondents were not generally satisfied with the amount or quality of sexual information they received from health professionals, they

tended to accept the status quo and make excuses for the health professionals. Patients felt that the health professionals were justifiably more interested in treating the cancer and attending to their more immediate needs. Justifying the lack of sexual information from health professionals, one patient responded:

"I suppose they wouldn't be able to say now. Again, I'm sure their main concern is to clear the cancer and it was mine, too. They did invite questions and maybe I didn't ask the right questions to get answers on that. As I say, it wasn't the top priority anyway. It was something I felt that if there was a problem, that we would deal with it later. So, I don't fault the medical people greatly on that".

Respondents tended to accept a lack of information better than incomplete information. When alternate procedures were considered during treatment decisions, if sexual consequences of a procedure were not pointed out, patients tended to assume there would be no sexual consequences with that particular procedure. When a less severe treatment procedure was chosen for the purpose of avoiding drastic sexual alterations and the patient was still left impotent, feelings of frustration and betrayal prevailed.

"When we were discussing alternative operations, he (Dr. X) mentioned that the removal of the prostate would probably leave me completely impotent. I suppose that was implying that the other one (TUR) wouldn't. He didn't really say what it (TUR) would. I guess, I assumed from that that the TUR would not. But, so far, anyway, it has. It has left me impotent".

Although some respondents felt that they could have received more sexual information from health professionals, a majority believed that whatever little information they received was sufficient since it was not their priority concern at the time. However, some inconsistency was noted between what they expected, and accepted. They believed that sexual information was not readily volunteered

by health professionals. They also believed that, given an opening and a general idea, they would ask pertinent questions.

Sexual Learning

Sexual learning of respondents was noted to happen on a casual basis. Any learning that occurred was more incidental than purposeful. Patients were not found to deliberately position themselves to gather sexual information. If it was given to them, they accepted it. They implied that they didn't have the needed emotional or physical energy to contemplate and absorb what information was given to them. They claimed that, before and during treatment, they were preoccupied with matters of survival and existence. To them, sexual concerns were more a question of future rather than what sexual information they needed to gather, internalize and utilize in the present.

All respondents felt that the treatment period was not the ideal time to discuss sexual matters or to do anything about them. They believed that it would be possible for them to concentrate on sexual matters once the more pressing worries about cancer were alleviated. Referring to such a notion, one respondent had the following to say.

*Really, during the treatment, I don't think they would be in a position to give any information because you wouldn't know the results of your treatment yet. I think that type of information would have to follow the results of your treatment period. You wouldn't know what type of questions to ask. How long you are going to live? That's the main concern. There is no sense in worrying about something that is two days or six months around the corner. I think if you start worrying about things that aren't actually in front of you and you got to face

right now, you're going to dig yourself into a hole so deep, you will never get out of depression, as far as I'm concerned."

Since some patients so vehemently believed that sexuality was not a crucial issue for them, any sexual information they had received was not internalized. To them, personalizing such information regarding sexual alterations meant accepting them and agreeing to deal with them. They were of course agreeable to store it for consideration at a later time. One patient was not interested in even discussing treatment for his impotence. For example:

Interviewer: In your readings have you come across any treatment for impotence?

Patient: Well, nothing specific, other than that there is a treatment. But, what is suitable for me, I don't know. I guess, the thing I noticed, some old guy had got an implant and ended up in court over it. I don't know if it was permanent. It worked anyway. I suppose probably anything like that would be delayed until they were sure they were done with the treatments. Like, as far as I'm concerned, that's the most important thing. Let's get that (cancer) straightened out first and if we can fix the other (sex) later, okay".

It was apparent that a majority of patients did not consider sexual knowledge as essential to cope with their illness experience. It was clear that given some time, patients would be more focused on matters of sexuality after dealing with their illness and its therapy. However, it was true at least with two patients that they would like to hear about sexual consequences of therapy to assist them with their treatment decisions.

To summarize, the patients identified the period surrounding the diagnosis and treatment of their prostatic cancer illness as an inappropriate time to receive complete information regarding their sexual predicament. While the patients did not want to focus on and deal with their sexual concerns until after the

completion of their therapy, they were clearly insistent that they wanted to know and understand the sexual consequences of their selected treatment prior to receiving such treatment.

Findings - Summary

The study findings presented in this chapter followed three major categories--Sexual Being, Sexual Coping, and Sexual Knowledge. Under each category, the conceptualizations of the data were described as identified properties of the respective categories.

Examination of the data revealed that sexuality was viewed as an important aspect of their lives by all respondents. The respondents were found to have led a fairly active sexual life until the diagnosis and treatment of their prostatic cancer, after which, they noted various alterations in their sexual function, expression and response. The changes in these aspects of their sexuality were identified as interactive--a change in one aspect influenced a change in one or both of the other two aspects.

A majority of patients experienced erectile and ejaculatory functional changes, and believed those changes to be most visible and significant. Although the respondents agreed their sexual alterations had impinged on their masculinity, they reasoned that they were able to maintain their self opinion of manliness by demanding less of themselves sexually, and reported that their wives cooperated supportively in expecting less also.

The respondents regarded their prostatic cancer to be life-threatening and, in the face of probable death, their sexual meaning in life had drastically changed. They regarded sexuality matters to be of much less importance as opposed to matters of survival. They felt they were not ready to even discuss sexuality matters, let alone deal with them. They believed that this was also the view of their spouses.

The respondents had adopted many coping behaviors to adjust to the sexual impact of their illness and treatment--Comparing, Justifying, Adjusting, Priorizing, and Supporting and Growing. The respondents constantly compared events of their own illness experience with that of other prostatic cancer patients. The negative or positive outcomes of these comparisons were used to reassure normalcy, summon courage and build hope, within the context of their illness. One of the ways they lessened the impact of their illness was by attributing changes in their sexual life to such pre-existing factors as age, medication, and other illnesses. This may have allowed them to reduce the perceived impact of the present illness, and hence, make the illness appear less life-threatening and easier to cope with.

