

**EMPOWERMENT OF MEN NEWLY DIAGNOSED WITH PROSTATE  
CANCER IN TREATMENT DECISION MAKING**

**By**

**B. Joyce Davison, R.N., B.N., M.N.**

**A Thesis**

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CANCER IN TREATMENT DECISION MAKING

BY

B. JOYCE DAVISON

A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

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## ABSTRACT

Background: Previous research has shown men newly diagnosed with prostate cancer want to be informed, but it was unknown if providing them with information would have an effect on the way in which they participated in medical decision making. The purpose of this study was to explore the hypothesis that assisting these men to obtain information would enable them to assume a more active role in treatment decision making, decrease their levels of anxiety and depression, and increase their levels of personal control in the patient-physician relationship.

Methods: Sixty men were randomly assigned to receive either a self-efficacy information intervention that consisted of a written information package with discussion, an audio tape of the medical consultation, and a list of questions they could ask their physician ( $n = 30$ ), or a written information package alone ( $n = 30$ ). Men completed measures of preferred decisional role at the pre-test; anxiety and depression prior to the intervention, and at six weeks post-intervention; and assumed decisional role, and personal control at six weeks post-intervention.

Results: The majority of men (63%) demonstrated a definite preference for keeping or sharing decisional control with their physician. Men in the intervention group assumed a significantly more active role in treatment decision making, and demonstrated lower levels of state anxiety at six weeks. The groups did not differ significantly in terms of their levels of trait anxiety or depression at six weeks. Men in the control group had higher levels of personal control in the patient-physician relationship at six weeks. The audio tape was ranked as most useful, and was used mainly to review what the physician had said and/or share information with other family members.

Conclusions: Empowering these men to get the information they required was shown to increase their participation in the decision making process. Efforts are required to provide such an intervention in other community urology clinics.

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## CHAPTER ONE: INTRODUCTION

### 1.0 Statement of the Problem

Cancer of the prostate is the most common malignancy and second most common cause of male cancer-related deaths in both Canada and the United States (American Cancer Society, 1996; National Cancer Institute of Canada, 1996). In 1996, an estimated 18,200 cases will have been diagnosed in Canada with 1,050 (5.8%) of these cases occurring in Manitoba. Prostate cancer is predominantly a tumor in older men with approximately 94% of men newly diagnosed being 60 years and older (National Cancer Institute of Canada, 1995). Although the aging population is a major contributor to the increased incidence of prostate cancer, it should not be considered as the only explanation. Improvements in clinical diagnosis (mostly due to the use of a blood test to measure prostate specific antigen) combined with increased testing of asymptomatic men, and the ease and safety of transrectal ultrasound guided needle biopsies of the prostate, are primarily responsible for the increase in diagnosis. The number of men with prostate cancer needing medical intervention and follow-up in oncology clinics is expected to increase significantly in the near future.

The medical management of all stages of prostate cancer is highly controversial (Ahmann, 1985; Bretton & Fair, 1991; Perez et al., 1993), and men are faced with difficult treatment decisions at the time of diagnosis. The good news is these men have more opportunity for choosing between treatment modalities than is the case with more homogeneous cancers. Physicians vary widely in their use of surgery, radiotherapy, and hormonal manipulation for treatment of each stage of disease. Treatment choice is dependent on many variables such as stage of disease, patient's age, expected survival, coexistent medical problems, and desire to maintain potency (Bagshaw, Cox, & Ramback, 1990). Although 60% of these men will usually present with tumors that appear localized to the prostate gland (Fleming, Wasson, Albertsen, Barry, & Wennberg, 1993), a substantial number prove to have more advanced disease when surgical staging is performed (Walsh &

Lepor, 1987). Several investigators have found that when staging lymphadenectomy is performed, two-thirds of men initially diagnosed with localized prostate cancer will have more advanced disease (Chodak, Keller, & Schoenberg, 1988; Thompson, Ernst, Gangai, & Spence, 1984; Thompson, Rounder, Teague, Peek, & Spence, 1987). In Canada, pelvic lymphadenectomy is the most common method used to confirm or rule out the presence of lymphatic involvement (Kemp, 1992).

Although the medical management of localized disease has evolved considerably, there is still much debate over which treatment offers the best cure rate. Radical prostatectomy remains the 'gold standard' for treatment of localized disease (Kemp, 1992) but both external beam radiation and radical prostatectomy have been reported to offer equally favorable long-term outcomes (Hanks, 1992; Joensuu, Blomqvist, & Kajanti, 1995). Radiotherapy has tended to be used for men who are at an increased surgical risk due to poor medical status or advanced age, and those who prefer not to have surgery (Badalament, & Drago, 1991; Bagshaw, Ray, & Cox, 1985; Hanks, Diamond, Krall, Martz, & Kramer, 1987). Having no treatment or 'watchful waiting' also has been reported to be another reasonable treatment alternative for localized disease in selected cases (Chodak, 1994; Fleming et al., 1993; Gerber, 1994). Orchiectomy and/or hormonal manipulation are usually reserved for metastatic disease.

Physicians must discuss a great deal of information with these men at the initial treatment consultation to ensure these patients make informed treatment decisions. However, there are several barriers to communication of this essential information. Psychological research confirms that situations of uncertainty (such as a diagnosis of prostate cancer) are stressful for people, especially when they feel they are not in control of the situation (Lazarus, 1966; Lazarus & Folkman, 1984). Since the majority of cancer patients experience a loss of personal control (Gray, Doan, & Church, 1991; Northouse & Northouse, 1987) and significant levels of depression and anxiety in this initial stage of

their care (Cassileth, Lusk, Hutter, Strouse, & Brown, 1984), it is not surprising that feelings of powerlessness may be exhibited.

Information has been identified as a major source of personal control for cancer patients to cope with the circumstances surrounding their illness (Brandt, 1991; Dodd, 1990; Liang, Dunn, Gorman, & Stuart-Harris, 1990). Although the majority of oncology health care professionals believe they should provide information to patients so they can participate in treatment decision making (Northouse & Wortmann, 1990), many of these patients experience difficulties in obtaining information they need to achieve meaningful participation in decision making (Messerli, Garamendi, & Romano, 1980). This situation is further compounded when anxiety and perhaps denial prevents them from remembering or assimilating information they have received.

Investigators have shown there are significant benefits to providing cancer patients with information. Some of these benefits include: increasing participation in treatment decision making and satisfaction with treatment choice (Cassileth et al., 1989); increasing satisfaction with the consultation (Damian & Tattersall, 1991); gaining control and coping with the stress of diagnosis (Fisher & Britten, 1993); decreasing levels of anxiety, mood disturbance, and affective distress (Rainey, 1985); increasing ability to cope during and after treatment (Johnson, Nail, Lauver, King, & Keys, 1988); and assisting in communication of illness-related information to family (Hogbin & Fallowfield, 1989; Johnson & Adelstein, 1991; Reynolds, Sanson-Fisher, Poole, Harker, & Byrne, 1981). Research is required to determine if a group of men newly diagnosed with prostate cancer could accrue these benefits through the empowerment process.

Empowerment is a transactional process of helping people to assert control over the factors that affect their health through the sharing of resources and collaboration (Gibson, 1991). Empowerment links people with resources (Jones & Meleis, 1993), results in greater energy, well-being, and realization of health potential (Brown & Schultz, 1991), and is an important promoter of health (Wallerstein, 1992). The provision of self-efficacy

information as an empowering intervention provides patients with the knowledge and skills "to make rational decisions, sufficient control and resources to implement their decisions, and sufficient experience to evaluate the effectiveness of their decisions" (Funnell et al., 1992, p.55). The process of empowerment fosters a sense of control by emphasizing treatment decisions that incorporate patients' treatment preferences in decision making (Speedling & Rose, 1985). The loss of personal control typically experienced by the majority of newly diagnosed cancer patients made empowerment in decision making a relevant issue to study (Gray et al., 1991).

In recent years, health care providers have adopted a model of care that encourages patient autonomy and participation in treatment decision making. This model consists of providing patients with information and choices, but it is not clearly understood whether this is what these consumers really want. Cancer patients who are given the opportunity to participate in making decisions about their treatment experience benefits such as: less anxiety and depression (Fallowfield, Hall, Macquire, & Baum, 1990; Morris & Royle, 1988); increased satisfaction with treatment decisions and care received (newly diagnosed prostate cancer patients) (Cassileth et al., 1989); and a higher degree of hope (Cassileth, Zupkis, Sutton-Smith, & March, 1980). Findings in non-cancer patients have identified benefits such as: less stress; decreased levels of symptom distress and illness concern; and increased functional status, coping, control over illness, self-efficacy, understanding of and commitment to the treatment plan, and satisfaction with their physician (Brody, Miller, Lerman, Blum, & Smith, 1988; Greenfield, Kaplan, & Ware, 1985; Schulman, 1979).

Several clinical interventions have been identified as increasing participation in treatment decision making among cancer patients, such as: provision of information pertinent to individual needs, time to consider decisions, and inclusion of family (Jassak, 1992; Johansson, Steineck, Hursti, Fredrikson, Furst, & Peterson, 1992; Weiss, 1986); and provision of detailed information (Cassileth et al., 1989). There is currently a gap in the cancer-related literature with respect to which methods of providing information would

be most beneficial in assisting individuals during the decision making stage of their illness trajectory.

Information needs of newly diagnosed cancer patients have been identified but few investigators have implemented these findings clinically. A recent survey (Davison, Degner, & Morgan, 1995) of 57 men newly diagnosed with prostate cancer found that although the majority of these men had a preference to delegate decisional responsibility to their physician, they wanted to be informed. Likelihood of cure, stage of disease, and types of treatments available were identified as the three preferred categories of information within the first six months. Men recently diagnosed (0 to 13 weeks) were found to be significantly more likely to prefer a passive role in treatment decision making. A trend was also identified for men who were less educated (less than a high school diploma), married, and had early stage disease to prefer a passive role in decision making. The main focus of this present study was to determine whether assisting men newly diagnosed with prostate cancer to obtain the amount of information they wanted, would empower them to become more active participants in the decision making process.

### **1.1 Statement of Objectives and Hypotheses**

The hypotheses for this experimental study were developed from the theoretical model, and a review of the literature. The specific objective of this study was to determine if providing self-efficacy information to a group of men newly diagnosed with prostate cancer would result in an empowering experience. It was hypothesized that the empowerment intervention would increase their levels of personal control in the patient-physician relationship, decrease their levels of anxiety and depression, and increase their participation in treatment decision making. The conceptual and operational definitions for this study can be found in Appendix A. Men newly diagnosed with prostate cancer referred to men who had been told by their physician they had prostate cancer, but had not had their medical treatment consultation or made a final treatment decision. The specific hypotheses for this study were:



1. Men newly diagnosed with prostate cancer who receive the empowerment intervention will assume a more active role in treatment decision making than men who did not receive the empowerment intervention.

2. Men newly diagnosed with prostate cancer who receive the empowerment intervention will experience less anxiety at six weeks post treatment consultation than men who did not receive the empowerment intervention;

3. Men newly diagnosed with prostate cancer who receive the empowerment intervention will experience less depression at six weeks post treatment consultation than men who did not receive the empowerment intervention; and

4. Men newly diagnosed with prostate cancer who receive the empowerment intervention will report having a higher degree of participatory (personal) control in the patient-physician relationship at six weeks post treatment consultation than men who did not receive the empowerment intervention.

## **1.2 Conceptual Framework**

The Empowerment Model by Conger and Kanungo (Conger, 1989; Conger & Kanungo, 1988) was used as the conceptual framework to guide this study. This Model was developed using management and psychology theories for the purpose of providing managers with a framework to empower employees at the organizational level. Conger and Kanungo (1988) used Bandura's self-efficacy notion to conceptualize empowerment in motivational terms. The authors defined empowerment as a process whereby an individual's belief in his or her self-efficacy is enhanced, or belief in personal powerlessness is decreased. This model follows a process theory approach to empowerment as a motivational phenomenon by relating it to expectancy (Lawler, 1973) and self-efficacy (Bandura, 1977, 1986) theories.

In expectancy theory, an individual's motivation to increase his or her effort in a given task is seen as dependent on his/her expectation that this effort will result in a desired level of performance, and that his/her performance will produce desired outcomes (Lawler,

1973). In self-efficacy theory, the former expectation is referred to as the self-efficacy expectation, and the latter as the outcome expectation (Bandura, 1986). When individuals are empowered, their self-efficacy expectations are strengthened, but their outcome expectations are not necessarily affected. They develop a sense of personal mastery regardless of hopes for favorable performance outcomes. Conger and Kanungo (1988) stated that empowerment means to enable, and it implies raising subordinates' convictions in their own effectiveness (successfully executing desired behavior) rather than raising subordinates' hopes for favorable performance outcomes.

Conger and Kanungo (1988) viewed the process of empowerment as including five stages. These five stages included the psychological state of the empowering experience, its antecedent conditions, and its behavioral consequences. The first three stages of the empowerment process were: 1. identification of the sources of powerlessness; 2. identification of empowerment strategies; and 3. provision of self-efficacy information (and removal of sources of powerlessness identified in stage one). The fourth stage, or the actual empowerment was thought to occur as a result of the first three stages. The fifth stage involved measuring the behavioral outcomes of the empowerment intervention, or the provision of self-efficacy information. The first three stages of the Empowerment Model by Conger and Kanungo (1988) were used to develop the Empowerment Intervention--provision of self-efficacy information. Stages three through five were empirically tested in this study (Appendix B). The five stages were used as a framework for the literature review in Chapter Two.

### 1.3 Summary

Men newly diagnosed with prostate cancer, as consumers of health care services, should be informed and have the right to participate in treatment decision making to the extent they wish. These men may not be receiving the information that would permit them to assume a more active role. Treatment decisions are usually made within the first few weeks following diagnosis, which is the time frame when these men need information and

support in the decision making process. Considering the high incidence of prostate cancer and the uncertainty of treatment outcomes, it was considered appropriate to conduct this empirical study to measure if providing them with self-efficacy information at the time of diagnosis would increase the degree to which they participated in treatment decision making. Findings generated from this study were expected to provide an empirical basis to guide information sharing and decision making in the clinical area, provide a basis for future research, and contribute to a higher quality of care for this group of men.

## CHAPTER TWO: LITERATURE REVIEW

### 2.0 Introduction

The five stages of the Empowerment Model were used as the framework for this review of the literature. The first stage identifies conditions or circumstances that may contribute to a psychological state of powerlessness in individuals diagnosed with cancer. Stage two identifies strategies capable of enabling cancer patients to become more equal partners in the practitioner-patient relationship, and variables having an effect on the empowerment process. Interventions previously used to provide patients with information are identified in Stage Three, and the empowering experience is described in Stage Four. Stage Five provides an overview of cancer-related literature relevant to participation in decision making, information needs, and predictors of role preferences. Each section will conclude with a summary of relevant research findings.

#### 2.1 Stage One: Identification of Sources of Powerlessness

Power can be viewed from two different perspectives. As a relational construct, it becomes a process by which power is delegated and resources are shared with subordinates. Power is viewed as a motivational construct in the Empowerment Model by Conger and Kanungo (1988). As a motivational construct, power and control are used as motivational and/or expectancy belief states that are internal to the individual. Individuals are assumed to have an inherent need for power known as a power motive, force, or drive (McClelland, 1975) where power refers to an internal urge to influence and control other people. From a motivational perspective, power refers to an intrinsic need for self-determination (Deci, 1975), or a belief in personal self-efficacy (Bandura, 1986). A state of powerlessness occurs when individuals perceive they do not have power, or when they believe they cannot cope with events, situations, and/or the people they confront. For the purpose of this discussion, sources of powerlessness were defined as factors or circumstances that lead to a loss of individual power or control, or a state of disempowerment.

The phenomenon of powerlessness has received much attention in the social and political science literature. A review of the literature by Wallerstein (1992) revealed powerlessness has often been referred to as alienation, victim-blaming, learned helplessness, internalized oppression, or hidden injuries. From a management perspective, Conger (1989) stated certain circumstances appear to lower feelings of self-efficacy, which results in subordinates perceiving themselves as lacking control over their immediate situation, or lacking the resources, capability, or discretion needed to accomplish a task. He stated that these types of experiences maximize feelings of inadequacy and lower self-confidence, which in turn appear to lessen motivation and effectiveness. These factors or circumstances lead to a potential state of powerlessness.

Northouse and Northouse (1987) identified loss of control as the most important problem confronting cancer patients. This loss of control in cancer patients refers to "the feelings of powerlessness and helplessness that result from the inability to predict or have an impact on events surrounding their illness" (Northouse & Northouse, 1987, p. 18). A diagnosis of cancer is regarded with more fear than any other medical diagnosis. The diagnosis itself leads to a sense of powerlessness because of the universal belief that it is a life-threatening disease equivalent to suffering and death. Cancer is also a disease surrounded by a high degree of uncertainty with regard to cause, diagnosis, treatment, and prognosis. It is different from other illnesses (such as cardiovascular disease), because cancer patients often feel helpless in being able to affect the course of the disease.

The loss of control cancer patients' experience frequently includes a diminished ability to maintain normal relationships with others. Relationships with family, friends, and co-workers may change due to the impact of the disease and treatment, and communication may become awkward. The negative perceptions society holds about cancer patients tends to shift the power in the direction of healthy persons (Gray & Doan, 1990). Cancer is perceived more negatively than other medical conditions, and since it is associated with

death, healthy persons may feel alienated from or afraid of individuals with cancer. In fact, some individuals still believe the myth that cancer may be communicable.

People usually enter the health care system to seek help from health care professionals when they are ill. They may also enter the system to reaffirm they are healthy as a health promotion strategy, and find out they require investigative interventions. When an individual is told he or she requires some type of medical intervention, he or she enters a system that predominantly views the person (now reclassified as a patient) as a passive recipient of care. The experience is both unfamiliar and frightening. The patient is vulnerable, and experiences a loss of control. These feelings of powerlessness may be manifested by behaviors such as withdrawing, passivity, indecisiveness, and lack of information-seeking (Fuchs, 1987; Mahon-Darby, Richmond, & Gates, 1988; Smith, 1985).

In addition to dealing with the uncertainty of the illness and its symptoms, the individual's feelings of control are likely to be threatened by the relationship with the health care practitioner (Schorr & Rodin, 1982). The physician-patient interaction is a power relationship based on the medical profession's monopoly of knowledge, skills, and expertise in health care. Physicians are perceived as holding high social status, and this increases the power gap even further (Gray & Doan, 1990). This model of professional power over patients is central to the concept of the sick role in the medical sociology literature. When individuals seek professional medical help, they are conveying the message that they do not have the competence to deal with their medical problem or the associated symptoms. The degree of control a patient acquires is often dependent on the practitioner-patient relationship that is established, and the degree to which the sources of power are shared. However, the impact of emotional stress at the time of diagnosis creates communication difficulties (Grahm & Johnson, 1990) that act as further barriers to the establishment of the relationship, and sharing of information.

The type of language used in the practitioner-patient relationship can also have an effect on the communication of information, and increase feelings of disempowerment. Health care professionals have an advantage over most cancer patients because they are able to use a highly technical vocabulary that is unfamiliar to those outside the profession. This vocabulary can be used to further strengthen the role of authority by confusing, intimidating, and even mystifying the patient into assuming a dependent position in the relationship (Roberts & Krouse, 1988). The provision of information in a format patients can understand helps them deal with the reality of the situation and adjust to it (O'Hara & Harrell, 1991). Dr. Raisa Deber (Administrator, University of Toronto's Faculty of Medicine) stated that the reason patients want to be informed but prefer a passive role in decision making is patients are overwhelmed when decisions involve technical knowledge. She also found that in clinical practice, value-based decision making and scientific problem-solving must be separated in order for patients to want to participate in the decision making process (cited in Leaney, 1993). She stated if these two elements are not separated, there is a good possibility patients will turn over control of treatment decision making to the physician.

In cancer care, many of the treatment decisions have a life and death dimension and must be made within a short time frame. Sharing information and encouraging patients to participate in medical decisions may be seen as time consuming. The traditional practitioner-patient relationship is much easier to assume in these cases because the communication aspect of the relationship is more predictable, and the patient passively accepts the treatment that is recommended. This type of relationship is characterized by an imbalance in the sharing of power and results in the cancer patient feeling powerless. Informed consent is the individual's right to accept or decline a proposed treatment and to be ethically and legally valid, it must be made by a competent individual who has been given sufficient information to make the decision (Lynch, 1988). Control of information can influence actions and hence negate the patient's autonomy in decision making.

Recently there has been a shift from a paternalistic style of medical practice to a more consumerist-based and disclosure-focused system. This new ideology is based on the physician and/or other related health care professionals sharing their sources of power with the patient or in this case the consumer of health care (Northouse & Northouse, 1987). This consumerist stance constitutes a challenge to physician authority. It implies the practitioner-patient relationship is based more on a bargaining model than on a dominance model. In cancer care, the sharing of control is necessary because of the extreme loss of control cancer patients bring with them into the interaction. From a bargaining perspective, both the patient and the physician bring different resources to the encounter, and each must be prepared to negotiate an acceptable set of terms for the relationship (Haug & Lavin, 1981). In this type of relationship, neither participant is automatically in charge, and the relationship established is dependent on the resources each player brings to the encounter. Physicians and health care professionals possess not only medical knowledge, skills, and experience, but they are also the gatekeepers to the health care services required by cancer patients. Patients come armed with their own knowledge and life experiences, previous experience with the health care system (self, family, friend, and/or acquaintance), and the ability to seek a second opinion if the medical care they receive, or are about to receive is not acceptable. However, the majority of sources of control and power are held by health care professionals from the onset of the relationship.

Information is a primary method for cancer patients to gain a sense of power or control over the circumstances surrounding their illness, which may result in an improved functional status and sense of well-being (Dodd, 1990). Although information has been identified as one of the top three psychosocial needs of cancer patients not only at the time of diagnosis but also during follow-up care (Liang et al., 1990), physicians have been reported to base the amount of information exchanged on the patient's nonverbal behavior and initiative to ask for further information (Angell, 1984), and the type of information on the patient's prognosis. Blanchard, LaBrecque, Ruckdeschel, and Blanchard (1990)



reported a better prognosis was related to the physician discussing future tests and treatments, whereas a poor prognosis was indicative of physicians inquiring about signs and symptoms.

The consumerist movement in health care supports the rights of competent adults to be informed about their medical condition, and to participate in decisions concerning their health (Angell, 1984). Barriers to the effective communication of information may result when patients do not understand or cannot recall the information provided to them, when information is presented in an incomprehensible manner, or when the information provided is inadequate (Siminoff, 1989). There is considerable evidence that the lack of sufficient information to support effective control over an outcome decreases the desirability of control (Rodin, 1986). The majority of newly diagnosed cancer patients do not have the knowledge or skills to know what information they require. Some patients may also believe physicians may interpret questions as a lack of trust in their skills as a physician. This type of practitioner-patient relationship places the cancer patient in a situation of powerlessness, as without information, he or she cannot participate in health care decisions.

Several investigators have found cancer patients want to be informed about their illness (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Dennis, 1987; Lind, Good, Seidel, Csordas & Good, 1989; Lloyd, Parker, Ludlam, & McGuire, 1984; Loehrer et al., 1991; Newall, Gadd, & Priestman, 1987; Reynolds et al., 1981; Taylor, 1988). Although physicians are the primary source of illness-related information for the majority of cancer patients (Frank-Stromberg & Wright, 1984; Loehrer et al., 1991; Oberst, 1984), cancer patients are dissatisfied with the amount of information they receive from medical staff (Cassileth, Volckmar, & Goodman, 1980; Lloyd et al., 1984; McIntosh, 1974; Wiggers, Donovan, Redman, & Sanson-Fisher, 1990). Physicians also tend to overestimate the amount of information they give patients, underestimate the patient's desire for information, and give varying amounts of information in response to the patient's

education, income, sex, and age (Waitzkin, 1985). Waitzkin reported patients who were middle-class, more seriously ill, more educated, and middle-aged received more information from their doctors than their counterparts.

It has been observed that some physicians withhold information from cancer patients to prevent them from becoming alarmed, worried, or anxious (McIntosh, 1974), as a way to maintain hope (Good, Good, Schaffer, & Lind, 1990), and as a way of enhancing their power in the relationship (Waitzkin & Stoeckle, 1972). Still others believe patients might be negatively affected by telling them that they are unsure of which treatment is more effective (McIntosh, 1974; Taylor, Shapiro, Soskolne, & Margolese, 1987). Many practitioners also have refrained from giving patients and their families information about their cognitive, emotional, and physical status because it is deemed harmful, negative, or too complicated for nonprofessionals to comprehend. Such a stance not only reinforces the patient's position of ignorance about his condition, dependence on others, and helplessness, but it also inhibits the individual's progress from being a victim to a survivor (O'Hara & Harrell, 1991).

Information disclosure practices of physicians are dependent on numerous factors. McIntosh (1974) identified the type of information physicians provide to cancer patients was influenced by: physician's personal philosophy; philosophy and demands of clinic setting; patient's age, personality, and social class; the physician's perception of what the patient wants to know; and the patient's desire for, and ability to understand information. Greenwald and Nevitt (1982) also reported some physicians are uncomfortable communicating with cancer patients, and the amount of information disclosed is often dependent on the amount of experience the physician has in treating cancer patients. Physicians' disclosure of diagnosis, which is an important component of communication, has been shown to be affected by the patients' emotional status, patient's request for diagnostic information, and wishes of the family members (Hardy & Hardy, 1979). Good et al. (1990) also reported the disclosure practices of physicians appear to be related to

cultural definitions of hope, perspectives on the mind-body split, the efficacy of available treatments, truth-telling, and the nature of the patient-physician relationship.

Robinson and Whitfield (1985) conducted a study to identify the influence of specific verbal behaviors used by physicians on patients' comments and questions about the advice and instructions given during their interaction. The results showed inexperienced physicians provided patients with significantly more information than experienced physicians and asked their patients more treatment-related questions. Patients of inexperienced physicians asked more questions and provided more comments about their treatment than patients seen by experienced physicians. The authors concluded that experienced physicians may not encourage patients to contribute to the discussion resulting in patients assuming a less active role in their care.

Certain disease and patient characteristics have been found to have an effect on the amount of information physicians share with patients. Although a patient has no control over the majority of these variables, they can be considered as sources of powerlessness. Amir (1987) conducted a study to identify the considerations that guide physicians when informing cancer patients about their diagnosis and prognosis. She found if patients were perceived as being intelligent, they asked questions, and their condition was serious, they would receive full information about their diagnosis and a realistic prognosis. Mosconi, Meyerowitz, Liberati, and Liberati (1991) also reported young, well-educated females were provided with more information concerning their diagnosis.

Older individuals who experience a health crisis often experience a loss of control (Brown & Furstenberg, 1992) and some investigators have made the assumption that less aggressive treatment equates with less patient power. For example, Greenfield, Aronow, Ganz, and Elashoff (1989) studied the effect of age on the medical management of patients with breast and prostate cancer. Data for this study was obtained from retrospective chart reviews conducted from the years 1980 to 1982 in 17 American hospitals. In the breast cancer sample ( $N = 374$ ), 67.4% of the patients who were 70 years of age and older

received appropriate treatment versus, 83.4% in the 50 to 69 year old age category. Preliminary prostate cancer findings revealed that in a subgroup of 165 patients, who had no coexisting conditions that would compromise the potential benefit from active treatment, there was an increased tendency to mismanage or under treat patients as their age increased. In the oldest age group (75 years or older), 49 of the 59 patients with potentially curable cancer were either given hormone therapy or no therapy at all. This is in contrast to the 50 to 64 year old group in which only 13 of 49 men received hormones or no therapy, and the 57 men in the 65 to 74 year old age group in which 26 men did not receive appropriate medical management. The authors concluded there is an age bias in the treatment of breast and prostate cancer. They also suggested that if such a patient is in good health at the time of diagnosis, he or she should be given the same equal opportunity to survive that younger patients receive. Current medical practice suggests that less aggressive treatment is the most appropriate for elderly men with prostate cancer.

### Summary

This discussion has focused on the identification of sources of powerlessness experienced by cancer patients. Loss of control was cited as the most important problem confronting cancer patients (Northouse & Northouse, 1987). The major sources of powerlessness for cancer patients identified were: the uncertainty of the disease (Northouse & Northouse, 1987); the negative view society has about cancer (Gray & Doan, 1990); the emotional stress at the time of diagnosis (Grahn & Johnson, 1990); being an older cancer patient (Greenfield et al., 1989); communication difficulties with health care practitioners (Gray & Doan, 1990; Roberts & Krouse, 1988; Siminoff, 1989); and the lack of, or control of information given to the patient (Lynch, 1988; Oberst, 1984; Siminoff, 1989). Information was identified as a major source of power or control for cancer patients to cope with the circumstances surrounding their illness (Brandt, 1991; Dodd, 1990; Liang et al., 1990). The degree to which information was shared with the cancer patient was found to be dependent on the quality and type of practitioner-patient relationship established.

## 2.2 Stage Two: Identification of Empowerment Strategies

The process of empowerment involves a shift in the power alignments in the practitioner-patient relationship. As early as 1956, Szasz and Hollander identified three types of relationships that may be established--dependent on the urgency of the medical situation. The first one was the activity-passivity relationship that occurs in an emergency situation where the patient is unable to make decisions and the doctor must take control. In guidance-cooperation, the physician is in the position of power and the patient is expected to cooperate. Mutual participation, the third type, is where the patient and physician are interdependent, share power, and pursue a common goal. Although the third type of relationship is indicative of an empowering relationship, Szasz and Hollander suggested reserving this model for patients of greater intellect, education, and experience. In 1992, the Emanuels (Emanuel & Emanuel, 1992) outlined four models of the patient-physician relationship--paternalistic, informative, interpretive, and deliberative. While the paternalistic physician would act independently, the deliberative physician would engage the patient in active discourse in order to incorporate the patient's perspective when determining the optimal course of action. The deliberative model resembled the model of mutual participation proposed earlier by Szasz and Hollander.

In medical ethics, respect for an individual's right to determine his own actions and to decide for himself what is in his best interests is a fundamental principle (Zander, 1985). In order to incorporate this belief into practice, health care professionals must view the patient as an autonomous individual and be willing to share their knowledge and expertise. This commitment to empowerment is seen as the first and most important strategy in the empowerment of cancer patients. Only those practitioners who feel secure about their own power will be able to see empowerment as a gain rather than a loss. Schorr and Rodin (1982) identified enhancing greater feelings of control in patients should have important benefits for health care professionals. The first benefit is health care professionals may feel more successful and be more satisfied with the health care relationship because patients

may be more likely to adhere to treatment regimes, and have better health outcomes. These better outcomes are capable of enhancing the practitioner's feelings of control and efficacy. Second, the additional time initially spent with the patient to enhance feelings of control may result in the practitioner having to spend less time with the patient later on in the relationship to deal with patient demoralization, non adherence, and dissatisfaction with care.

The second empowerment strategy involves the actual establishment of the practitioner-patient relationship in which both parties share their perceptions, experiences, and expectations of the relationship in treating the illness. The management literature would classify this strategy as the establishment of a participative management style.

Empowerment assumes "individuals typically understand their own needs better than others, and that it is optimal for individuals to have the greatest possible control in determining various aspects of their lives" (Gray and Doan, 1990, p. 37). The expected outcome of this strategy is that the patient achieves a sense of control, reciprocal trust, and thus a higher level of satisfaction with the care provided.

Schorr and Rodin (1982) cited several studies that reported by the time a patient sees a practitioner, they have often developed a definition of their areas of concern, expectations of and goals for the health care interaction, and some ideas about how their illness should be treated. The role of the practitioner in this step would be to openly discuss patients' expectations and views regarding their chosen medical treatment, demonstrate respect for their viewpoints, and provide appropriate feedback. Blanchard et al. (1990) identified four variables that predicted cancer patients' satisfaction with physician behavior. The patient's perception of needs addressed was found to be the strongest predictor of patient satisfaction with physician behavior, rather than the actual occurrence or absence of those behaviors. Other patient predictors were perception of emotional support provided by the physician, being an older physician, and physician discussing treatment with patient. Physicians who shared information on treatment, diagnosis, and tests were perceived by

patients as meeting their needs or providing emotional support. Factors identified as increasing satisfaction with care, and encouraging an exchange of information and participation in decision making between older patients and physicians include: a longer interaction (Beisecker & Beisecker, 1990; Derdarian, 1989; Lloyd et al., 1984); information pertinent to individual's needs, time to consider decisions, and inclusion of family (Weiss, 1986); providing detailed information (written, verbal, and audio) (Reynolds et al., 1981); showing concern (Thorne, 1988); and using first name to address patient, providing privacy for physical examination, examining patient's trunk, and discussing test results with patient (Blanchard et al., 1988).