The respondents perceived that their spousal and family support was crucial in their struggle to adapt to the impact of their illness experience. They adopted activities that brought them closer to their spouses and family. Spending more time with spouse and family was seen by patients as one of their priorities in their

personal redefining and reordering of their life events. The life-threatening nature of their illness had necessitated reassessment and reordering of their priorities. This was seen by all respondents as a growing experience and having changed them for the better. In their reordered life, although sexual activity was still considered important and necessary, it was not valued enough to be dealt with through seeking of knowledge. Hence, they did not actively seek sexual knowledge.

The respondents accepted sexual dysfunction as a necessary evil of their illness experience. They were found to be willing to deal with matters of their sexuality once the threat to their life had diminished. Since their sexuality needs were not deemed immediate, their resolve to obtain sexual information was not present. They did not object to the notion of resolving their sexual concerns, but they felt the timing was inappropriate and should be delayed until after their recovery from treatment. However, they felt that it was imperative for them to know the sexual effects of therapy prior to their treatment decisions.

The respondents viewed health professionals as not forthcoming with regard to sexual information. In particular, they did not regard nurses as a source of sexual information. They felt that nurses were generally silent about matters of sexuality and did not initiate discussions of a sexual nature. They believed that given an opening and understanding, they would ask questions about their sexual concerns.

CHAPTER V

Discussion of Findings

Introduction

The findings of this study contribute to the knowledge about sexuality within the experience of prostatic cancer. The major purpose of this study was to understand prostatic cancer patients' perceptions and reactions to their illness and/or treatment induced sexual alterations. The main topics addressed were sexual concerns, sexual adjustment, and sexual knowledge.

In the phenomenological sense, nursing's goal is to learn about human conduct and to use that knowledge in its practice. To learn about human conduct is to understand human thoughts and actions. "Human conduct is considered action only when and insofar as the acting person attaches a meaning to it and gives it a direction which, in turn, can be understood as meaningful" (Wagner, 1970, p. 8).

The central focus of this study was to gather and describe a sense of what meanings prostatic cancer patients attached to their illness experience as a whole and, in particular, to the nature of their sexuality through the illness experience. This was deemed possible only through patients' own descriptions of perceived events in their illness experience. To this end, the study was an exploratory-descriptive one designed to allow maximum flexibility in obtaining qualitative in-

depth data from its true source in the real world--the prostatic cancer patient.

The primary goal of descriptive phenomenological methods is not, in itself, to generate substantive theories or models (Field & Morse, 1985). The purpose is, however, to propose a framework that integrates and synthesizes gathered facts and insights into a consistent descriptive structure (Giorgi, 1975).

The descriptive structure presented in this study is intended to explain and discuss the findings identified in the study. Included in the discussion is relevant literature regarding the subject matter, to either support or distinguish the researcher's conceptualizations. The study's research questions will be used as a guide to discuss the major findings of the study.

Arising from this study will be possibilities for future research and recommendations for further sexuality research related to prostatic cancer patients. The investigator's conclusions regarding the implications for health professionals in general, and nursing practice and education in particular, will also be outlined.

Sexual Concerns

The nature of sexuality of seven respondents was examined to identify their perceived sexual concerns arising from prostatic cancer illness experience. Two major findings were noted regarding their sexual concerns--one related to concerns regarding their sexual activity, and the other, related to their feelings of masculinity.

Sexual Activity

It was significant that, although sexual activity had generally declined for all patients prior to treatment, it was deemed an important aspect of their life. Beginning with the diagnosis of their prostatic cancer, their sexual activity was found to decline drastically, reaching its lowest ebb during and after treatment. To understand and explain this phenomenon of decreased sexual activity, various factors in the illness experience of prostatic cancer patients should be considered.

One significant factor identified for such sexual non-activity among respondents was their experience of sexual alterations. All respondents were found to have experienced some degree of alteration in their sexual expression, function and/or response. Erectile, ejaculatory, and orgasmic changes were the most significant. These findings are congruent with claims made in an array of scholarly literature and results of several research studies investigating the sexual impact of various forms of prostatic cancer therapy (Bachers, 1985; Balducci et al., 1988; Bergman et al., 1983; Eggleston & Walsh, 1985; Fowler et al., 1988; Goldstein et al., 1984; Huben & Murphy, 1986; Nishimoto, 1987; Rowan, 1986; Schover et al., 1984; Swanson, 1981; Vikram & Vikram, 1988).

The study by Bergman et al. (1983) included patients undergoing similar treatment procedures as patients in the current study. They also identified various sexual alterations in prostatic cancer patients undergoing radiotherapy, estrogen therapy and orchiectomy. These investigators noted that, for a significant number

of patients, erectile impotence occurred most frequently, followed by ejaculatory and orgasmic dysfunctions, with all three forms of therapy. It is important to note that impaired erectile capacity was the reason given commonly by patients for their decreased sexual activity and/or enjoyment. Similar findings have been reported by Goldstein et al. (1984) and Nishimoto (1987) regarding prostatic cancer patients undergoing radiotherapy and prostatectomy respectively. Although vast evidence exists that prostatic cancer treatments cause sexual changes, due to the relatively advanced age of patients, the sexual effects of these treatments are seldom discussed (Bergman et al., 1984).

Relatively advanced age of most prostatic cancer patients is also viewed as being partially responsible for their decreased sexual activity by many patients and health professionals alike. Age-related physiologic sexual changes are known to cause reduced sexual activity (Masters & Johnson, 1966; Woods, 1987). Most respondents in the present study frequently related their lack of sexual activity to their old age. Woods (1987) suggested that increasing age is known to cause decreased sexual activity, not cessation of sexual function. It is also known that sexual function and activity have been maintained in a high percentage of older patients, even following radical prostatectomies, when nerve sparing techniques are used (Walsh & Mostwin, 1984). A majority of patients in the present study tended to assume an inverse relationship between age and sexual activity, without duly considering the type, degree and timing of their sexual changes. Such

assumptions may reduce the likelihood of seeking change, negatively affecting one's motivation for self-education and impeding necessary sexual adjustment, especially when faced with a life-threatening illness.