Conger (1989) stated that certain situations might not warrant empowerment, and certain empowerment practices might not be appropriate for all situations. He stated that if employees are unwilling or unable to assume greater ownership or responsibility, the result may be opposite of what you are seeking--a sense of powerlessness. The third empowerment strategy includes assessing the type and amount of information desired, and the degree to which cancer patients want to be involved in the decision making process. The type and amount of information desired by patients varies with the individual. Although seeking information has been found to be an effective way to gain control of an uncertain event such as cancer (Gerard, 1963; McIntosh, 1974; Molleman, Krabbendam, Annyas, Koops, Sleijfer, & Vermey, 1984), Brockopp, Hayko, Davenport, and Winscott (1989) reported there was a weak correlation between the need for information and gaining personal control. Several investigators have reported that giving information in an effort to enhance or maintain control may not be appropriate for all patients, and should be highly individualized (Brockopp et al., 1989; Dennis, 1987; Lazarus & Folkman, 1984). A literature review by Bagley-Burnett (1988) reported that information-seeking activities of an individual are determined by: the amount of information he or she has; experience with the health care system; amount of time spent identifying health care resources; time spent in

actual decision process; sociodemographic variables; perceived risks, benefits, and costs of searching for information; and need factors related to the critical nature of the problem.

A disparity currently exists between the information needs of cancer patients, and the information needs of these patients as perceived by health care professionals. Goldberg, Guadagnoli, Silliman, and Glicksman (1990) reported primary care physicians did not appreciate the importance of several major areas of care that were considered important to newly diagnosed cancer patients. The two major areas of discordance were found to be related to information patients wanted about treatment, and concerns about communicating with their doctors. Health care professionals have been found to overemphasize or misconstrue cancer patients' information needs (Nehemis, Gerber, & Charter, 1984). Reynolds et al. (1981) reported that asking patients what type of information they desired could be more effective than simply providing detailed information to all patients.

Medical consumerism emphasizes the importance of people assuming more bargaining power in their relationships with health care professionals. This process involves consumers actively listening to what the professional has to say, actively questioning the professional and seeking additional information if required, and subsequently taking responsibility for making their own health-related decisions. Current support for this ideal of medical consumerism is based on the assumption that most people desire some degree of control over treatment decisions, and that exercising such control will have a positive influence on their survival and quality of life (Degner & Aquino-Russell, 1988). However, there is no empirical evidence to support the assumption that such activism is effective for all people. Indeed, several investigators have suggested that an individualized approach may be both more appropriate and more effective (Degner & Beaton, 1987; Degner & Sloan, 1992; Farrow, Wartman, & Brock, 1988). Forcing people to take more responsibility in decision making than they feel comfortable in assuming may be yet another approach to prescribing roles in health care.



Knowledge is an essential prerequisite for an individual to make informed decisions (Zander, 1985). However, the majority of cancer patients do not have sufficient knowledge of their illness (at the time of diagnosis) to become actively involved in decision making (Mackillop, Stewart, Ginsberg, & Stewart, 1988). The fourth empowerment strategy involves the practitioner sharing the information required by the cancer patient to define his or her situation to make an informed treatment decision. Communication involving information sharing between the patient and physician is critical to help persons understand and cope with what is happening to them, and know what treatment options are available and recommended. Both participants have crucial information that the other requires to make a treatment decision. Some patients need information about the disease and its consequences, even though they have read about cancer since their diagnosis (Mages & Mendelsohn, 1979; Weisman & Worden, 1976). When information is not exchanged, information control occurs, which may result in patients being unable to participate in the medical treatment decision making (McCorkle, 1980; Trandel-Korenychuk & Trandel-Korenychuk, 1986).

Traditionally, physicians have been exclusively entitled to impart medical information relative to proposed treatments, informed consent, and curative activities. In contrast to this, nurses have been limited to explanations of nursing care and reviewing information already given to the patient by other members of the health care team (Trandel-Korenychuk & Trandel-Korenychuk, 1986). Thorne (1988) found cancer patients reported physicians as the major source of information relating to the disease and treatment, while nurses tended to communicate information about the treatment and illness experience, and give advice. The majority (90.5%) of patients in this study rated such advice as unhelpful. Today, the distinction between what is medical and nonmedical information is less than clear. The current nursing ideology is that it is the nurse's obligation to provide patients with the information necessary to make treatment choices, make adjustments in their lives, and reduce the anxiety caused by illness (Canadian Nurses Association, 1991).

### Summary

"Optimal empowerment may depend not so much on the absolute amount of information or decisional control made available but rather on allowing the patient to control how much information s/he will get, and to what degree s/he will participate in decision making" (Gray & Doan, 1990, p. 38). Information is a potential source of control for cancer patients, but for it to be empowering it must be presented in a way that it can be understood and used effectively. Sharing this source of power is regarded as a transactional process that occurs as part of the communication aspect of the practitioner-patient relationship. Mutual participation in medical decisions is a legitimate goal in the practitioner-patient relationship, but it may not be what every patient wants, and unless effective communication is established, we will never know (Mackillop et al., 1988). This section has identified four strategies health care professionals can use to empower cancer patients. These strategies include:

1. commitment of health care professionals to the empowerment of cancer patients;
2. establishment of a participatory type of practitioner-patient relationship;
3. assessment of the type and amount of information, and degree to which cancer patients want to be involved in treatment decision making; and
4. sharing information required by the cancer patient to make an informed treatment decision.

### **2.3 Stage Three: Provision of Self-efficacy Information**

Stage three of the empowerment process involves providing self-efficacy information to the cancer patient, and removing the sources of powerlessness. In cancer care it is often impossible to remove the sources of powerlessness. For example, it is not possible to alter the uncertainty of the disease, age of the patient, or the need to rely on health care professionals to access the health care system. Making changes to how our society views cancer and eliminating the bureaucracy of the health care system will take time. However, making changes in the way information is communicated to newly

diagnosed cancer patients is a strategy capable of removing one of these sources of powerlessness.

Self-efficacy refers to the belief that an individual has the skills to be able to cope with and exercise control over a given situation (Bandura, 1977). Any strategy that increases an individual's sense of self-determination will tend to make that individual feel more powerful (Conger, 1989). Self-efficacy information refers to the provision of information utilizing the empowerment strategies identified in Stage Two. These planned interventions provide the individual with the knowledge and skills to be able to cope with, and exercise personal control in a given situation. Perceived self-efficacy affects the actions individuals use, the length of time they persevere, and the effort they put forth. In social learning theory, judgments of self-efficacy refer not to generalized feelings of competence, success, or control, but rather to judgments of how well an individual believes he or she will perform in specified settings. "The effects on coping outcomes of interventions that consist of instruction in self-care activities for specific experiences that patients encounter during physical illness may be mediated by self-efficacy processes" (Johnson & Lauver, 1989, p. 50). This section will identify the five most frequent interventions previously used to provide patients with information and the reported clinical outcomes of each.

### **Written Information**

**Supplemental written information.** Ellis, Hopkin, Leitch, and Crofton (1979) provided a group of medical patients with supplementary, written information and studied the effect on their understanding and recall of both general information and specific recommendations. Patients in the experimental group ( $n = 30$ ) were given verbal and written information, and those in the control group ( $n = 26$ ) were given only verbal information. Each patient was seen at follow-up and asked about the discharge information received. A significantly better response was found in the group who received the written information in the categories of information relating to diagnosis, general advice, and drug treatment, but not for scores relating to prognosis or follow-up arrangements. The authors

concluded that the provision of brief, supplementary written information improved understanding and recall in all categories of the discharge information subjects received. They also recommended all patients leaving hospital should be given such information.

**Information pamphlets.** Messerli et al. (1980) surveyed 58 breast cancer patients and 77 physicians to identify the information needs of cancer patients and the availability of this information. The response rate for patients and surgeons was 39% and 51%, respectively. The majority (86%) of the patients reported having unanswered questions relating to treatment. Forty-seven percent of the patients did not raise their concerns with the physician because they were not sure what questions to ask, and 23% stated they were too emotionally upset to ask any questions. Both patients and physicians agreed information pamphlets were an important resource for cancer patients, but 78% of the physicians in this study did not possess any written information they could give to their patients. The patients identified this written information as more important than a sensitive and understanding physician.

**Written information and inclusion of family.** Cassileth et al. (1989) investigated the effect of giving detailed written information about possible treatment choices to a group of newly diagnosed prostate cancer patients ( $N = 147$ ) with Stage D metastatic disease. The patients were asked to discuss the information they received and make the treatment decision with their wives/families at home. Patients and their spouses were asked to complete separate questionnaires following the decision, and then again 3 to 6 months later. The follow-up questionnaires showed 93% of the patients, and 91% of wives were satisfied with the treatment choice they made. This study demonstrated that if this group of men are given the information, they are able to play an active role in decision making and remain comfortable and satisfied with their choices.

**Written information, individualized counseling, and follow-up telephone calls.** Derdarian (1989) studied the effect of providing individualized information to a group of newly diagnosed (3 to 10 days) male cancer patients and their

spouses. The Patient-Informational Needs Assessment and Spouse-Informational Needs Assessment tools were used to assess information needs, and the Patient-Satisfaction and Spouse-Satisfaction instruments were used to measure satisfaction with information received and coping with the implications of diagnosis. Patients and spouses in the control group ( $n = 30$ ) received routine, informal verbal or printed information, counseling, referral, or follow-up care from the clinic upon their request or as indicated by the Patient- and Spouse-Informational Needs Assessment. Patients and spouses in the experimental group ( $n = 30$ ) received individualized formal information, counseling and referral (if indicated by the patient's response to the pretest instruments), and a written information and resource package. Telephone calls were made to each subject to check the adequacy of information provided. The same instruments were independently administered to all participants and their spouses prior to and then 5 to 10 days later. No statistical differences were found between the groups in terms of coping, but both patients and spouses in the experimental group were significantly more satisfied with the information they received. All groups requested the most, and attached the highest importance to information on disease, personal, family, and social categories.

**Letters outlining consultation.** Damian and Tattersall (1991) conducted a randomized study to assess whether letters to patients outlining the oncology consultation would have an influence on their satisfaction and recall of information, and whether they would be useful to cancer patients and their families. Although patients who received the letter were more satisfied ( $p < .014$ ) with their consultation, there was no difference between the groups in terms of information recalled. The majority of patients in the control group thought a letter outlining their consultation would be useful even if it contained bad news. Patients who had received bad news in their letter found the letter significantly more useful in helping them understand and remember what they had been told in the consultation. Patients read their letters an average of 2.6 times (range 1 to 8), and 20 of the 24 patients had shown it to at least one other person.

This study also sought the views of referring doctors about using this approach. Forty general practitioners and 22 specialists completed the questionnaire. The majority (79%) of health care professionals welcomed the idea. They also identified situations in which the letter would be especially helpful such as following the initial consultation or when the consultation contained distressing news. The majority of physicians (79%) also believed that a copy of the letter should be sent to the referring doctor.

**Access to medical records.** Providing patients with access to their medical records also has been shown to be a safe adjunct to patient care. Fisher and Britten (1993) interviewed 32 cancer patients to determine if they wanted to see their medical record. Seventeen of the 20 patients who chose to do so found the records helpful and reassuring, even if the information was bad. Twelve of the 20 patients had difficulty understanding the medical terminology, but stated they would ask their doctor for clarification. Giving the patients access to their records helped them question the meaning of their diagnosis, satisfied their curiosity about whether the doctor was withholding information, and helped them plan for the future. Nineteen of the 20 patients who chose to read their medical record wanted access to know the truth in order to clear their minds, give them control, and to assist them in coping with the stress of having cancer.

#### **Provision of Audio or Audiovisual Taped Information**

**Audiovisual.** Rainey (1985) conducted a study to determine what effect an audiovisual patient education module would have on cancer patients' treatment-related knowledge and affective status during radiation therapy. The sample ( $N = 60$ ) consisted of an equal number of males and females with a mean age of 50 (range 21 to 75 years). The majority of the participants were married, unemployed, of a higher socioeconomic status, and had an average of 14.1 years of formal education. Head and neck cancers were the most common primary tumor sites followed by breast, brain, cervix, and prostate cancer. Data were first collected from a series of 30 new patients receiving standard care. The intervention was implemented and then the experimental group was recruited. Subjects in

the intervention group were individually shown a 12 minute slide-tape information program. All patients were given a copy of the booklet "Radiation Therapy and You", provided by the National Cancer Institute.

The Avoidant-Vigilant Sentence Completion Test (SCT) and the Modified Repression-Sensitization Scale (RS) were used to classify coping style. Patient knowledge of radiation therapy was assessed by a 21 item questionnaire developed for the study. Anxiety level during the course of treatment was assessed by the "State" form of the State Trait Anxiety Inventory (A-State). Patients were assessed at the beginning of radiation therapy and during the last week of treatment. At the initial evaluation, the experimental group showed greater accuracy of treatment-related knowledge, and had lower anxiety and mood disturbance scores. The two groups did not differ in affective status or coping style. At the second evaluation the experimental group reported significantly less anxiety, less mood disturbance, and less affective distress (regardless of coping style). Both groups had the same level of knowledge by the end of the treatment. The author concluded patient education in a radiation therapy setting can effectively increase patients' knowledge, and decrease the levels of anxiety and emotional distress experienced during treatment.

**Audio tape.** Johnson et al. (1988) conducted a randomized study to determine whether knowledge gained from prior research on the effectiveness of preparatory information interventions on coping would generalize to a group of men ( $N = 84$ ) with prostate cancer (Stage A, B, and C) being treated with curative radiation therapy. The mean age of the men in this study was 67.9 years. The majority of the men were retired, married, and had at least a high school education. The information intervention consisted of four audio taped messages that dealt with the treatment planning experience, the experience of receiving radiation therapy, the experiences that could occur during treatment and the possible side-effects, and the experiences that could be expected to occur following the completion of treatment. The Sickness Impact Profile measured coping efforts, and the Profile of Mood States emotional response to the treatment and intervention. These two

measurements were used during the first, third, and last week of treatment, and at the first and third month after treatment ended. Men in the experimental group reported less disruption in usual activities (increased coping) each time a measurement was made. The largest differences in the two groups were found during the latter weeks of treatment and early in the post-treatment phase. Patients in both groups reported very little mood disturbance; however, being younger and having more side-effects were found to be associated with a mood disturbance occurring. The authors concluded that providing these men with detailed descriptions of the impending experience in concrete terms can be expected to increase their ability to cope both during and after radiation therapy.

#### **Audio Taping Consultation With Physician**

Reynolds et al. (1981) surveyed 67 recently referred cancer patients to determine how much information they wanted about diagnosis, parts of the body affected, symptoms, investigations, treatments, side effects, and prognosis. The majority of these patients (89-97%) wanted to be informed about all aspects of their illness. In the second phase of this study, an oncologist informed 25 females and 17 males (selected from the original group) about their illness/treatment in one of three ways. Patients in the first group were asked whether or not they wanted information about specific aspects of their illness and were given a audio tape of the their meeting. Patients in the second group were treated in the same manner as group one, but they were not given an audio tape of the meeting. The oncologists followed normal practice procedures with the control patients in group three. All subjects were interviewed five days after their meeting with the oncologist to determine the amount of information they desired, the amount of information retained from the prior meeting, and the degree of satisfaction with the amount of information obtained. A similar interview was also conducted six weeks after the original meeting. No differences were found among the three groups with regard to desire for information and satisfaction with information received. The majority of patients in this study reported being highly satisfied with the care regardless of the amount of information they were given. Providing cancer



patients with an audio tape of the consultation did not enhance their recall of the information however, it did assist their family members to understand the illness better. The authors suggested that asking patients what type of information they wanted may be a more effective way of determining the type of information provided.

Hogbin and Fallowfield (1989) also studied the effect of providing a group of general surgical cancer patients with an audio tape of the treatment consultation with their physician. These patients were given the tape to take home and asked to return it to the surgeon together with a questionnaire when they had finished listening to it. Patients used the tapes to communicate and give accurate information about their diagnosis to their family, and to help them recall medical terminology or procedures about which they were unfamiliar. The tapes also provided them with a greater trust and confidence in their physician, and decreased their anxiety about future treatment. Physicians found this intervention helpful for patients who came to the consultation alone. Recording the consultation also made the physicians more aware of the need to do it properly, and attach even more importance to the consultation process.