All respondents in the present study perceived their diagnosis of prostatic cancer as a threat to their life. It is well documented that life-threatening illnesses, in addition to physical effects, are known to evoke many emotions and feelings in their hosts--fear, anxiety, anger, embarrassment, depression, and grief, to mention a few (Smith, 1981; Weisman, 1979). These negative emotions have been implicated in the neurological diminishing or extinguishing of one's sexual capacities (Lazarus, 1978). Particularly, depression has been found to cause sexual apathy, and hence, decreased sexual activity (Bergman et al., 1984). In the present study, only some of the aforementioned emotions and feelings were exhibited by the respondents, or perhaps were not identified by the investigator. It is conceivable that such emotions and feelings were present, but not overtly expressed by the respondents because of their male socialization, where males have been taught to be strong and not to show emotions (Smith, 1981). Also their unfamiliarity with the investigator's role may have prevented them from expressing their true emotions. However, some respondents were found to be labile, anxious, embarrassed and somewhat depressed.

Masculinity

To date, most research studies examining the sexual impact of prostatic cancer therapy have focused on its biologic aspect (Zilbergeld, 1979). There is little data available regarding male patients' reactions to sexual effects of therapy (Fisher, 1983). Central to the purpose of this study was to understand the overall sexual impact of prostatic cancer therapy, including patients' perceptions and reactions.

Woods (1987) suggested that changes in any one dimension of sexuality, such as sexual function, cause changes in other dimensions also, thus affecting total sexual health. One other significant finding was related to patients' sexual self-concept--their image of themselves as men. It is frequently mentioned in the literature that a man's feelings of masculinity may be diminished if his sexual function was threatened or affected (Bachers, 1985; Leiter, 1984; Pietropinto, 1986; Shipes & Lehr, 1982; von Eschenbach et al., 1981). Nowinski (1984) contended that men's nature of relating sexual ability and performance with their masculinity is rooted in the male sexual socialization, and the limitations imposed on their sexuality by such socialization. He suggested that "men are socialized to value the "machismo" image of masculine sexuality, which includes qualities such as initiative, pursuit, perseverance, technical skills, and high performance (p. 287)." Since men are socialized to associate male sexuality with such qualities, it is

believed that a man's perception of his masculinity would be diminished if those qualities could not be maintained for some reason.

The findings of this study did not support this stance. Although a minority of patients expressed feelings of decreased masculinity, the majority did not severely doubt their manliness. This apparent contradiction may be explained by the responses of patients to the diagnosis and treatment of prostatic cancer.

Many respondents suspended their sexual activity and avoided all sexual contact perceived as leading to coitus. They reasoned that they were able to maintain their sexual self-identity (masculinity) by assigning little or no value to the act of sexual intercourse and by demanding less of themselves sexually. It is known that men with erectile dysfunctions are apt to suspend all sexual activity and sexual contact with their wives (Pietropinto, 1986). It is, however, possible that respondents in the present study were less concerned about their masculinity as a result of avoiding sexual activity and decreased demand for sexual performance by their spouses. The notion that for some patients illness and sexual dysfunction may actually provide a welcome relief from previously expected sexual activity (Schoenberg, 1984; Stoklosa, 1984), may also explain the finding that some respondents in the present study were not overly concerned about their masculinity. Also, the respondents ignoring those matters, which they perceived to be directly related to their illness and treatment, may be viewed as an attempt to make their illness situation easier to cope with.

Sexual Adjustment

The patients in this study perceived their diagnosis as life-threatening. The respondents adopted many coping behaviors in their attempts to adjust to the impact of prostatic cancer in general, and to the sexual impact of illness and its treatment in particular. The most significant finding was that the greater the degree of their perceived threat to life, the lower the importance they ascribed to sexual needs and concerns. This inverse relationship was dynamic and three dimensional. That is, as the degree of their perceived threat to life decreased, the importance they ascribed to their sexual concerns appeared to increase as they progressed from diagnosis to post-treatment period. During the first interview, the respondents stressed that they were more concerned about their life than their sexuality. Soon after diagnosis sexual aspects of their life was not even a consideration. At the time, sexual activity was desirable but not essential.

This is contrary to the popular belief that the sexuality need of patients is paramount even when they are faced with a life-threatening illness (Zilbergeld, 1979). Literature concerning sexuality of cancer patients has repeatedly stressed the importance of sexuality needs of patients during the experience of such an illness (von Eschenbach et al., 1981). The notion that in the face of a life-threatening illness the existential needs of patients may supersede their sexuality needs (Derdiarian, 1987a), has been regarded by some experts in the field as an

excuse used by many health professionals for not addressing sexuality matters (Golden & Golden, 1980; Zilbergeld, 1979).

One reason for this view may be that their concept of sexuality includes sexual activity and much more (Haas & Haas, 1990, von Eschenbach, 1981). Perhaps during an illness it is not the coital aspect of sexuality that is stressed. However, when the general term of sexuality is used, it is not clear which specific aspect(s) of sexuality one is referring to. Ver Steeg (1981) cautioned clinicians about this very point, not to be general but to be very clear and specific when addressing matters of sexuality (p. 292). It is true that a patient's need to be loved, touched, hugged, kissed, and caressed may actually increase and assume renewed meaning in the face of a life-threatening illness (Stoklosa, 1984). However, it is also important to recognize that not all patients will have sexual concerns, or that the concerns may be a selected few of particular importance to the patient.

There is ample support for the claim that sexual concerns may be viewed a low priority when life-death issues are foremost in the minds of patients (Stoklosa, 1984; von Eschenbach et al., 1981). Both Gonick and Rodriguez, in case discussions with their coauthors (von Eschenbach et al., 1981), suggested that the major concern of most prostatic cancer patients is the threat to their life, not sexuality. Such a notion is consistent with the Theory of Motivation proposed by Maslow (1962), where basic physiologic needs necessary for survival are believed

to precede other needs. Although human sexuality is believed to have a biological basis (Gecas & Libby, 1976, p. 33), treating sexuality as strictly a biologic need that should be met immediately is to ignore the holistic nature of human beings, and their sexuality.

However, to say that the respondents in the present study were not at all concerned about their sexuality is to ignore the data completely. Although the respondents had sexual concerns, they were unable to deal with them during the diagnosis and treatment period due to their illness related uncertainty and vulnerability. In the face of possible death, they were preoccupied with redefining and reordering their sexual and other life values and priorities.

A majority of respondents, having thought of their own mortality, had revalued and repriorized many of their needs, wants and relationships. They had acquired a renewed perspective on all that they neglected, or highly valued, before the onset of their illness. They valued life and health more, had assigned greater importance to quality and quantity of time with family, and relationships, and had accorded lesser importance to coital activities but, greater importance to other aspects of sexuality.

Smith (1981) has written extensively, and eloquently so, about experiences of patients who have had an encounter with death. In her study of patients experiencing serious illness, she found very similar results. A great majority of the respondents in her study had changed values and priorities, which they attributed

to their heightened awareness of death and their own mortality. She found a majority of the patients to have become generally more open, more caring, more family oriented, more humanistic, and less materialistic. She also found that they had begun to see themselves with renewed value, other people with greater compassion, and things in life with more beauty (pp. 19-33). It is interesting to note that patients did not refer to sexuality at any time. Of course, Smith (1981) was not focusing on the topic of sexuality. However, since the questions were asked in an open ended manner, one would expect some reference to sexuality. The fact that sexuality was not referred to in any form, is consistent with the findings of this study. It may be that sexual matters were not deemed important enough to be talked about while faced with, or having survived a life-threatening illness.

The responses about changed values and priorities in the current study were not as extensive as found in Smith's (1981) study. However, the responses were similar in content and quality. Similarly, as with Smith's study, some respondents in the present study felt that the heightened awareness of death and the changing of values and priorities were a growth experience. It could have been their way of adjusting to the impact of prostatic cancer illness and treatment--sexual and other.

While respondents' refusal to deal with their sexual concerns may be easily and simply dismissed as denial of their sexual alterations, or illness itself, it

behoooves the investigator to further examine if it is denial in the first place, and if it is, is it understandable and acceptable? The term "denial" has been negatively understood as intentional concealing of realities. Webster's (1979) dictionary defines it as "refusal to believe or accept (p. 166)." Weisman (1979) defines it as "how one simplifies the complexity of life (p. 44)." Weisman's (1979) book, *Coping with Cancer*, is a synthesis of research findings from Project Omega, a study conducted to identify the coping process in newly diagnosed cancer patients. The findings of Weisman's study support the findings and conceptualizations related to the sexual adjustment of prostatic cancer patients in the present study.

Weisman (1979) believed that "vulnerability originates in existential despair (p. 79)." He found that existential concerns were uppermost in the minds of newly diagnosed cancer patients. The author equates vulnerability, a distressed state of uncertainty in the face of a life-threatening illness, with non-coping. Denial, which, according to the author, temporarily mutes distress, is used to decrease vulnerability, and hence, enhance coping--"what one does to bring about relief, reward, quiescence, and equilibrium (p. 27)." Weisman believed that denying, in its mild form, is an act within the coping process. The dissociation of sexual concerns from their illness experience by patients in the present study, then, is denial in its mild form. Herein lies the support for the sexual adjustment process of prostatic cancer patients in the present study. Their ascribing little importance to sexual matters is perhaps a phase of their coping process by way

of denying their sexual concerns, on the way to managing the overall impact of the illness and its treatment. Weisman (1979) further stated that, accepting and denying can and do coexist.

However, some experts in the field of psychiatry have preferred to use the more neutral term "minimization" to that of denial, since the latter is ambiguous and judgemental. Lipowski (1970) described patients' denial of undesirable aspects of their illness as a cognitive mode of coping, and referred to it as "minimization". This style of cognitive coping "is characterized by a tendency to ignore, deny, or rationalize personal significance of information input related to one's illness, or consequences" (Lipowski, 1970, p. 95). According to Lipowski, people employ minimization as their preferred mode of cognitive response to illness in order to reduce its threatening aspects and obtain relief.

The previously posed question can now be safely and completely answered. The prostatic cancer patients' accepting of their illness while denying, or minimizing, their sexual concerns may be understandable and acceptable.

In coping with or adjusting to their sexual impact, the respondents in the present study were found to exhibit the following behaviors.

1. Redefined and reordered their life priorities.
2. Shared and compared their concerns with others (patients in a similar situation).
3. Ignored their sexual concern.

4. Recognized their sexual predicament, but related it to something more apparent and less threatening than their illness and treatment, and did not discuss the matter with health professionals.

These findings have been partly or completely supported by a number of other research findings (Degner & Beaton, 1987; Smith, 1981; Weisman, 1979). Sharing and comparing effects of illness and treatment among patients was mentioned by Smith (1981). She considered this behavior an enactment by patients to primarily summon hope and reassure themselves. Degner and Beaton (1987) have described the behavior of finding something less threatening than their illness to attribute their symptoms to, as a coping behavior. They also alluded to the notion of not discussing matters of concern with health professionals as denial used to cope with their life-threatening illness.

The finding that the study respondents, in their sexual adjustment process, believed life-death issues to be more important than issues regarding sexuality was well supported by other literature. However, it was also important to the purpose of this study to identify what sexual knowledge the respondents desired, and how and when it should be actualized.