Johnson and Adelstein (1991) also reported on the positive effects of providing a group of various types of surgical cancer patients with an audio tape of their initial treatment consultation with their oncologist and any further discussions with the nursing staff. Twenty-nine patients completed a questionnaire after the initial discussion and then two weeks later. An analysis of the questionnaires revealed the majority of the patients had: played the tape more than four times, played it to at least one other person (often a close family member), acknowledged hearing new information, and reported that it increased their understanding of their disease. Five patients expressed some discomfort in having their consultation taped. The majority of patients reported they felt well-informed, hopeful, confident, and cared about when they listened to the tape. Two patients felt morose feelings while listening to the tapes, and eight subjects had mixed feelings of confidence and hope, as well as frustration and anger. The physician had a tendency to provide more explicit,

detailed, and carefully conducted discussions when he knew he was being taped. The taped session did not take longer than other similar patient interviews, and the need for subsequent repetition of previously provided information was considerably less. The authors concluded that providing audio tapes of initial consultations not only facilitated communication between the cancer patient, family, and physician, but it also improved the way patients cope with their illness.

North, Cornbleet, Knowles and Leonard (1992) conducted a pilot study with a group of advanced cancer patients to determine whether audio taping the initial treatment consultation would decrease levels of anxiety and depression. Thirty-four patients completed the Hospital Anxiety and Depression (HAD) questionnaire and answered 11 questions to evaluate the level of knowledge they had about their illness. Subjects were then randomly allocated to either have their consultation tape-recorded ( $n = 18$ ) or not ( $n = 16$ ). The same information was given to each patient by their physician to ensure all patients received the same topics and facts. All patients were asked to return one week later to complete the HAD scale and a questionnaire to measure their level of knowledge. Patients who had their initial consultation audio taped were reported to have increased retention of information, significantly reduced levels of anxiety, and lower depression scores. Although the majority of patients ( $n = 17$ ) expressed positive feelings about the tapes they had received, one female patient said listening to the tape at home upset her. Tapes were used by patients to help them remember information, assist in treatment decision making, explain their illnesses to their families, and share information with their general practitioners. The authors concluded taping the initial consultation was both beneficial to patients and cost-effective to implement in the clinical area.

Dunn et al. (1993) also studied the effects of providing cancer patients with an audio tape of their initial medical oncology consultation or a general information tape. Patients ( $N = 142$ ) were randomized to receive an audio tape of their consultation, an audio tape describing cancer in general terms, or no tape. The modal respondent in this study was

a married female with local disease being seen for the first time in an outpatient department. For the overall sample, the mean age was 52 years, mean length of time from first diagnosis was 29 months, and mean time from most recent diagnosis was 2 months. All patients completed the Spielberger State Anxiety scale prior to the consultation. A structured telephone interview was conducted 1 to 3 weeks following the consultation to determine how often they had listened to their tape and to assess recall of information. Questionnaires to assess patient satisfaction, along with the Psychologic Adjustment to Cancer scale were mailed out. Ninety-two of the patients returned the psychologic adjustment and satisfaction questionnaires, and completed the follow-up interview.

The investigators reported patient satisfaction with medical care was significantly higher in the group of patients who received the audio tape of the consultation. However, the audio tape did not improve recall of information or affect psychologic adjustment to cancer. Anxiety was found to be significantly correlated with psychologic adjustment, but had no effect on the number of times the tape was played, satisfaction with the tape, or satisfaction with the consultation. Overall, 90% of the full sample wanted all information and 74% preferred to be involved in decision making. Information and involvement preferences had no significant effect on the number of times the patients played their tapes however, patients who preferred more information and greater involvement listened to their tapes more frequently. Patients who preferred greater involvement, and more information did not attain better scores on any outcome measures.

Tattersall, Butow, Griffin, and Dunn (1994) conducted a randomized study that compared whether providing cancer patients ( $N = 182$ ) with an audio tape of the medical consultation followed by a letter outlining the main points of the consultation, or the letter followed by the tape, would be more beneficial. Eligible participants completed the Hospital Anxiety and Depression scale (HAD), and two items on involvement and information preferences derived from the Information Styles Questionnaire developed by Cassileth, Zupkis, et al. (1980), prior to the consultation. Patients were telephoned 10 days

after the consultation to determine how often they had used the first intervention they had received, and to assess their information recall. Questionnaires to measure their satisfaction with the first intervention, and levels of anxiety and depression were mailed separately. This procedure was repeated after the second part of intervention was mailed out. For example, patients who initially received the audio tape were sent a letter outlining the consultation, and patients who initially received the letter outlining the consultation were then sent an audio tape of the medical consultation.

Although both groups used the first intervention they received more than the second, this effect was more marked if the letter was received first. Two thirds of patients shared the letter or tape with at least one other person, if not several. Patients listened to the tape on average 2.3 times and read the letter 2.8 times over 4 weeks. Age, sex, type of cancer, and inpatient/outpatient status did not influence intervention aid usage. Satisfaction with the tape and letter were high and they did not differentially affect recall of information. However, patients rated the tape as significantly more effective in reminding them of what the doctor had told them in the consultation. Single patients, and those who wanted noninvolvement in treatment decision making found the tape significantly less useful. Patients ( $n = 7$ ) who did not use the tape were characterized by high anxiety levels before the consultation and at follow-up. Anxiety scores decreased significantly for both groups over the three assessments; however, levels of depression were similar for both groups at all assessments. Despite the randomized design, a significant difference in depression was observed between the groups at baseline, and differences in anxiety scores at baseline were almost significant. Mood was included as a confounding variable where appropriate. The authors concluded audio taping new patient consultations should be considered by clinicians as a method of improving communication.

McHugh et al. (1995) conducted a randomized clinical trial to assess whether providing cancer patients ( $N = 117$ ) with audio tapes of their clinical interviews would improve information recall and reduce psychological distress. The study included patients

who were either seeing an oncologist to receive the news of their cancer diagnosis or patients with an established diagnosis in whom initial treatment had so far been unsuccessful. Each patient completed the General Health Questionnaire and Hospital Anxiety and Depression scale (HAD) at the clinic prior to the consultation and at one month. These two measures along with an information retention questionnaire were mailed out at five months after baseline to all patients. Those in the tape group also received an attitude to tape questionnaire at five months. At six months patients who received the tape reported positive attitudes to the audio tape and were able to recall significantly more information about their illness than did controls. There was no difference between levels of psychological distress between the two groups at 6 months. The authors concluded that although providing cancer patients with an audio tape of the initial clinical interview promotes retention of factual information, it does not reduce psychological distress. It was further suggested that providing audio tapes to patients who use denial as a coping mechanism may actually increase their anxiety levels and prevent the use of this adaptive defense mechanism.

#### **Assisting Patients Formulate Questions to Ask Physician**

A discrepancy exists between the amount and type of information cancer patients desire, and the questions they ask health care professionals to obtain this information (Grahn & Johnson, 1990). Roter (1977) cited several studies that suggested patients do have many questions that are not asked in the medical interaction. When patients do not ask questions and wait for the physician to give them the information, the physician may become more active or vocal, as the patient becomes quieter and/or more passive. This may result in a one-way communication of information, and explain why several investigators report the majority of cancer patients are dissatisfied with the amount of information they receive. Several explanations about why cancer patients do not ask questions includes: the impact of emotional stress presented by the diagnosis of cancer creates communication problems; patients' learning styles differ; variability of patients' readiness and capabilities to assimilate information; lack of time for patients to ask their physicians questions; and

patients not knowing what questions to ask their physician to obtain the information they do want to have. One method of assisting patients to formulate questions to ask their physician is through role induction. Systematic role induction procedures in both individual and group psychotherapy have reported positive results, but they are not commonly used with patients about to receive medical care.

**Role induction.** Merkel, Rudisill, and Nierenberg (1983) studied the effects of role induction in a group of family practice patients. The experimental intervention consisted of showing the patients a four minute video suggesting ways for the patient to interact with the physician. Patients were encouraged to ask questions about the various aspects of their care. Following the video, the research assistant repeated the major points of the video using a flip chart. All patients in the study completed the Ware Patient Satisfaction Scale immediately following their appointment with their physician. The ten family practice residents who saw the patients completed the Social Factors in Illness and Doctor-Patient Relations subscales of the Attitude Toward Social Issues in Medicine Questionnaire. Physicians were reported to like inducted patients significantly more than patients in the control group, and physicians encouraged inducted patients to be more active. Role inducted patients were less satisfied with the convenience of their medical care than control patients. No significant differences were found between the experimental and control groups in terms of their overall satisfaction with the medical care. However, older patients in the experimental group and younger patients in the control group reported being more satisfied. Patients in the control group from small families, and inducted patients from larger families were more satisfied. Physicians were not able to predict patients' level of satisfaction with the medical care provided. The authors suggested further research was required to determine the effect of increased 'physician liking' in the physician-patient relationship. They also suggested role induction may begin a process that will only become apparent and be able to be measured over time.

Roter (1984) studied the effect of an intervention that was designed to: increase patient question asking during routine medical visits, and measure patient satisfaction with such an intervention. The randomized sample included patients seen in a medical community health clinic who were mainly female, poor, and black, with a mean age of 43 years. The experimental intervention consisted of a 10 minute individual session with a health educator prior to the medical appointment. The protocol was to review questions of concern to patients and to provide the patient with a list of questions to take to the medical visit. The control group received a 10 minute session in which they received information unrelated to patient communication. All medical visits were audio taped and patients from both groups completed a satisfaction questionnaire following the medical visit.

Questions' patients asked were categorized as direct (questions initiated by patient to seek new information), or indirect (questions asked by patient as a result of information the physician offered). Patients in the experimental group asked more direct questions on all medically relevant categories. A significant positive relationship was found between indirect questions, and patient satisfaction in both groups. Although no relationship to satisfaction was reported in the experimental group with regards to direct questions, a relationship was found in the control group. Patients in the experimental group asked fewer questions in every category on their list, except diagnosis.

**Coaching.** Greenfield, Kaplan, and Ware (1985) reported on a clinical intervention that: increased patients' preferences for active involvement in medical decision-making and involvement in the interaction with the physician; and decreased the limitations imposed by the disease on patients' functional ability. The randomized sample of patients with peptic ulcer disease consisted of 91% males with a mean age of 55 years. The intervention consisted of patients attending a 20 minute session prior to their medical appointment in which a clinic assistant helped them read their medical record, coached them to ask questions, and provided guidance in how to negotiate medical decisions with their

physician. This intervention was compared to a group of patients who had received a standard educational session of equal length. Audio recordings of patients' office visits (prior to, and after the intervention) were analyzed to determine the effect of the intervention on the doctor-patient interaction. All patients completed a variety of instruments to measure the variables. No significant differences were found between the groups regarding satisfaction with care. However, patients in the control group had significantly higher knowledge of ulcer disease than patients in the experimental group.

Patients are often anxious when they meet the physician to discuss treatment. As a result, information may be misunderstood and questions left unanswered. Robinson and Whitfield (1985) studied a group of surgery patients seen by two general practitioners to determine if encouraging patients to check their understanding of the information given to them would increase the frequency of questions and comments during the treatment consultation, and reduce the incidence of misunderstanding information. Patients' consultations were audio taped, they were interviewed, and then they were randomly given three types of written information. The first group (normal group) was given a slip of paper which asked for their permission to have their consultation taped for a research study that was looking at how well patients and doctors understand each other. All three groups received this written information. The second group (permission group) was given an additional second slip that gave them explicit permission to ask the doctor questions. The third group (guidance group) received a different message than the second group. It asked them to think about questions they may like to ask the doctor concerning their treatment, and to raise questions if the recommendations were not consistent with their expectations. Interviews were conducted after the consultation to determine if patients understood what they had been told, and if they had questions they did not ask.

Results showed patients in the guidance group asked more relevant questions and comments during the consultation, and made fewer errors in recalling the information given to them than the patients in the other two groups. Simply giving patients' permission to ask



questions did not have a significant effect on the communication of information in the physician-patient treatment consultation. The authors concluded if patients were encouraged to check their understanding of the information at the time of the consultation, they would gain a more accurate understanding of what the treatment involved.

Tabak (1988) conducted a study with a group of family medicine patients who were randomly assigned to one of two educational conditions prior to their medical visit. The objectives of this study were to determine if patients could be trained to use question-asking in medical visits, and if asking questions would result in a higher satisfaction with care. The modal respondent was a young, educated, employed female. Patients in the experimental group received a booklet outlining the importance of recognizing their information needs and encouraging them to ask for information. Patients in the control group were given a booklet similar in format but not in content. All medical appointments were audio-taped, and all patients completed a questionnaire to assess patient satisfaction following the medical visit. The results showed the mean number of questions asked by the two groups did not differ significantly, and question-asking did not correlate with patient satisfaction.

Gotcher and Edwards (1990) reported cancer patients who asked the most questions of health care professionals reported significantly greater satisfaction with information received and quality of communication. Successful fear management strategies also were found to be significantly related to satisfaction with communication. The investigators used a modified version of the Survey of Imagined Interaction to investigate communication and coping by examining both the actual and imagined communication interactions experienced by cancer patients. This questionnaire was completed by 48 cancer patients with a mean age of 62 years. The investigators suggested imagined interactions may be useful for cancer patients to: use as a coping strategy, formulate questions to ask their physician, and talk to their family about their illness.

Neufeld, Degner, and Dick (1993) described a nursing intervention designed to provide decisional support for cancer patients who wanted to participate in medical treatment decision making. The intervention consisted of assessing the extent to which patients preferred to participate in decision making, helping them to identify questions to ask the physician, and supporting them in getting the information they wanted. This intervention was tested and found to be effective in an oncology clinic setting with a group of women who had either breast or gynecological cancer. The authors suggested further research was required to evaluate whether providing decisional support to cancer patients would have an effect on their quality of life.

### **Sharing Information With Significant Others**

Families and/or significant others play an important role in providing support to the cancer patient (Jassak, 1992; Kesselring, Lindsey, Dodd, & Lovejoy, 1986; Rose, 1990; Ward, Leventhal, Easterling, & Love, 1991), and assistance in treatment decision making (Cassileth et al., 1989; Dermatis & Lasko, 1991; Hilton, 1994). Providing information to the family (with the patient's permission) enhances their awareness, understanding, and acceptance of the patient's condition during the illness trajectory, and allows both the patient and his or her family to feel they are equal partners in the treatment process (O'Hara & Harrell, 1991). Jassak (1992) identified six interventions oncology nurses can use to help families cope with the cancer experience. The six interventions identified were- asking the patient and family (together) to identify their needs, providing the family with answers to commonly asked questions, providing information to the family as a unit, assisting the patient and family to identify resources, providing feedback to validate perceived abilities and needs, and periodically reassessing both the patient and the family's needs.

The influence of social support on health maintenance and coping with illness has become an important field of research. Kesselring et al. (1986) conducted a study in this area to determine the nature and quality of social support and the network as perceived by a group of Swiss cancer patients. A convenience sample of 45 breast and lung cancer patients

who had or were receiving treatment completed the Norbeck Social Support Questionnaire (NSSQ). The majority of the participants were female, married, and had advanced disease. The mean age of the subjects was 58 years. Results of the study showed the family was the most important source of support. Health care providers and clergymen were perceived as providing minimal support. Patients who had larger social support networks and felt more affirmed by others had a more favorable view of their illness. The investigators concluded the family was an important component of cancer care. The results also demonstrated the need for additional support for those patients who have little or no social network.

Rose (1990) conducted a study to identify who adult cancer patients considered as most important to assist them cope with their illness experience. The sample included 50 women and 14 men, with a mean age of 45 years. The majority of the participants were married and the median level of education was three years college. The average length of time since diagnosis was 18 months. Although the majority of patients had received treatment at the time of diagnosis, two thirds were not receiving treatment at the time of measurement. Patients completed a Profile of Mood States to assess their psychological adjustment, and three separate questionnaires. The first questionnaire was completed before their appointment with their health care professional, the second before time spent with family, and the third before being with a friend. The results showed spouses were the most important source of support followed by adult children, siblings, and parents. Friends of the same sex were identified as the most important source of support by 84% of the subjects, and 25% of these friends had cancer. With regard to health care professionals, 84% choose their family physician or oncologist, 8% their surgeon, and 8% the oncology nurse administering their chemotherapy. Patients were found to have a significantly greater desire for open communication with their health professionals than with family members or friends. All three sources (physician, family, and friends) were considered as a source for

reassurance, esteem, advocacy, and directive guidance. Family members were considered as the most important source of tangible aid.

The variables of sex, education, and severity of illness were not found to have a significant effect on the desired sources of support. However, a poorer prognosis was significantly correlated with the patients' desire for emotional support from health care professionals, a greater desire for advocacy from family and health professionals, a need for more tangible aid from friends, and more directive guidance from all three sources. The findings from this study demonstrate the importance of assessing the sources of support cancer patients consider to be the most important as this may have an affect on the way in which information is shared and treatment decisions are made.