Sexual Knowledge

Sexual knowledge was initially examined as a factor in the sexual adjustment process of the respondents. However, later, it was identified as a separate category since there were valuable data and a definite pattern pertaining to information gathering and learning of sexual information. Two significant findings were noted. First, discussions about sexual matters were seldom initiated by either the health care professionals or the respondents. Secondly, respondents believed that learning about and dealing with sexual concerns should occur after completion of prostatic cancer treatment.

During the data collection period, from diagnosis to end of treatment, the respondents were not found to deliberately and actively seek sexual information. While they appeared quite disinterested in sexuality related information soon after diagnosis, they seemed to probe for sexual information from the investigator during the second interview, after completion of treatment. Even after treatment, although they were then more aware of their sexual alterations, most respondents appeared to be seeking information in accordance with the hierarchy of concerns perceived important by them--primarily, life expectancy and recurrence of cancer. However, a minority of the patients overtly exhibited a need for sexual information.

These findings are again reflective of their coping process mentioned earlier--where their existential concerns predominated their sexual concerns. Similar

findings have been reported by Derdarian (1987b), who examined the nature, relevance and scope of informational needs of recently diagnosed cancer patients in relation to disease, personal, family and social concerns. She found that the need for information of an overwhelming majority of the subjects were significantly based on the importance value they attached to their survival concerns. These were, in order, disease (prognosis and treatment), personal (physiological and psychological well-being and career), family (relationship with loved ones), and social (other relationships). It is important to note that the hierarchy of basic human needs, developed by Maslow (1962), was used as part of the theoretical framework for the study by Derdarian (1987b). Derdarian contends that the relevance of informational needs may be determined by the hierarchy of needs as well as the perceived amount, imminence, and likelihood of threat(s) associated with survival. This certainly appeared to be the *modus operandi* with prostatic cancer patients in the present study. Based on such theory and research findings, perhaps it is prudent to suppose the following: those respondents who did exhibit an interest in sexual information did not perceive a threat to their survival at the time, or had successfully coped with such a threat.

The amount and imminence of threat to one's survival perceived from a life-threatening illness such as cancer and its rigorous therapy may be much greater than that perceived from a non-life-threatening illness and its less severe treatment. Some interesting findings were noted in a study involving patients who

had undergone transurethral prostatectomy for benign enlargement of the prostate (Libman, Creti, & Fichten, 1987). These investigators found that a great majority of patients would have liked much more information regarding sexual matters before the surgery than they received. This particular finding is in contradiction to the findings of the present study. This may be due to the fact that Libman and colleagues' sample were not confronted with the life-threatening illness of cancer.

Libman et al. (1987) also found that lack of information or misinformation about sexual matters contributed to patient discomfort. Yet another finding similar to the present study is that a vast number of patients indicated they should be particularly told about the sexual consequences of treatment procedures considered for them. In the present study, although they did not desire an abundance of sexual information, some respondents were angry and frustrated that they were not told of the consequence they experienced, especially when they perceived it to be a direct result of the therapeutic procedure.

A comparative study of patients treated for prostatic cancer and benign prostatic hypertrophy would provide a clear understanding as to whether or not the nature of their illness is a determinant factor in assessing informational needs about sexual matters. The study conducted by Nishimoto (1987) is one such endeavour. However, the primary focus of this study was not informational needs of patients. Nishimoto found that subjects in her study exhibited a voracious appetite for sexuality related information, regardless their illness was malignant

or benign. Perhaps it is important to note that these patients were interviewed an average of 12 to 15 months after surgery. By this time, the patients with prostatic cancer were probably ready to deal with their sexual concerns. Also, one other finding of interest dealt with patients' perceived source of sexual information. While doctors, friends and literature were considered a source, not one patient remembered nurses ever discussing any information, or any matter, related to sexuality. Similar findings were also reported by Bullard et al. (1980). These findings are strongly reinforced in the present study.

There are several possible reasons for the lack of sexuality-related discussions, and for the failure of both the patients and the health professionals to initiate such discussions (Lister, 1984). As far as the patients are concerned, it has already been identified that sexual matters were not one of their primary concerns. Apart from the fact that sexuality is a personal and sensitive topic for many to discuss, it is possible that their sexual socialization as males, their age, and learning style were also factors in their reluctance to approach the subject matter.

In addition to some of the aspects of male socialization already mentioned, men are also known to have been taught to be self-reliant, independent, decisive and strong (Cowling & Campbell, 1986; Kolodny et al., 1979; Nowinski, 1984; Pietropinto, 1986; Zilbergeld, 1978). Some other aspects of male socialization have already been identified. Such male role expectations imposed by society and

by society and by men themselves may prevent men from achieving optimal health (Forrester, 1986). According to Forrester (1986), "men may be reluctant to admit or even to recognize their health needs, let alone to seek assistance in meeting these needs (p. 16)." This is a compelling argument when attempting to understand why men may not initiate discussions or ask questions regarding their sexual concerns.

Another societal myth is that the elderly are asexual, and it is abnormal for them to be sexual (Glass & Dalton, 1988). Men and women have been socialized to think that as they age, it is not proper to engage in sexual activity. Sviland (1978) stated that such societal expectations may make the older person feel shameful, embarrassed, and guilty for possessing healthy sexual aspirations. For fear of being discovered that they may still be sexually interested, they may actually hide their interest in sexual matters. This may also explain why prostatic cancer patients, who are generally older than 50 years of age, may not exhibit interest in sexuality related matters. In addition, the extent of search for information has been found to diminish as adults age (Lenz, 1984).

Yet another factor that may have caused respondents' reluctance to initiate sexuality related matters is their learning style as adults. Malcolm Knowles (1989), father of contemporary adult learning theory, suggested that adults have a psychological need to be self-directing. He characterized adult learners, among others, as intrinsically motivated, and task and problem centred. This may provide

an explanation for respondents' reluctance to initiate sexuality related conversations. Their motivation to learn about sexual matters may have been dampened by the nature of their illness, and they may have perceived the problem to be their disease, and managing more immediate concerns of their illness to be their task.

Perhaps as adults, prostatic cancer patients are best suited for self-directed learning. Knowles (1989) insisted that self-directed learning is appropriate "whenever more complex human performances are required, especially those requiring judgement, insight, creativity, planning, problem solving, self-confidence and the like (p. 49)." Sexuality is a complex phenomenon. The performance of maintaining sexual health requires all skills mentioned by Knowles, and much more. Knowles presented the following advice for motivating adults to learn: 1. legitimize involvement of learners; 2. help them become aware of their needs; and 3. provide a role model.

Three factors in the literature that may be helpful in explaining the health professionals' failure to initiate and discuss sexual matters with respondents in the present study are: 1. their discomfort with addressing matters of a sexual nature; 2. their lack of knowledge regarding human sexuality; and 3. their personal beliefs and attitudes regarding sexuality. Lister (1984) investigated doctor-patient communication and found such factors to be barriers to sexuality related conversations. Similar results have also been reported by Williams et al. (1986)

about nurse-patient communication. It is concerning to note that these investigators found that the nurses in their study felt uncomfortable or did not feel responsible for discussing sexual matters. Puritanical, negative attitudes and beliefs of some health professionals about sex and gender are frequently cited reasons for not discussing sexuality matters with their patients (Golden & Golden, 1980). According to Forrester (1986), male nurses and physicians may feel uncomfortable to discuss matters of sexuality with male patients, as they may feel men do not discuss such things with other men. These findings, however disconcerting, may to some extent explain lack of sexuality related discussions between health professionals and patients, and prostatic cancer patients in particular.

One other significant finding was related to dealing with sexual concerns and the timing for such intervention. A majority of patients in the present study believed they were not yet ready to learn about, and deal with, their sexual concerns. They also believed that any sort of serious and concerted intervention with respect to their sexual concerns should occur after recovery from the treatment of their prostatic cancer--physiologically and emotionally. While some respondents demanded that they would have wanted to learn about possible sexual side effects of their treatment choices to aid in their treatment decisions, some did not want and some did not care. Only a minority of patients received such information prior to their treatment.

Research findings in this area are controversial. Reimer, Keintz, & Glassman (1985) have suggested that "optimally, the amount of information should be tailored to the patient's coping style (p. 803)." These authors, citing numerous research findings, concluded that patients have different educational needs and wants at different stages. Also, what patients perceive as their learning needs are not necessarily what nurses and other health professionals deem important, or what patients end up learning (Libman et al., 1987).

Providing accurate and appropriate information at the right time may render the illness experience a positive one. It has been shown that prostatic cancer patients receiving relevant information prior to therapy have been spared of disruptions in usual activity and even some expected side effects (Johnson et al., 1988). This finding may provide merit to frustrations of respondents in the present study who did not receive an explanation about expected sexual side effects prior to their therapy. Libman et al. (1987) have reported similar findings. These investigators suggested that "information delivered in written form, in conjunction with a verbal explanation, may be an optimal means of providing patients with needed information (p. 150)".

Summary

It is the aim of a research study to not only substantiate already existing knowledge, but also to generate new knowledge. To this end, in depth data were

generated and, in all, a total five major findings were identified and discussed. A majority of these findings are consistent with findings of other related research studies or established theoretical formulations. However, some findings of this study were noted to be distinct. Contradictions and controversies are viewed as positive and growing aspects of scientific endeavour.

It was most significant that although all patients identified and acknowledged various sexual concerns, their need to deal with those concerns was firmly based on what their illness meant to them. Since, without exception, all respondents perceived their illness as life-threatening, the concern for their existence and survival superseded their sexual concerns. Through the illness experience, as the perceived threat to their life decreased, their interest regarding sexuality matters increased. Prior to and during treatment, they wanted to be informed of sexual implications, but not seriously deal with any sexual concern until they were confident that their perceived threat to life and health was no longer their primary concern.

CHAPTER VI

Conclusion and Recommendations

Conclusion

Orem's (1985) theories of self-care were adopted in this study to formulate implications for nursing, arising from the study findings and discussion. Orem's conceptual perspective for the study is presented in chapter three (and appendix A). In terms of Orem's theory, prostatic cancer patients presented themselves as having the capacity for their self-care although they identified and experienced their health situation as a life-threatening illness. It is the investigator's belief that these patients were experiencing sexual self-care deficits and required supportive-educative nursing system assistance for sexual self-care. The many recommendations made here will be based on the self-care aspects of prostatic cancer patients' sexuality.

The descriptive structure that emerged from the study indicated certain deficiencies in the health care delivery of prostatic cancer patients, particularly in the area of sexuality. Hence, arising from the study findings, the following important implications are proposed for the health care system in general, and nursing practice, education, and research in particular.

Implications for Practice

The study findings have implications for all professionals in the health care system who may be expected to deal with the sexuality of prostatic cancer patients. It has been established that prostatic cancer patients undergoing treatment do have sexual concerns and that they do need assistance with their sexual self care. With regard to sexual information required by prostatic cancer patients, the issue is one of amount, method and the timing of its delivery.

The study findings indicate that the information given to patients be individualized based on their particular coping style and needs. Hence, the following recommendations are proposed.

1. That all urologists in the province as a group, in consultation with a sexuality expert, develop written and video educational self-care tools explaining sexual effects of possible prostatic cancer treatments and what the patient can do if and when they note any sexual dysfunction.
2. That urologists, while discussing treatment options with prostatic cancer patients, provide them with educational material along with an open and honest verbal explanation and an invitation for further discussion of any sexual matter at any time.
3. That a follow up mechanism be established to assess sexual concerns and needs of patients after their recovery from therapy.