Dermatis and Lesko (1991) studied a group of adult cancer patients ( $N = 39$ ) undergoing bone marrow transplantation. One of the areas investigated was perceived quality of patient-physician communication. The physician was identified as the primary source of both information and assistance in treatment decision making. The support of family and friends was found to account for 59% of the assistance given to make a treatment decision. Patients who were married were most often likely to receive help in decision-making from their spouse (50%), followed by their non primary physician (36%), family (26%), and friends (5%). Patients who were not married were most likely to receive help with decision-making from their family (71%), physician (47%), and friends (30%). These findings demonstrated the importance of including the spouses and significant others in the treatment decision making process.

Ward et al. (1991) cited several studies that showed social support is associated with a more favorable quality of life, lower levels of stress and distress, and higher levels of satisfaction and self-esteem. The authors also cited studies that had identified the spouse or other family members as the most important source of support. In 1991 they conducted a study with a group of cancer patients receiving chemotherapy. Higher levels of communication and greater self-esteem were found if additional information was shared

with both the cancer patient and his or her significant others. Since the majority of subjects were female and married, the effects of gender and marital status were not able to be studied. The authors concluded that if a patient and his or her significant other are exposed to and share the same information about chemotherapy, communication about the treatment and disease enhances self-esteem. The authors cautioned there was a need to investigate the negative effects of using such an intervention as a means of increasing self-esteem, as all patient-family relationships are different.

LaBrecque, Blanchard, Ruckdeschel, and Blanchard (1991) studied 473 interactions (patient only,  $n = 374$ ; patient and family,  $n = 99$ ) between oncologists and cancer patients to determine the impact of the physical presence of the family on the physician's behavior and on the patient's evaluation of the interaction. Data was based on follow-up visits to the outpatient clinic as the initial consultation was felt to represent a 'unique interaction'. All interactions were audio taped and analyzed using a modified Physician Behavior Check List. Following the interaction, all patients were asked to complete a Patient Satisfaction Questionnaire. The comparison of family and non-family demographics and disease revealed there were no significant differences in age and sex, but there were significant differences in diagnosis, performance status, and reason for visit. Patients who had a family member present during the interaction tended to have a poorer performance status, be undergoing active treatment, and have a diagnosis of lung cancer or a diagnosis of other. Physicians were reported to have spent more time with the patients when family members were present. In general the physicians also provided more information when patients were accompanied by family members, or if no family were present, when the patient had a worse performance status. Patient satisfaction and quality of life were rated lower for patients with a worse performance status and were not affected by physician behaviors. The authors suggested that future research was required to study the impact of performance status on the patient's evaluation of the patient-physician interaction.

### Summary

This section identified five different interventions that have been used to provide information to patients. The first method of providing written information to cancer patients through various methods (pamphlets, supplementary information, letters, and access to charts) has been shown to increase their satisfaction with the treatment choice made and ability to make treatment decisions (Cassileth et al., 1989), increase their satisfaction with the medical consultation (Damian & Tattersall, 1991), and assist them in gaining control and coping with the stress of having cancer (Fisher & Britten, 1993). Providing newly diagnosed male cancer patients and their spouses with an individualized information package was reported to significantly increase their satisfaction with the information they received (Derdiarian, 1989). Ellis et al. (1979) also reported that the provision of supplementary, written information to a group of medical patients increased their understanding and recall of information.

The provision of taped information (audio or audiovisual) to cancer patients prior to the treatment consultation has been reported to result in a decreased level of anxiety, less mood disturbance, less affective distress (Rainey, 1985), and an increased ability in coping during and after treatment (Johnson et al., 1988). However, Rainey (1985) reported there was no difference in the level of knowledge as a result of this intervention.

Studies involving the benefits of providing cancer patients with an audio tape of their medical consultation have produced conflicting results. Several investigators have reported that providing cancer patients with an audio tape of the initial treatment consultation with their physician assisted in communication of illness-related information to family (Hogbin & Fallowfield, 1989; Johnson & Adelstein, 1991; Reynolds et al., 1981; Tattersall et al., 1994). Still others reported that cancer patients found the tapes to be a source of new information, assisted them in recalling information (Hogbin & Fallowfield, 1989; Johnson & Adelstein, 1991), decreased their anxiety about the future treatment (Hogbin & Fallowfield, 1989), and was recognized as a way to cope with their illness

(Johnson & Adelstein, 1991). Reynolds et al. (1981) found that providing a tape recording of the consultation had no effect on recall of information or patient satisfaction. Dunn et al. (1993) reported that although audio tapes of the initial consultation increased satisfaction with the medical consultation, it had limited potential to increase recall of information and had no effect on psychologic adjustment to cancer. Tattersall et al. (1994) also reported that an audio tape of the initial consultation did not differentially affect recall of information or levels of anxiety, and depression at four weeks. However, North et al. (1992) found this approach increased the retention of information and decreased levels of anxiety in a group of patients with advanced carcinoma. Although McHugh et al. (1995) found that this intervention did not have an affect on levels of psychological distress at 1 or 6 months, they did report that patients who received an audio tape of the initial clinical interview were able to recall significantly more information about their illness than did controls at six months. Physicians have also been reported to plan their treatment discussion more carefully when they knew they were being audio taped (Hogbin & Fallowfield, 1989; Johnson & Adelstein, 1991). McHugh et al. (1995) suggested that providing an audio tape may not be helpful for a cancer patient who is in denial as it could prevent the patient from using this adaptive defense mechanism.

The fourth method of assisting patients to formulate questions to ask the physician has been shown to increase older medical patients' satisfaction with medical care (Merkel et al., 1983), increase the number of questions asked (Roter, 1984; Robinson & Whitfield, 1985), and increase the understanding and recall of information (Robinson & Whitfield, 1985). Greenfield et al. (1985) and Tabak (1988) reported question-asking did not have an effect on medical patients' satisfaction. However, when a group of cancer patients received this intervention, Gotcher and Edwards (1990) reported their satisfaction with the information and the quality of their communication was increased and as a result of the improved communication, they were able to manage their fears better. Neufeld et al. (1993) also reported that a nursing intervention which included assisting female cancer patients to

identify questions to ask the physician was effective in assisting them to participate in treatment decision making to the extent they desired.

The literature has also shown that spouses and/or significant others play an important role in providing support to the cancer patient (Jassak, 1992; Kesselring et al., 1986; Rose, 1990; Ward et al., 1991), and assistance in treatment decision making (Dermatis & Lesko, 1991). Although the presence of a family member in a patient-physician interaction has also been reported to result in the physician spending more time with the patient and providing more information, it was not found to have an impact on patient satisfaction or quality of life (LaBrecque et al., 1991). Empirically based studies related to the effect of including significant others in information sharing were identified as lacking.

Few investigators have studied the effect of using one or more of these interventions for the purpose of assisting cancer patients in the treatment decision making process. Cassileth et al. (1989) were the only investigators who studied if the provision of written information to men newly diagnosed with prostate cancer would have an effect on their participation in treatment decision making. Men newly diagnosed with prostate cancer were identified as an understudied population.

#### **2.4 Stage Four: Empowering Experience**

The expectation of self-efficacy is the belief certain behavioral outcomes will result when an individual has the skills to cope with and exercise control in a given situation (Bandura, 1977). Feelings of self-efficacy may be one of the factors that determine whether control is desirable. Bandura, Adams, Hardy, & Howells (1980) demonstrated feelings of self-efficacy in a threatening situation are excellent predictors of the level of coping exhibited in the situation. Self-efficacy theory states the relationship is mediated by the amount of effort expended in coping with the stressful event, with greater feelings of self-efficacy leading to greater efforts at coping. Individuals who have greater feelings of self-efficacy have been shown to be more highly motivated to be in control of their situation,



have an increased ability to cope with the aversive event, and have lower levels of fear (Bandura et al., 1980).

Stage four of the empowerment process states that the empowering experience will lead to measurable behavioral outcomes. The degree to which a man newly diagnosed with prostate cancer preferred to participate in treatment decision making was believed to be directly related to the perceived degree of personal control he had in the patient-physician relationship, and level of anxiety and depression being experienced. It was hypothesized that providing these men with self-efficacy information would decrease their levels of anxiety and depression and increase their degree of personal control in the patient-physician relationship, which would enable them to assume a more active role in the treatment decision making process.

### **2.5 Stage Five: Measurement of Behavioral Outcome**

The process of empowerment fosters a sense of control by emphasizing treatment decisions incorporate patients' preferences in decision making (Speedling & Rose, 1985). Provision of self-efficacy information (by the methods previously identified in Stage Three) was expected to provide these men with the knowledge and skills necessary to make treatment decisions, and sufficient control and resources to implement their decisions. This philosophy was consistent with the consumer model as patients were provided with the opportunity to become more active participants in treatment decisions that would have an impact on their future quality of life.

### **Participation in Decision Making**

The current emphasis on increased patient involvement in health care decision making can be attributed largely to current ethical, legal, and social concerns of a consumer conscious society. Ethically, the provision of information is necessary in a society that supports patient autonomy and self-determination. Legally, informed consent places respect for a patient's self-determination at the center of the physician-patient relationship, and recognizes that an active role in treatment decision making is often the best guarantee that

these decisions will promote well-being (Forrow et al., 1988). Socially, patients as health consumers are advocating a more equal relationship with health care professionals.

Although the patient's desire for information and the use of such information for the purpose of decision making has been studied by many researchers, it is still not understood if the provision of information necessarily leads to more patient involvement in the decision making process, or even if such involvement is appropriate for all individuals (Northouse & Wortman, 1990).

Investigators have produced conflicting findings regarding the type and degree of participation that patients prefer to have in medical decision making. Although advocacy of shared decision making by patients and clinicians is supported in theory, many clinicians doubt whether patients actually want to participate in medical decision making. Clinicians frequently maintain that patients should not participate in decision making because they do not have the knowledge required to participate in making critical choices, and that even if patients did, they might suffer psychological harm if the outcomes of the decision they made were negative (Degner & Beaton, 1987). There is little empirical evidence to support these beliefs.

Some early studies suggested that the general public, as well as patients with cancer, may prefer a collaborative role in medical treatment decision making. For example, a random sample of 200 Canadians surveyed by Vertinsky, Thompson, and Uyeno (1974) concluded that although the majority of respondents did not wish to take the entire responsibility for medical decision making, they also did not wish to be entirely passive in the patient/physician relationship. A similar study by Haug and Lavin (1981) which surveyed 466 members of the general public and 86 physicians, found that a substantial proportion of the public wished to assume a consumerist position, and take some responsibility for medical decision making. In 1980, Cassileth, Zupkis, Sutton-Smith, and March conducted a survey of 300 patients with metastatic cancer to determine information and decision making preferences. Two-thirds of the patients indicated a preference for

participating in medical decisions. Hack, Degner, and Dyck (1994) examined the relationships between preferences for involvement in decision making and preferences for information in a group of 35 women with early stage breast cancer. The investigators found that 80% of the women in this study preferred either an active or collaborative role in choosing their treatment.

Further evidence that patients may prefer a pattern of shared decision making was provided by several investigators. Strull, Lo, and Charles (1984) studied a group of hypertensive patients and concluded that better assessment of individual preferences for information, discussion, and decision making authority, may result in enhanced patient participation in decision making. These conclusions were supported by Greenfield et al. (1985) who found that providing a group of ulcer disease patients with detailed information and encouraging them to participate in decision making resulted in them being more involved in the patient-physician interaction and assuming a more active role in decision making. Robinson and Whitfield (1985) also reported that a group of surgery patients gained a more accurate understanding of the suggested treatment when they were encouraged to ask the physician questions about the treatment recommendations. Recent studies of women with breast cancer have found that both women and their husbands who were offered choice of treatment (lumpectomy versus mastectomy) had lower anxiety levels, irrespective of the choice they made, when compared with patients whose surgeon made the treatment choice (Fallowfield et al., 1990; Morris & Royle, 1988).

### **Information and Decision Making**

In most oncology settings, health professionals believe they should provide the information needed by cancer patients to actively participate in treatment decision making (Northouse & Wortman, 1990). However, research findings have consistently demonstrated that the majority of patients cared for in such settings were dissatisfied with the kind and/or amount of information they received from physicians and nurses (Degner, Jerry, & Till, 1991). These patients also have been found to experience difficulties in

obtaining information they needed to achieve meaningful participation in decision making (Messerli et al., 1980; Strull et al., 1984).

Several investigators have identified the information needs of cancer patients, but few have conducted studies to determine the best methods of delivering this information for the purpose of increasing participation in treatment decision making. Previous investigators (Feldman, 1976; Greenleigh Associates, 1979; Jones, 1981; Weisman & Wordon, 1976) reported that information desired by cancer patients falls into four major categories (in hierarchical order): disease, personal, family, and social. Following diagnosis, the informational needs cancer patients perceived as necessary for effective coping with each of these categories were identified as follows: disease-related-- diagnosis, tests, treatments, and prognosis; personal-related-- impact of the disease and/or the treatments on their physical well-being and ability to function, their psychological well-being and emotional stability, their job/career, and their plans/goals for the future; family-related-- impact on spouse/significant other, children, parents, and siblings; and social-related-- contractual, leisure, and intimate relationships.

Derdiarian conducted several studies (1986, 1987) to identify the informational needs of recently diagnosed cancer patients. The information requirements of the patients studied were reported to be related to the four categories of disease, personal, family, and social. Although in the 1986 study Derdiarian indicated few differences in the informational needs among the patients related to age, gender, and stage of cancer, in her 1987 study she reported that men in general attached more importance to information about tests, physical well-being, and spouse. The older adults tended to need less information on relationships with spouse, parents, and career than the younger subjects. Patients with local and regional disease also were found to need more information than those with disseminated disease. Since no other differences were found when the patients were stratified according to gender, stage of life, marital status, education, time lag since first symptoms, and having read about cancer, she concluded that the results of the study would be useful to provide a

baseline to predict the informational needs of these patients in the future course of their treatment. In the 1986 study, she concluded that although more research is needed, the information needs of recently diagnosed cancer patients may be universal.

An extensive review of the literature carried out in Canada identified items of information that were important to people with cancer generally and, more particularly with breast cancer (Degner, Farber, & Hack, 1989). The literature revealed nine major areas of importance for women with breast cancer that included physical, psychological and social aspects of care and treatment and included information on the spread of disease, likelihood of cure, impact on social life, effect on family and friends, self-care, sexual attractiveness, treatment options, risk to family of getting the same disease, and treatment side effects. Likelihood of cure, spread of disease, and treatment options have been found to be the three most important information needs of both breast cancer patients (Bilodeau & Degner, 1996; Degner et al., 1996; Luker, Beaver, Leinster, Owens, Degner, & Sloan, 1995) and men with prostate cancer (Davison et al., 1995). Information concerning sexual attractiveness (females) and sexual function (males) was ranked last in these studies. These findings supported Derdarian's conclusion that information needs may be universal among various cancer populations.

Cancer patients have been found to vary with respect to the extent to which they want to be involved in the decision making process (Cassileth, Zupkis et al., 1980; Sutherland, Llewellyn-Thomas, Lockwood, Trichler, & Till, 1989). Several investigators (Cassileth, Zupkis et al., 1980; Hack et al., 1994; Sutherland et al., 1989) found a positive relationship between decision making and identified information needs in cancer patients, with those preferring more active roles in decision making desiring more information. It also has been suggested that patients who prefer a more active role in treatment decision making may require different types and amounts of information than do patients who are concerned primarily with coping with the effects of the treatment(s) and disease (Degner & Sloan, 1992). However, patients who assume a more active role in treatment decision

making do experience significant benefits over their more passive counterparts. Some of these benefits include: increased satisfaction with treatment decisions; increased satisfaction with care received; less anxiety and depression both pre- and post-operatively; and a higher degree of hope (Cassileth et al., 1989; Cassileth, Zupkis et al., 1980; Morris & Royle, 1988).

**Predictors of role preference.** Certain sociodemographic characteristics have been reported to have an impact on the preferred role in treatment decision making. Blanchard et al. (1988) reported older males, and married cancer patients preferred a less active role in decision making. Cassileth, Zupkis et al. (1980) reported older, less educated cancer patients preferred the physician to make treatment decisions. These findings also were supported by Degner and Sloan (1992) who reported older, less educated patients were found to prefer less control in decision making, and being an older male with a cancer of the reproductive system was a significant predictor of preferring a passive role in decision making. Llewellyn-Thomas, McGreal, and Thiel (1995) also found that cancer patients preference for a less active role in treatment decision making was significantly related to being older ( over 50 years), less educated, and male.