4. That nurses involved with the care prostatic cancer patients educate themselves regarding human sexuality with a special appreciation for male sexuality.
5. That nurses explore and examine their own sexuality prior to dealing with their patients' sexuality.
6. That nurses provide an opening to patients under their care, in a non-judgemental manner, to discuss any sexual matter if they so wish.
7. That nurses facilitate prostatic cancer patients' self-directed learning by providing them with the educational material along with an open and honest verbal explanation and an invitation for further discussion of any sexual matter at any time.
8. That nurses who are unable to provide any type of counselling, refer the matter to another health professional who is able to do so.

Implications for Education

1. That nursing educational institutions ensure that a course in basic human sexuality is included in the curriculum.

2. That the basic course in human sexuality include the values clarification component to examine students' own beliefs, attitudes and misconceptions regarding sexuality.
3. That the basic course in human sexuality include open discussions among students to explore and clearly understand the differences and similarities between female and male sexuality.
4. That the nursing faculty be encouraged to explore and examine their own sexual beliefs, values, attitudes and misconceptions.

Implications for Research

Sexuality of female patients with cancer is a fairly well researched topic. However, a paucity of research concerning male sexuality, particularly of prostatic cancer patients, was evident. Examining the present study's topic with a larger sample and with combined qualitative and quantitative measures would generate more reliable, valid and generalizeable findings. The optimal time for conducting a similar exploratory study would be one to three months after completion of patient's therapy as sexual concerns may be more apparent, patients having adjusted to the impact of illness itself. It would be even more valuable to conduct a longitudinal study, with data collected at three month intervals. This would then accommodate contributions from patients who may experience sexual concerns at a slow pace.

A concurrent study of sexual concerns of prostatic cancer patients and their spouses may generate invaluable insights into their concerns as couples and help the health professionals deal with their sexual concerns, together, as couples. In terms of prostatic cancer patients, some other important topics for future research would be--sexual needs assessment at different stages of the illness experience; perceptions of masculinity, age and learning style as variables of sexual adjustment; and the relationship between time of delivery of sexual information and sexual adjustment. The development of a self-reporting tool for assessment of sexual concerns would be of great benefit.

Summary

This study has attempted to understand the sexuality related matters surrounding prostatic cancer and its treatment, from the patient's perspective. This research endeavour has answered some specific questions, raised many more, and given direction to future nursing activity in the area of sexuality of prostatic cancer patients.

The phenomenological approach was appropriate and facilitative in examining the sensitive topic of sexuality. It allowed the investigator to capture the essence of the meaning of sexual experiences held by prostatic cancer patients--the most legitimate source.

Orem's theoretical perspective provided an insight into the nature of sexual self-care of prostatic cancer patients and guided the recommendations arising from the study. In terms of the study's focus on patients' perceptions, Orem's perspective and the phenomenological approach were both vastly congruent.

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APPENDICES

APPENDIX A

Definition of Terms in Dorothea Orem's Theory

Self-care:

- Care required by individual self to maintain his [or her] health and life.
- "The production of actions directed to self or the environment in order to regulate one's functioning in the interests of one's life, integrated functioning, and well-being" (Orem, 1985).
- Purposeful action that has pattern and sequence, and when performed contributes in specific ways to human structural integrity, human functioning, and human development.

Self-care Agency:

- Ability of the individual to carry out activities required for self-care.
- "The complex capability for action that is activated in the performance of the actions or operations of self-care" (Orem, 1985).

Self-care Agent:

- Provider of self-care.

Self-care Requisites:

- "The purposes to be attained through the kinds of actions termed self-care are named self-care requisites" (Orem, 1985).
- Three types of self-care requisites are identified by Orem--Universal, developmental, and health deviation.

Universal:

Materials and functions that support life processes--air, water, food; bonds of affection, love, and friendship; etc.

Developmental:

Conditions and events occurring during various stages of the life cycle--prematurity, pregnancy, etc.

Health-deviation:

Requisites associated with genetic and constitutional defects and human structural and functional deviations and with their effects, and with medical, diagnostic and treatment measures.

- exists for persons who are ill, are injured, have defects and disabilities, and who are under medical diagnosis and treatment.

Therapeutic Self-care Demands;

- "The measures of care required at moments in time in order to meet existent requisites for regulatory action to maintain or promote health and development and general well-being" (Orem, 1985).

Self-care Deficits:

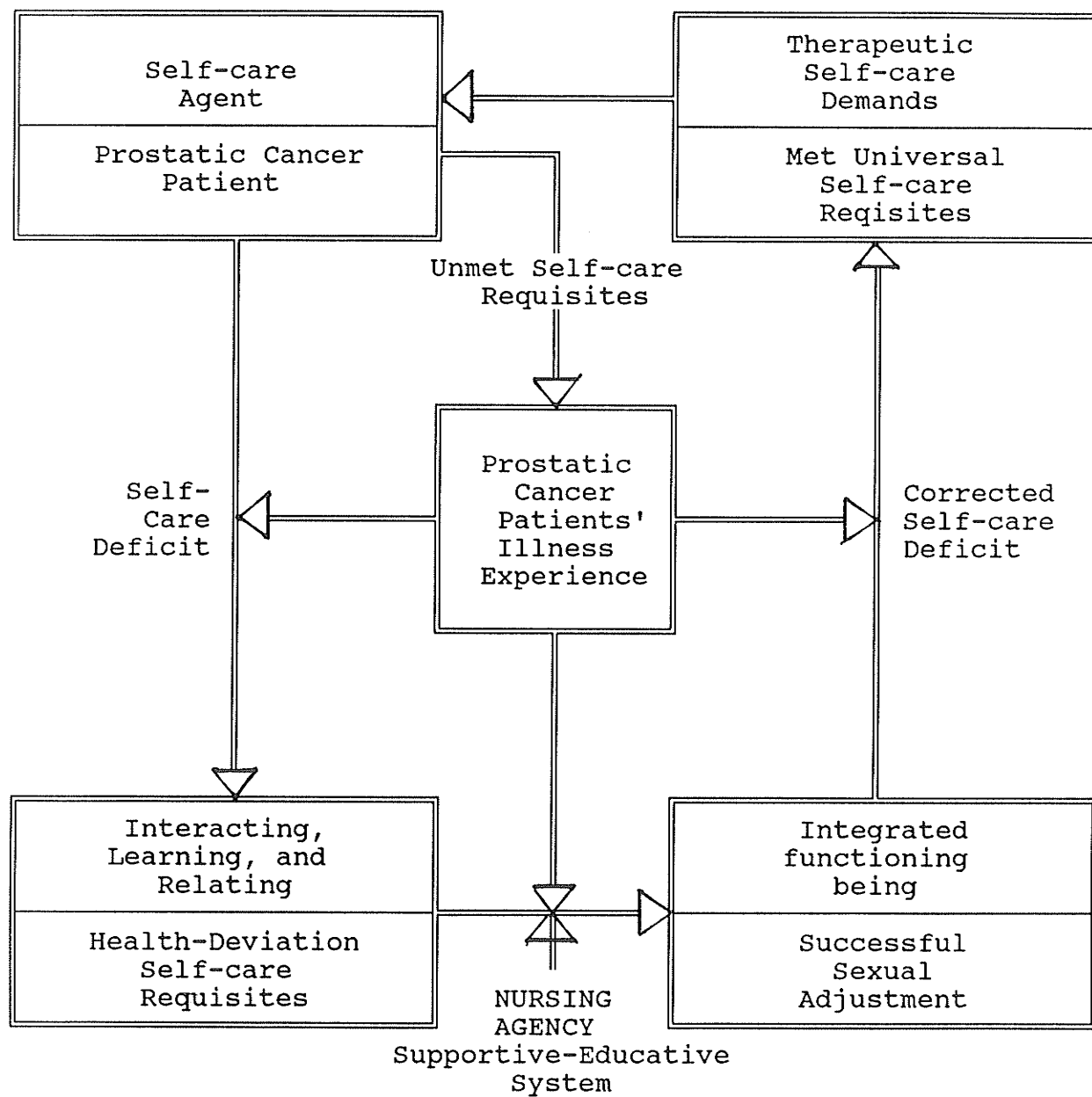
- "A relationship between self-care agency and therapeutic self-care demand in which self-care agency is not adequate to meet the known therapeutic self-care demand" (Orem, 1985).

Nursing Agency:

- "The complex capability for action that is activated by nurses in their determination of needs for, design of, and production of nursing for persons with a range of types of self-care deficits" (Orem, 1985).

APPENDIX B

Conceptualization of Prostatic Cancer Patient
According to Orem's Theory



APPENDIX C

Sample Interview Questions

Common to both interviews:

- * Would you please describe to me, in detail, all that you have experienced with your prostate problem?
- * What would you like to add to what you have already said?
- * What concerns you most at this time?
- * In your opinion, what information regarding sexual activity would be helpful to you?

First interview:

- * What adjustments have you had to make since you started experiencing problems with your prostate gland?
- * How has the prostate problem made a difference in your usual sexual activities?
- * What do you fear most about your sexual activity?
- * What has helped you cope with your sexual problems?
- * What are your thoughts concerning your wife/sexual partner?
- * Would you please describe to me what your thoughts are regarding surgery/treatment in terms of your sexuality?

Second interview:

- * How has your prostate problem changed your life?
- * What do you think the surgery/treatment did for you?
- * How has the surgery/treatment changed the way your body works?
- * What do you feel now that you did not before, or what didn't you feel before that you do now?
- * What are your thoughts about any changes you have experienced in your sexual functioning?
- * What are your feelings about the changes you may have had to make in your usual sexual activities?

APPENDIX D

Patient Information and Consent Form
Perceived Sexual Concerns and Sexual Adjustment of Patients
Undergoing Prostatic Cancer Therapy

Dear Mr. _____

My name is Peri Venkatesh. I am a graduate student in nursing at the University of Manitoba. I am interested in learning about your concerns regarding your prostate problem and related sexual matters, before and after treatment. I would greatly appreciate your cooperation in helping me learn about your illness.

If you agree to participate, this study will involve the following:

1. My visiting you twice in your home, or at place you choose, to interview you about your prostate problem and related sexual concerns.
2. Tape recording our conversation which may last one and one-half hour per interview.

Your name and any identifying information will not be used in the study, or revealed. In order to ensure confidentiality, my notes will be identified by a code only, and I alone will know your identity.

YOU ARE UNDER NO OBLIGATION TO PARTICIPATE IN THE STUDY. You may refuse to participate without any effect on your future care. If you agree to participate, you may withdraw from the study or refuse to answer any question at any time without any effect on your care.

The information learned from all the participants may be used to publish findings. Your identity will not be revealed in any manner.

If you have any questions regarding this study, please do not hesitate to ask in person or by phone. My phone number is 489-6476. If you would like you may ask for a copy of the results.

Thank you for your cooperation.

Yours truly,

Peri Venkatesh

I understand the nature of the study and consent to participate. I acknowledge receipt of a copy of this consent form.

Date: _____

Signature: _____

Witness' Signature: _____

The University of Manitoba

SCHOOL OF NURSING

ETHICAL REVIEW COMMITTEE

Proposal Number N#87/38

Proposal Title: "Sexual Concerns of Prostatic Cancer Patients:
A Descriptive Study."

Name and Title of

Researcher(s): Peri Venkatesh

Graduate Student

Master of Nursing Program

Date of Review: November 7, 1987

Decision of Committee: Approved: Nov.25/87 Not Approved: _____

Approved upon receipt of the following changes: _____

Approved with changes submitted on November 12 and November 21, 1987.

Date: Nov. 25/87.

Theresa George, RN, Ph.D. Chairperson
Associate Professor
University of Manitoba

NOTE:

Position

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.