Poor prognosis is usually positively correlated with advanced stage of cancer. Researchers have produced conflicting findings regarding the impact of prognosis on the preference for information and preferred role in treatment decision making. Cassileth, Zupkis et al. (1980) reported cancer patients whose prognosis was positive preferred an active role in treatment decision making and detailed information. However, Blanchard et al. (1988) reported cancer patients who preferred an active role in decision making had a poor prognosis. Ende, Kazis, Ash, and Moskowitz (1989) reported the desire of medical patients to make treatment decisions decreased as the severity of the illness increased. The clinical hypothesis that sicker cancer patients prefer less control in treatment decision making was not supported in the study conducted by Degner and Sloan (1992).

### **Summary**

The degree to which cancer patients choose to participate in medical decision making may be contingent on variables other than the strategies used to provide self-efficacy information. Age, gender, marital status, and level of education have been identified as having an effect on the role cancer patients assume in the decision making process. The main goal of the empowerment intervention identified in Stage Three was to assist these men to interpret the events more clearly, and to see their responses to treatment choices as meaningful. Chapter Three will outline the methodology used to achieve the study's main objective.

## CHAPTER THREE: METHODOLOGY

### 3.0 Research Design

This prospective study used an experimental design. Experimental designs are the most precise method a researcher can employ to generate evidence in support of postulated causal relationships among variables (Brink & Wood, 1989). The pre-test/post-test design provided a baseline for determining the effect of the independent variables prior to the introduction of the intervention, and indicated the confidence that a causal link existed between the independent and dependent variables. Subjects were randomized in blocks according to physician to ensure study groups were comparable on preexisting factors that might affect the outcome, and to minimize the effects of threats to internal validity.

### 3.1 Population, Sample and Sample Selection

The target population included all men newly diagnosed with prostate cancer in the province of Manitoba in 1995 ( $N = 850$ ). The sampling units for this study ( $N = 60$ ) included men newly diagnosed with prostate cancer who were seen by two urologists at one Winnipeg community clinic. Approximately 30 percent of Manitoban men diagnosed with prostate cancer are seen in this clinic annually. The sample size, alpha of .05,  $df = 1$ , permitted detection of a large effect (.75) with a power of 90% for the secondary outcomes of personal control, anxiety, and depression.

Selection criteria for this study included all patients who had been referred to one of the urologists for diagnosis and treatment of prostate cancer; were aware of their diagnosis (as confirmed by the pathological results from a transrectal ultrasound guided needle biopsy); had not had their treatment consultation; were able to read, speak, and write English; and showed no evidence of mental confusion as assessed by the investigator.

### 3.2 Instrumentation

The following scales were chosen because of their proven reliability and validity in studies conducted with cancer patients, and also to enable the investigator to compare the results of this study with results of other studies currently being conducted by oncology



nurse researchers at the University of Manitoba. All questionnaires were short, decreasing subjects' response burden. Approximately 15 to 30 minutes was required to complete the forms.

The patients' preferred and assumed roles in treatment decision making were measured by the **Control Preferences Scale** (see Appendix C). This tool was developed as a result of a pilot study (Degner & Aquino-Russell, 1988) and has been subsequently tested with newly diagnosed cancer patients (various types of cancers) (Degner & Sloan, 1992), breast cancer patients (Beaver et al., 1996; Bilodeau & Degner, 1996; Degner et al., 1996; Hack et al., 1994), and men with prostate cancer (Davison et al., 1995). The instrument consists of five cards containing statements about different roles in treatment decision making, ranging from selecting one's own treatment, through a collaborative role with the physician, to leaving all decisions to the physician. Psychometric data previously obtained using unfolding analysis had confirmed the majority of patients do have systematic preferences about keeping, sharing, or delegating away decisional responsibility (Degner & Sloan, 1992).

Anxiety was measured by the **Spielberger State-Trait Anxiety Inventory** (STAI- X Form) (see Appendix D). The STAI is a short self-report measure of both state and trait anxiety. State anxiety is defined as a transitory emotional state or condition characterized by subjective, consciously perceived feelings of tensions and apprehension. Trait anxiety is defined as a personality trait regarding the tendency to perceive stressful situations as dangerous or threatening. This inventory has two scales of 20 statements each, one asking subjects to indicate 'how they feel at the moment' and the other 'how they usually feel' (Spielberger, Gorsuch, & Lushene, 1970). This scale was designed for a fifth grade reading level. Previous construct validity had been determined by subjecting participants to testing under stress and nonstress conditions. Both scale segments had high degrees of internal consistency (Spielberger et al., 1970). Reliability coefficients in the alpha coefficient range of .83 to .92 had been reported in studies conducted with surgically

treated cancer patients (Oberst & Scott, 1988), newly diagnosed breast cancer patients (Scott, 1983), and men with genitourinary cancer (Scott, Oberst, & Bookbinder, 1984).

Depression was measured by the **Centre for Epidemiologic Studies Depression Scale** (CES-D) (see Appendix E). This short self-report scale consists of a 20 item rating scale originally developed to measure depressive symptoms in the general population (Markush & Favero, 1973). The scale had also previously been used to compare measurements of depressive symptoms in the general population (Radloff, 1977), psychiatric populations (Radloff, 1977), and more recently in cancer patients (Barkwell, 1991; Lasry et al., 1987; Wales, Kane, Robbins, Bernstein, & Krasnow, 1983). Discriminant validity (Weissman, Scholomskas, Pottenger, Prusoff, & Locke, 1977), high test re-test reliability at 24 hours (Wales et al., 1983), and high internal consistency reliability (coefficients between .88 and .97) had been reported (Lasry, 1991; Radloff, 1977). Population norms with this instrument and psychiatric symptom cutoffs had been previously established (Radloff, 1977).

The **Participatory Control Questionnaire** (PCQ) (see Appendix F), derived from Cognitive Social Learning Theory of Control, was used to measure the respondent's appraisal of the degree of control achieved in the patient-physician relationship. This questionnaire was developed as a result of three previous field studies which measured participatory control relationships between: nurses and patients (Reid & Ware, 1974), elderly males and physicians (Grifone, 1986) and breast cancer patients and physicians (Grifone, 1989). The 13 item self-report questionnaire used a seven point scale ranging from 1 (strongly disagree) to 7 (strongly agree). The authors reported an alpha coefficient reliability of .92 (Grifone, Lee, & Reid, in press) with tested discriminant and convergent validity with related measures. Changes were made to this form such as: physician changed to doctor, present tense changed to past tense, and one negative statement was changed to a positive statement. These changes were required to gain clinical access to the subjects.

The **Sociodemographic Profile Questionnaire** (Appendix G) was developed by the researcher. The first part of the questionnaire was used to gather data on the following variables: age, education, and marital status. These variables were chosen because they had been previously reported to have a significant impact on the extent to which older male cancer patients participated in the decision making process. The second part of the questionnaire was used to obtain data on treatment, other sources of information used, and contact with other subjects in the study. This data was used to control for extraneous variance that may have contributed to differences between groups, and to provide a sociodemographic description of the study participants. Open- and closed-ended questions also were included in Part two of the questionnaire to evaluate the intervention.

### 3.3 Procedure

Data collection for this research project was initiated on March 1, 1995 following ethical approval from the Faculty of Nursing at the University of Manitoba and the Clinic's Ethical/Access Committee.

Physicians provided names of potential subjects to the investigator. Subjects were approached by the investigator when they came to the clinic for their bone scan. The investigator informed these men about the nature of the study at this time, and asked them if they wished to participate. Written consent was obtained from all men at this time (Appendix H), and each participant was given a copy of the consent form. The initial interview was conducted at this time. The number of men who refused to participate in the study was recorded by the investigator.

Men were assigned to either the control or experimental group by the investigator. A randomized block design was used for each physician's patients. The group to which the subject was assigned was predetermined by the use of a random numbers table. For example, a series of 20, 10, 6, and 4 numbers per block were randomly selected from a random numbers table prior to initiating the study. The lowest numbers in each sequence were used to identify subjects to be assigned to the experimental group, and the highest

numbers were used to identify subjects who were to be assigned to the control group. This method ensured the creation of equal sized treatment groups, controlled for experimental attrition, decreased the threat of selection bias, and increased the sensitivity of the study by decreasing random variation.

### **First Interview: Experimental and Control Group**

The first interview was conducted by the investigator prior to the treatment consultation with the physician. At the first interview, the researcher met with all the patients and their spouses and/or significant others (who were with them). All subjects were introduced to the idea that decisions would have to be made about treatment and that the investigator was interested in assessing the extent to which they would like to participate in making those decisions. The cards of the Control Preferences Scale were presented in a fixed order (B, D, C, A, and E), two at a time until their entire preference order over the five alternatives was obtained. The STAI and then the CES-D measurement scales were completed at this time. Selected sociodemographic data was collected at this initial interview (Appendix G), and the relationship(s) of the significant other(s) present was documented. All subjects were provided with a written information package that consisted of five brochures containing various types of information about prostate cancer (disease process, treatment options with advantages and disadvantages of each, diagnostic tests, PSA blood testing, and so on) (see Appendix I).

**Intervention: Experimental Group.** Men in the experimental group were asked to think about the type of information they needed to assist them in deciding which treatment would be best for them. A list of questions was reviewed with these men and their significant other(s) to give them an idea of the types of questions they might wish to ask their physician to get the type and amount of information they needed to make a treatment decision (see Appendix J). The investigator then showed these men the contents of the information package and identified where the information they wanted could be found. Additional questions that arose from the discussion were added to the list, and the

final list of questions was given to the participant. This list was developed from previous clinical experience with this patient population, and questions adapted from a brochure from the National Coalition for Cancer Survivorship (National Coalition for Cancer Survivorship, 1991). Men were encouraged to read the information package, and use the list of questions to obtain the information they required to make a treatment decision. At this time the investigator explained that people often forget information discussed at the treatment consultation, and one way of helping them to remember the information presented would be to have an audio tape recording of the consultation. Each individual was given a blank audio tape and told the physicians knew they may be asked to tape the consultation, but it was up to the individual to ask their physician to audio tape the consultation. These men were also encouraged to participate in deciding which treatment option was best for them, and to bring their spouse/significant other to the treatment consultation.

**Control Group.** Men in the control group and their significant other(s) were given the information package and shown what it contained. They were told that it might be helpful to read the information prior to, or following the initial treatment consultation with their physician. The remainder of the interview was social in nature.

#### **Second Interview: Experimental and Control Group**

The current practice with regards to pre-operative and post-operative appointments at the clinic varied between the physicians. The second part of the questionnaire was therefore, completed via a phone interview at approximately 5 weeks after the initial interview. Data on intended or received treatment, other sources of information used, and whether subject had contact with other subjects in study was collected at this time. Men in the experimental group were asked additional questions to evaluate the effectiveness of the intervention. The CPS, PCQ, CES-D, and STAI were sent out in a self-addressed envelope the same day of the telephone interview. The order of the tools was different from the initial interview to compensate for any learning effect caused by using the STAI and CES-D tools at both measurement times. Men were asked to complete the forms in the order they were

received. The four forms were stapled together in the order they were to be completed. The number of men who refused to participate in the second interview or return the completed forms was recorded.

Statements on the Control Preference Scale cards were changed to the past tense to measure the role assumed in treatment decision making. For example, the card "I prefer to leave all decisions regarding my treatment to my doctor", now read "I left all decisions regarding my treatment to my doctor". The five statements were presented on one sheet of paper in the same order as the first interview (B, D, C, A, and E). Men were asked to select the one statement that best described the way in which their treatment decision was made.

### 3.4 Analysis

Parametric tests were used as the main method to test each of the hypotheses. The usual descriptive statistics (percentages, means, standard deviations) were applied to the sociodemographic data to provide a profile of the participants. The STAI, CES-D, and PCQ were multiple item, unidimensional Scales with interval levels of data. A critical alpha value of .05 was used to test the significance of the results obtained. Psychometric assessment of the STAI, CES-D, and PCQ Scales were conducted prior to data analysis. Cronbach's coefficient alpha was used to evaluate the internal consistency of these scales.

**Hypothesis One: Men newly diagnosed with prostate cancer who receive the empowerment intervention will assume a more active role in treatment decision making than men who did not receive the empowerment intervention.**

**Preferred role.** Coombs' (1976) unfolding technique was used to verify that the men did perceive their role in treatment decision making along a single dimension. This scaling method is based on the theory of preferential choice. Each subject was asked to rank-order the cards in terms of their proximity to his personal preference in the role he wished to play in treatment decision making. The individual preference orders were unfolded to determine whether they were consistent with the existence of an underlying

psychological dimension, providing a direct test of the hypothesis that participants did have systematic preferences about the degree of control they wanted in treatment decision making, ranging from no control to complete control. Preference orders fell on the dimension if they were in a sequence that captured the hypothetical rank order of the decisional roles and the midpoints between them. The combination of five decisional roles and their midpoints produced a dimension with 12 possible sets of 11 response patterns each.

Traditional chi-square testing and t-tests were used to compare the distribution of role preferences between the groups and to examine predictors of decisional preferences. Traditional chi-square testing also was used to determine if the groups differed in terms of their assumed role in decision making. The first card selected was used in decisional role analyses for both preferred and assumed role.

**Hypothesis Two: Men newly diagnosed with prostate cancer who receive the empowerment intervention will experience less anxiety at six weeks post treatment consultation than the men who did not receive the empowerment intervention.**

A one-tailed multi-way analysis of variance (MANOVA) was used to analyze pre-test/post-test state and trait scores of the two groups. This statistical procedure allowed for testing the effect of one or more treatments on different groups by comparing the variability between groups to the variability within groups. An analysis of covariance (ANCOVA) was also applied to this data to block out differences in pre-test state anxiety scores.

**Hypothesis Three: Men newly diagnosed with prostate cancer who receive the empowerment intervention will experience less depression at six weeks post treatment consultation than the men who did not receive the empowerment intervention.**

The same statistical procedures (as in Hypothesis Two) were applied to the CES-D scores. Since scores were similar for both groups at both measurement times, ANCOVA was not done with this data.

**Hypothesis Four: Men newly diagnosed with prostate cancer who receive the empowerment intervention will experience a higher degree of participatory (personal) control in the patient-physician relationship at six weeks post treatment consultation than the men who did not receive the empowerment intervention.**

A one-tailed t-test was used to compare the two groups in terms of their PCQ scores.

### 3.5 Ethical Considerations

Informed written consent was obtained from all subjects who agreed to participate in this study, once they had received complete disclosure as to the purpose of the investigation and following assurances of confidentiality. All participants were offered a copy of the consent form. Subjects were told their participation in the study was voluntary, and they could withdraw at any time. They were also assured their withdrawal would in no way affect their medical or nursing care.

The respondent's names were not on the questionnaires thereby assuring confidentiality and anonymity. Subjects were given an identification number so that the names would not be part of the data collection forms. However, a master list of chart numbers, names and identification numbers was kept to check the raw data if necessary. The nurse researcher, Dr. Lesley Degner, and a statistician did have access to the questionnaires. Questionnaires were stored in a locked filing cabinet. Subjects were told the questionnaires would not be destroyed for a minimum of ten years, and they would be destroyed at that time by means of a paper shredder.

Prior to data collection, it was decided that if: 1. a subject felt uncomfortable talking about his diagnosis and was anxious when asked if he wished to participate in the study he



would be asked to think about whether he wanted to participate in the study and to call the nurse within a few days if he wished to participate; 2. the nurse researcher assessed a subject was too anxious or upset, at the time of the initial interview, he would be asked if he wanted to withdraw from the study or reschedule the appointment (within a short time frame due to the nature of the study data required); and 3. a participant tried to elicit the researcher's opinion about which treatment she believed was most suitable for him, she would state "I do not have access to your medical history and there are many variables to consider. The decision must be made after you have discussed all your concerns with your physician. This information will help you get the answers you need to help you decide which treatment is best for you." It was also decided that if a patient was assessed as unable to complete the forms during the first interview, he would be given the information package and not be included in the study.

There were no perceived harmful effects of being in either the control or experimental group. The men in the experimental group did receive more information (through the planned empowerment intervention) than men in the control group however, both groups received the usual type and amount of information given to them by their physician. Subjects in the control group were given the opportunity to tell the researcher how they would prefer to be involved in decision making. There was no current evidence to indicate that withholding the experimental intervention would decrease the quality of care of men in the control group. The study provided all participants the opportunity to help current and future patients newly diagnosed with prostate cancer. This concern for patient welfare and the future direction for assisting these men in treatment decision making were important arguments supporting the benefits of this study. The benefits of the intervention were not known until the data analysis was completed.

### **3.6 Strengths and Limitations of Study**

Internal validity refers to "the approximate validity with which we infer that a relationship between two variables is causal or that the absence of a relationship implies the

absence of cause" (Cook & Campbell, 1979, p.37). The following threats to internal validity were considered:

Experimental attrition refers to the nonequivalent attrition of subjects from the experimental and control groups. The number of men who withdrew from the study was recorded. A sample size of 60 ensured the investigator could detect a large effect (.75) and have a power of 90 for the primary outcomes of personal control, anxiety, and depression. A larger size would have been more desirable, but this was not possible due to accessibility issues relating to this particular patient population.

Maturation refers to certain changes within the subjects that may occur over time and may not be related to any specific event, such as: subject becoming more knowledgeable from other means; and subject not receiving treatment selected due to extent of disease. The occurrence and effects of these events was controlled statistically.

Instrumentation refers to changes that occur in the measurement instruments, observers, or raters that may produce changes in the dependent variable measurements. All instruments had accepted reliability and estimator validity, and had previously been used with cancer patients. This study group however, was unique because it consisted of older males with cancer of a reproductive organ. It was expected that this could effect the reliability of the instruments. Psychometric estimation of the tools using the data from this study was used prior to testing the study's hypotheses, thereby establishing pre-set criteria for reliability and validity. Testing was also a problem because the STAI and CES-D measurement instruments were used twice, and there was a possibility that scores at time two could be influenced by a learning effect. Both groups were pretested with these two scales, and any sensitizing effects of the pretest was expected to be equally distributed. The order of giving the tools was altered at the second interview, and since there was approximately a 6 week time period between the testings, the effect of this threat was believed to be minimal.

Selection bias refers to the selection of subjects on a non-random basis that may produce differences in the experimental and control subjects with regard to the criterion measurement irrespective of the differential exposure to the treatment intervention. A random numbers table was used to predetermine the group to which the subject would be assigned. Since the order of the numbers was entirely random, the allocation decisions were entirely random and outside the nurse researcher's control, hence free of any risk of bias.

Diffusion or imitation of treatments refers to the introduction of a treatment that involves information when the experimental and control group subjects may be able to interact with one another, either directly or indirectly, and learn about information intended for others. There was a possibility this event could occur, but the waiting room in this clinic was composed of several patient populations so the chances of information being exchanged between patients was minimal. Interviews were arranged at different times so that subjects did not have contact with one other. The subjects were also asked, at the second interview, if they had met or discussed any information with other men in the study.

Compensatory rivalry by respondents in control group is a response by subjects in a no-treatment group. To help avoid this threat to internal validity, the study was single-blinded thus assuring the subjects did not know which group they had been assigned to. This was achieved by all subjects receiving the same written information in the same type of envelope. Other participants who saw another man leaving the clinic with such an envelope did not know if they were in the same or different groups.

Researchers are primarily concerned with the internal validity of their design; however, they are also interested in the generalizability or external validity of their findings. External validity refers to " the approximate validity with which we can infer that the presumed causal relationship can be generalized to and across alternate measures of the

cause and effect and across different types of persons, settings, and times" (Cook & Campbell, 1979, p.37). The following threats to external validity were considered:

Interaction of selection and treatment refers to the effects obtained that are applicable only to the specific subjects who participated in the study. Participation in the study was made as convenient and simple as possible. This decreased the likelihood of some subjects thinking they were more 'special than others'.

Interaction of setting and treatment refers to the effects obtained that are applicable only to the specific setting where the experiment is conducted. The potential subjects seen at this clinic were not considered to be different from men seen in other Winnipeg clinics. The question was whether the results obtained in this setting could be generalized to other settings in Manitoba and Canada.

Interaction of history and maturation refers to the effects obtained that are applicable only to the specific time period within which the study is conducted. Unusual occurrences may have occurred during the data collection period that may have made the extrapolation of results to other periods questionable. However, both interviews were conducted at specific times--the first prior to the treatment consultation, and the second 5 to 6 weeks post treatment consultation. Any notable historical events (for example, media releases on the best treatment to cure prostate cancer) were observed for during the data collection period. This was done to ensure the effect of these events could be statistically controlled.

Reaction or interaction effect of pretesting refers to the concern that subjects may no longer represent the target population following exposure to the pretest. The pretesting could have made the subjects in the control group more aware of certain issues of which they would not otherwise have been aware, and caused them to respond to the treatment in a unique way. Men in the control group were not encouraged to participate in decision making by the nurse researcher. They were given written information but again they were not encouraged to read it.

Reactive effect of experimental procedures refers to the effect produced by the intervention which may make the subjects who are exposed to these procedures no longer representative of the target population. The results were only able to be generalized to similarly pretested patient groups, decreasing the study's external validity. However, using one specific population from one site made the study more sensitive and decreased the variability of the data. The physicians did not have any knowledge of which group the subject had been assigned, but they could have recognized the men who were in the intervention group if they brought the list of questions or wished to have their consultation tape recorded. This may have had an effect on the physician's behavior and amount of information given to the patient. Physicians were asked not to disclose which group the patient has been assigned to if he asked. This effect was statistically controlled as subject randomization was blocked according to physician seen. No patients asked their physician to disclose the group to which they had been assigned.

Multiple treatment interference refers to the effects produced by multiple exposures of subjects to a treatment. The intervention was administered to the men after they had completed the pretest instruments. There was only one intervention planned. At the second interview, the subjects were asked what other sources of information were used to assist them in treatment decision making. The occurrence of this event was controlled for statistically.

### **3.7 Summary**

This study was conducted with 60 patients newly diagnosed with prostate cancer at one Winnipeg community clinic. The data was numerically coded and analyzed as outlined in this chapter. The Statistical Analysis System (SAS) was used to analyze the data. The ethical considerations, as outlined in this chapter were adhered to. Chapter Four will present the results of data analysis.

## CHAPTER FOUR: RESULTS

### 4.0 Introduction

This chapter will present the results of this randomized study. First, the sociodemographic characteristics of the men will be described. Data on each of the hypotheses will then be presented. Descriptive statistics will then provide a summary of how men in the intervention group used and evaluated the self-efficacy information. Chapter Four will conclude with a summary of the most important findings.

### 4.1 Sociodemographic Characteristics

The participants were 60 men diagnosed with prostate cancer at one community urology clinic in Winnipeg, Manitoba. Only those men who were newly diagnosed (within one week) and had not had their treatment consultation, were aware of their diagnosis, and able to speak and read English were asked to volunteer for the study. All men who were asked to participate in the study agreed to do so. Patients were randomly assigned to either the control or intervention group according to physician. One 80 year old man refused to complete the second set of questionnaires.

Most men had less than a grade 12 education (58.3%), were married (86.7%), retired (71.7%), and resided in Winnipeg (58.3%). The median age of men was 66.5 years in the intervention group and 69.5 years in the control group, with the largest group being 70 years or younger (see Table 1). Men in the control group were more likely to be older  $t(58) = 1.99, p = .0513$ , and retired. The two groups were not significantly different from one another with reference to age category, years of education  $t(58) = 1.152, p = .254$ , education category, marital status, residence, days from first interview  $t(58) = .079, p = .937$ , and intended/received treatment.

Seventy-five percent of men had started or received their intended treatment at the time of the second interview. For the purpose of this study, having a pelvic lymph node dissection was considered as part of the medical treatment protocol. Radical prostatectomy was the most frequent treatment received by men in both groups. Thirty-four men were

recruited from one physician and 26 from the other. Mens' ages  $t(58) = .157$ ,  $p = .876$ , and years of education  $t(58) = .461$ ,  $p = .647$ , were not found to vary with respect to physician seen.

**Table 1. Sociodemographic Characteristics**

	<b>Control</b> <b>n = 30</b>	<b>Intervention</b> <b>n = 30</b>	<b>X<sup>2</sup>(DF)</b>	<b>p</b> <b>Value</b>
<b>Age</b>				
Mean	69.8 ( <u>SD</u> = 5.0)	66.0 ( <u>SD</u> = 8.3)		
Median	69.5	66.5		
Range	53 to 81	41 to 80		
≤ 70	19 (63.3%)	21 (70.0%)	.300 (1)	.584
> 70	11 (36.7%)	9 (30.0%)		
<b>Education</b>				
Mean	10.4 ( <u>SD</u> = 2.9)	11.2 ( <u>SD</u> = 2.7)		
Median	10.0	11.5		
Range	6 to 17	7 to 18		
< Grade 12	20 (66.6%)	15 (50.0%)	1.714 (1)	.190
≥ Grade 12	10 (33.4%)	15 (50.0%)		
<b>Marital Status</b>				
Married/Partner	26 (86.7%)	26 (86.7%)	0 (1)	1.00
No Partner	7 (23.3%)	7 (23.3%)		
<b>Residence</b>				
Urban	21 (70%)	14 (46.7%)	3.36 (1)	.067
Rural	9 (30.0%)	16 (53.3%)		

<u>Cont'd.</u>	<u>Control</u>	<u>Intervention</u>	<u>X<sup>2</sup>(DF)</u>	<u>p</u>
<b>Employment</b>				
Retired	25 (83.3%)	18 (60%)	4.022 (1)	.045
Full-time/Part-time	4/1 (16.7%)	8/4 (40.0%)		
<b>Days From Pre-test to Treatment Consultation</b>				
Mean	1.6	1.5		
Median	0	0		
Range	0 to 16	0 to 7		
<b>Treatment</b>				
Radical Prostatectomy	13 (43.3%)	12 (40.0%)		
Radiation	9 (30.0%)	9 (30.0%)		
Orchiectomy	3 (10.0%)	1 (3.3%)		
Hormone	2 (6.7%)	4 (13.3%)		
Hormone and Orchiectomy	0	1 (3.3%)		
Watchful Waiting	3 (10.0%)	2 (6.8%)		
Alternative Treatment	0	1 (3.3%)		



## 4.2 Preferred and Assumed Roles in Treatment Decision Making

### Control Preferences Scale

The preference orders of 49/60 or 81.7% of the men unfolded onto the psychological dimension of preferences about keeping, sharing, or giving away control over treatment decisions to the physician. Transitive (valid) preference orders observed in this sample were as follows: ABCDE (5.0%), BACDE (6.7%), BCADE (3.3%), BCDAE (3.3%), CBDAE (5.0%), CDBAE (10.0%), CDBEA (18.3%), CDEBA (3.3%), DCEBA (10.0%), DECBA (5.0%), and EDCBA (11.7%) (see Figure 1). Coombs (1976) set the criterion for accepting the dimensionality of any particular scale at 50% plus 1 of observed preference orders having unfolded onto the dimension. This criterion was met in this sample as 81.7% of the preference orders fell directly on the dimension. The transitive preference order with the highest frequency ordering was CDBEA (18.3%). This order indicated these men preferred a collaborative role the most, and making the treatment decision themselves least.

Eleven intransitive preference orders (orders not included in the scale) observed in this sample were as follows: CBDEA (36.4%), ACBDE (27.3%), BDCAE (9.0%), CBDEA (9.0%), DCBEA (9.0%), and DBCAE (9.0%). Examination of these orders revealed the most frequent intransitive preference order to be CBDEA. This order revealed transpositions in the fourth and fifth positions, indicating that these men had difficulty deciding whether they wanted to make the final treatment decision themselves, or leave decisional responsibility to their physician. ACBDE was the second most frequent intransitive order. This order revealed transpositions in the second and third positions, indicating that the cards B, C, and D may not be sufficiently distinct from each other in terms of degree of decisional responsibility for some men to be able to discriminate among them.

**Figure 1. Psychological Dimension of Treatment Decision Making (n = 49)**

<b>Active Role- Patient Control</b>			
	<b>0</b>	<b>5</b>	<b>10</b>
ABCDE	X X X		
BACDE	X X X X		
BCADE	X X		
BCDAE	X X		
CBDAE	X X X		
CDBAE	X X X X X X		
CDBEA	X X X X X X X X X X X		
CDEBA	X X		
DCEBA	X X X X X X		
DECBA	X X X		
EDCBA	X X X X X X X		
	<b>0</b>	<b>5</b>	<b>10</b>
<b>Passive Role- Physician Control</b>			

### Preferred Role in Treatment Decision Making

The majority of men newly diagnosed with prostate cancer wanted to be involved in making their medical treatment decision. Twenty-five per cent wanted to select their own medical treatment, 43.3% wanted to select their treatment collaboratively with their physician, and 31.7% wanted their physicians to make treatment decisions on their behalf (see Table 2). At the pre-test, no significant differences were found between the role preferences of the two groups  $\chi^2 (2, N = 60) = 4.356, p = .113$ .

**Table 2. Preferred Roles in Treatment Decision Making**

<b>Role</b>	<b>Control (n = 30)</b>	<b>Intervention (n = 30)</b>	<b>All Men (N = 60)</b>
Active (cards A and B)	4 (13.3)	11 (36.7)	15 (25.0)
Collaborative (card C)	15 (50.0)	11 (36.7)	26 (43.3)
Passive (cards D and E)	11 (36.7)	8 (26.6)	19 (31.7)

Due to the small sample size, men who preferred either an active or collaborative role were combined and compared with men who preferred a passive role. Distributions of preferences for sub samples as defined by sociodemographic characteristics were compared using t-tests and chi-square. No significant differences between the two categories of role preferences were found with respect to the following variables: age in years  $t (58) = 1.476, p = .145$ ; age category  $\chi^2 (1, N = 60) = .154, p = .695$ ; years of education  $t (58) = .396, p = .693$ ; education category  $\chi^2 (1, N = 60) = 1.164, p = .281$ ; employment status  $\chi^2 (1, N = 60) = .726, p = .394$ ; residence  $\chi^2 (1, N = 60) = 1.164, p = .281$ ; and physician  $\chi^2 (1, N = 60) = .477, p = .490$ . The majority of both married ( $n = 34, 56.7\%$ ) and single ( $n = 7, 87.5\%$ ) men preferred to participate in decision making.

### Assumed Role in Treatment Decision Making

The majority of men newly diagnosed with prostate cancer believed they had assumed a significant degree of involvement in making their medical treatment decision. Thirty-seven per cent selected their own medical treatment, 41.7% selected their treatment collaboratively with their physician, and 21.6% had their physicians make the treatment decision on their behalf (see Table 3). As predicted, men who received the intervention did assume a more active role in treatment decision making than men in the control group  $\chi^2(2, N = 60) = 11.316, p < .001$ .

**Table 3. Assumed Roles in Treatment Decision Making**

Role	Control (n = 30)	Intervention (n = 30)	All Men (N = 60)
Active (cards A and B)	5 (16.7)	17 (56.7)	22 (36.7)
Collaborative (card C)	15 (50.0)	10 (33.3)	25 (41.7)
Passive (cards D and E)	10 (33.3)	3 (10.0)	13 (21.6)

In order to determine exactly how the groups differed in terms of role assumed it was necessary to carry out a series of three comparisons (2 X 2 contingency tables with 1 df): 1. active versus passive; 2. active versus collaborative; and 3. collaborative versus passive. Since three supplementary tests were conducted, each was tested at the 0.0167 level to maintain the overall type 1 error at 0.05. A critical value of 5.02 (after Yate's correction) for each of the supplementary tests was used. A comparison of the active and passive assumed roles resulted in a Chi squared value of 7.68, which exceeded the supplementary test value of 5.02. A significant difference in the proportion of men in the intervention group assuming an active role (17/20 or 85% of men in the intervention group, 5/15 or 33.3% of men in the control group) was found. The active/collaborative comparison resulted in a Chi squared value of 5.21, which also exceeded the supplementary test value of 5.02. A significant difference in the proportion of men in the

intervention group assuming an active role (17/27 or 63% of men in the intervention group, 5/20 or 25% of men in the control group) was found. No evidence was found to indicate that the proportion of men in the two groups differed in terms of assuming a collaborative versus a passive role (15/25 or 60% of men in the intervention group, 10/13 or 77% of men in the control group). In summary, the results indicated that the proportion of men in the intervention group who assumed an active role in treatment decision making was significantly higher than the proportion of men who assumed either collaborative or passive roles, and that the latter two roles did not differ significantly from one another.

Due to the small sample size, men who assumed either an active or collaborative role were combined and compared with men who assumed a passive role. Distributions of assumed roles in decision making for sub samples as defined by sociodemographic characteristics were compared using t-tests and chi-square. No significant differences between the two categories of assumed roles were found with respect to the following variables: age in years  $t(58) = .506, p = .615$ ; years of education  $t(58) = .683, p = .497$ ; education category  $\chi^2(1, N = 60) = .811, p = .368$ ; residence  $\chi^2(1, N = 60) = .070, p = .791$ ; and physician  $\chi^2(1, N = 60) = .2773, p = .096$ . A higher number of younger ( $\leq 70$  years) ( $n = 33, 55\%$ ), married ( $n = 40, 66.7\%$ ), and retired ( $n = 35, 58.3\%$ ) men participated in the decision making process.

### Role Congruency

The majority (55%) of men in this sample achieved their preferred role in treatment decision making. As Table 4 shows, men in the control group ( $n = 19, 63.3\%$ ) were more likely to assume their preferred role in treatment decision making than men in the intervention group ( $n = 15, 50\%$ ). The number of men in the control group who received more control in treatment decision making than they had originally wanted ( $n = 6, 20.0\%$ ) was slightly higher than those who received less control than they wanted ( $n = 5, 16.7\%$ ). However, in the intervention group a larger number of men were found to have received more control in treatment decision making than they had originally wanted ( $n = 11,$

36.7%). Only four men (13.3%) in the intervention group received less control than they wanted in the treatment decision making process.

**Table 4. Role Congruency**

Group		Assumed Role		
		Active	Collaborative	Passive
<b>1. Total (N = 60)</b>				
Preferred Role	Active	9	6	0
	Collaborative	8	15	3
	Passive	5	4	10
<b>2. Control (n = 30)</b>				
Preferred Role	Active	2	2	0
	Collaborative	2	10	3
	Passive	1	3	7
<b>3. Intervention (n = 30)</b>				
Preferred Role	Active	7	4	0
	Collaborative	6	5	0
	Passive	4	1	3

### 4.3 Levels of Anxiety

The internal consistency values of the STAI-X form as measured by Cronbach's alpha were as follows: pre-test state (.937), post-test state (.927), pre-test trait (.902), and post-test trait (.910). State and trait scores were correlated at both the pre-test (control  $r(28) = .589, p < .001$ ; intervention  $r(28) = .847, p < .001$ ), and post-test (control  $r(27) = .805, p < .001$ ; intervention  $r(28) = .856, p < .001$ ) measurement times. The possible range of total scores for each individual was 20 to 80 for both the state and trait measures, with a low total score indicating lower levels of anxiety. State and trait mean scores were

within normal ranges for men in the control and intervention groups at both measurement times (see Table 5).

**Table 5. Mean Levels of State and Trait Anxiety**

	Control Group (n = 30)		Intervention Group (n = 30)	
	Pretest	Posttest	Pretest	Posttest
	M (SD)	M (SD)	M (SD)	M (SD)
State	37.30 (11.68)	34.62 (13.16)	44.40 (12.50)	35.37 (10.78)*
Trait	30.47 (8.53)	32.86 (11.41)	34.53 (10.24)	34.20 (10.20)

\* $p < .005$ . Note. Normal mean scores for: 1. men 60-69 years- state ( $M = 32.1$ ,  $SD = 8.9$ ) & trait ( $M = 33.0$ ,  $SD = 8.5$ ); and 2. General medical surgical patients- state ( $M = 42.68$ ,  $SD = 13.76$ ) & trait ( $M = 41.33$ ,  $SD = 12.55$ ). In C. D. Spielberger, 1983, State-Trait Anxiety Inventory for Adults, p.61 and p.24.

Men in the intervention group had significantly higher levels of state anxiety than men in the control group  $F(1, 57) = 3.99$ ,  $p < .05$ , at the pre-test. However, when an ANCOVA was conducted using the pre-test scores as covariates, no significant differences existed between the groups in terms of their state anxiety levels at 6 weeks  $F(1, 56) = .561$ ,  $p > .10$ . An examination of each groups' state scores revealed that although pre- and post-test scores of men in the control group were similar  $F(1, 57) = .677$ ,  $p < .10$ , men in the intervention group had significantly lower state scores at six weeks  $F(1, 58) = 9.0$ ,  $p < .005$ . Preferred role in decision making  $F(2, 57) = .02$ ,  $p = .977$ ; age in years  $t(58) = .454$ ,  $p = .652$ ; and years of education  $t(58) = 1.292$ ,  $p = .213$ , were not found to have a significant effect on pre-test state anxiety scores.

There was no evidence that trait scores were different between groups  $F(1, 57) = 1.44$ ,  $p = .236$ ; between measurement times  $F(1, 57) = .96$ ,  $p = .332$ ; or between groups

and measurement times  $F(1, 57) = .213, p = .107$ . The hypothesis that men who received the intervention would have lower levels of anxiety than men in the control group at six weeks was not supported. However, men in the intervention group did have significantly lower state anxiety scores at six weeks.

#### 4.4 Levels of Depression

Internal consistency of the CES-D scale as measured by Cronbach's alpha was .887 at the pre-test and .833 at post-test. The possible range of scores for each individual was 20 to 80, with a low score indicating lower levels of depression. The hypothesis that men who received the intervention would have lower levels of depression than men in the control group at six weeks was not supported. Mean scores for the two groups at both the pre- and post-test measurement times were low (see Table 6). Multi-way anova (MANOVA) was used to compare the groups' levels of depression at pre- and post-test measurements. No significant differences in depression scores were found between the groups  $F(1, 57) = .44, p = .509$ ; between measurement times  $F(1, 57) = .08, p = .774$ ; or between groups and measurement times  $F(1, 57) = .69, p = .411$ .

**Table 6. Mean Levels of Depression**

	<b>Control Group</b>	<b>Intervention Group</b>
Pre-test Score	( $n = 30$ )	( $n = 30$ )
<u>M (SD)</u>	28.10 (9.00)	30.40 (9.00)
Post-test Score	( $n = 29$ )	( $n = 30$ )
<u>M (SD)</u>	29.41 (8.39)	29.77 (8.00)

#### 4.5 Levels of Personal Control in Patient-Physician Relationship

Internal consistency for the revised Participatory Control Questionnaire as measured by Cronbach's alpha was .853. Individual scores for this scale could range from 13 to 91, with higher scores indicating a higher level of perceived control in the patient-physician



relationship. The mean score for the control group was 85.07 ( $SD = 7.09$ ,  $Mdn = 90$ , range 69 to 91) and for the intervention group 80.9 ( $SD = 9.18$ ,  $Mdn = 84$ , range 56 to 91). The hypothesis that men in the intervention group would have higher levels of personal control in the patient-physician relationship than men in the control group was not supported. Scores of the two groups were not found to be significantly different from one another when they were compared using a two-tail t-test,  $t(57) = 1.947$ ,  $p = .056$ .

#### **4.6 Patients' Evaluation of Information Intervention**

Sources of Information. Seventy per cent of men in the intervention group sought and/or received information from one to three sources. However, the majority (53.3%) of men in the control group did not seek or receive information- other than the written information package they were provided with. Main sources of information used by the two groups were: 1. talking to someone with prostate cancer (30%); 2. talking to their own general practitioners, or other specialists (urologists, radiologists) (16.7%); 3. receiving verbal and/or written information from family and friends (15%); and 4. watching talk shows and/or PBS programs on television (8.3%). One patient's daughter gave him 36 pages of information that she had obtained from the Internet. This was a source of information that had not previously been considered.

Written Information Package. The majority (85%) of men read all or parts of the written information they were provided with at the initial interview. Although the majority of men received the written information the day of their consultation, many looked through the package before their late afternoon appointment. Six men in the control group and three men in the intervention group did not read the package. Reasons given for not reading the information were; "I didn't get to it", "I didn't think it would be helpful to read", "I have poor eyesight from my eye operation so my brother will help me read it later", "I didn't get to it but my wife read it all", "I didn't want to", "I had no time to read it before I went for surgery but I'll get to it now while I recover from my surgery". Married men reported their wives read most of the information package. This information package was shared with the

mens' children, friends, and neighbors. One rural patient even photocopied it for all his 'male coffee friends'.

Audio Tape. The majority (86.7%) of men in the intervention group had their initial treatment consultation with their physician audio taped. Four men did not get their consultation audio taped. Two of these men felt they did not want to have it taped, and two men were told by their physician that the tape recorder could not be found. Four men who did have their consultation taped did not listen to it so they would not comment on its usefulness. The four reasons given for not using the tape were- "I forgot about it", "I did not see the purpose of it", "I could not find my tape recorder", and "the tape would not play properly". Twenty-two men listened to their tape in the privacy of their homes or in some cases their cars. Of the 22 men who did use the tape, they reviewed it on an average of 1.86 times (range 1 to 4) in the six weeks following their treatment consultation. The majority (50%) of men used the audio tape to review the information given to them by their physician at the consultation and to share information with their family. Eight men used the tape just to review what had been said in the consultation, and one man used it only to share information with his family. Only two men reported that the tape was used to assist them in treatment decision making.

Question List. The majority of men reported the question list was helpful in formulating questions to ask their physician and knowing what information they should have before signing a consent for treatment. Several men took the list with them when they had their treatment consultation and asked the doctor to answer all the questions on the list. The number of men who took the question list to the consultation was not recorded, but all men used it to some extent to make sure they got the information they wanted.

Ranking of Information Interventions (see Table 7). Three men did not use the information package, question list, or get their consultation audio taped. A total of 22 men ranked the three main parts of the information intervention. The audio tape was ranked as the most useful, the written information package second, and the question list third. Men

had a difficult time deciding which rank order they would assign the written information package and the audio tape of the consultation, as they wanted to have both. The majority of men stated that it was difficult to rank the three information interventions as all were important to have, and one complemented the other.

**Table 7. Ranking of Information Interventions (n = 22)**

	<b>Written Information</b>	<b>Audio Tape</b>	<b>Question List</b>
First choice	8 (36.4%)	<b>13 (59.0%)</b>	1 (4.70%)
Second choice	<b>12 (54.5%)</b>	6 (27.3%)	4 (18.0%)
Third choice	2 (9.1%)	3 (13.7%)	<b>17 (77.3%)</b>

#### 4.7 Summary

The majority of men newly diagnosed with prostate cancer demonstrated a definite preference for keeping, or sharing decisional control with their physician. The data provided strong empirical support for the hypothesis that if these men were assisted to obtain the information they wanted, they would assume a more active role in medical decision making. The amount of decisional control men preferred or assumed was not found to be significantly related to any of the study variables. The hypotheses for the secondary study outcome variables were not accepted as the groups' levels of anxiety and depression were not found to be significantly different at the post-test measurement. Hypothesis four also was not accepted since men in the control group reported higher levels of personal control in the patient-physician relationship than men in the intervention group.

The majority of men and their partners in both groups read all, or parts of the written information package. Men in the intervention group were more active in seeking out other sources of information. The four major sources of information utilized by all men included: 1. talking to someone with prostate cancer, 2. talking to another physician, 3.

family and/or friends, and 4. television programs. Men in the intervention group ranked the information intervention as follows: 1. audio tape, 2. written information package, and 3. question list. Although the audio tape and written information were both considered essential by the men, they also wanted the question list. The audio tape of the medical treatment consultation was used mainly as a method to review what the physician had said, and/or to share information with other family members.

## CHAPTER FIVE: DISCUSSION

### 5.0 Introduction

The most important finding in this study was that men who received the empowerment intervention assumed a significantly more active role in medical decision making than men in the control group. It is believed that these findings can be generalized to men newly diagnosed with prostate cancer in the province of Manitoba who were seen at this clinic. It is unknown how representative this sample was of the total population of Manitoban men newly diagnosed with prostate cancer as this information was considered confidential by both the Manitoba Cancer and Treatment Foundation and the Manitoba Health Services Commission. This chapter will focus on a discussion of the major findings of this study with reference to the work of previous investigators.

### 5.1 Participation in Treatment Decision Making

#### Preferred Role

The majority (68.3%) of these men had a preference to participate in deciding which treatment was best for them in spite of their older age and relatively low educational level. The proportion of active (25%), collaborative (43.3%), and passive (31.7%) patients obtained in this study is dissimilar to that previously reported by Degner and Sloan (1992), Sutherland et al. (1989), and Davison et al. (1995) in their role preference data collected from other Canadian patient samples. Men in this study clearly wanted a more active role in treatment decision making. Sutherland et al. (1989) found that 10%, 27%, and 63% of patients, respectively, wanted to play active, collaborative, and passive roles. Degner and Sloan (1992) also found that the majority of men with reproductive cancer preferred a passive role in treatment decision making. Similarly, Davison et al. (1995) reported that the majority (58%) of men newly diagnosed with prostate cancer wanted to delegate decisional responsibility to their physician. See Appendix K for a more complete description of these studies.

There are at least two possible explanations for this finding. First, differences in the measurement technique may have influenced the results. In studies conducted by Degner and Sloan (1992) and Davison et al. (1995), patients considered five different roles in cancer treatment decision making, and compared them in subsets of two in every possible combination. In this present study, the order of presentation of the five cards was fixed so that order effects would be held constant across patients. Hack et al. (1994) and Degner et al. (1996) used this fixed procedure with groups of women with breast cancer. A comparison of the distributions of role preferences of Degner et al. (1996) and this present study demonstrated that in spite of gender, older cancer patients (50 to 69 years) have similar role preferences. Although Hack et al. (1994) reported a higher number of women wanted to participate in decision making, the small sample size and/or the age of women in his sample may have accounted for the differences in role preferences.

A second explanation is that men in this study were asked what role they preferred to play in treatment decision making prior to knowing their extent of disease, chance of cure, or the treatment options available. Several researchers have thought that the time since diagnosis could be used to predict how active cancer patients wanted to be in decision making. In fact, Davison et al. (1995) reported men with prostate cancer who were more recently diagnosed (between 0 to 13 weeks) tended to prefer a passive role in decision making. Degner and Sloan (1992) also reported time of diagnosis may have influenced the majority of patients in their study to prefer a passive role. Role preference data of 22 men who were one week from diagnosis and had already had their medical treatment consultation (Davison et al., 1995), were compared with the role preference data of this study. A higher proportion of men in this present study (68% versus 50%) indicated they wanted to participate in decision making when they were asked to identify their preferred role prior to the medical consultation. This finding indicates that the extent of decisional control may be dependent on the point of time at which role preference is measured, but further research is required to test this hypothesis.

The majority of men had a preference about the degree of decisional control they wanted, ranging from complete control to no control. In fact, 81.7% of these men's preference orders were found to be consistent with the ABCDE-EDCBA dimension. Similarly, a survey of 436 newly diagnosed cancer patients (Degner & Sloan, 1992) found that preferences to make treatment decisions did have a rank order. Recent studies that have used the same measure in women with breast cancer both in Canada (Degner et al., 1996) and in England (Beaver et al., 1996) have also reported decisional preferences formed a unidimensional scale. The results suggest that decisional preferences are unidimensional in men with prostate cancer as well as women with breast cancer.

Although certain sociodemographic characteristics have been reported to have an impact on the preferred role in treatment decision making, the sociodemographic variables in this study were not found to be predictive of preferring a particular decisional role. This finding is in contrast to those of previous researchers. Blanchard et al. (1988) reported older males, and married cancer patients preferred a less active role in decision making. Cassileth, Zupkis et al. (1980) reported older, less educated cancer patients preferred the physician to make treatment decisions. Degner and Sloan (1992) also reported older, less educated patients were found to prefer less control in decision making, and being an older male with a cancer of the reproductive system was a significant predictor of preferring a passive role in decision making. Llewellyn-Thomas et al. (1995) also found that cancer patients preference for a less active role in treatment decision making was significantly related to being older (over 50 years), less educated, and male. In a more recent study, Degner et al. (1996) also reported educational level as the most important predictor of role preference. Her findings were that women with breast cancer who had more than high school education were three times more likely to want an active role in decision making than were those with less than a high school education. Given the limited sample size of this present study, the sociodemographic variables were not adequately represented with respect to the three different role preferences. A larger sample is required to determine if

there are variables capable of predicting decisional preferences of men newly diagnosed with prostate cancer.

### Assumed Role

The results demonstrated that a significantly higher proportion of men who received the empowerment intervention assumed a more active role in decision making. This finding demonstrated that patients' preferences for involvement in treatment decision making might not be a static phenomenon as previously thought, and that these preferences could be influenced by the type and/or amount of information they receive. Results demonstrated that the empowerment intervention was effective in providing decisional support. Similarly, Neufeld et al. (1993) described a nursing intervention designed to provide decisional support for cancer patients who wanted to participate in medical decision making. The intervention she used consisted of assessing the extent to which patients preferred to participate in decision making, helping them to identify questions to ask the physician, and supporting them in getting the information they wanted. This intervention was tested and found to be effective in providing decisional support to a group of Canadian women newly diagnosed with breast and gynecological cancers (Neufeld et al., 1993).

Several possible explanations exist as to why men who received the intervention were willing to assume greater ownership for their treatment decision. One explanation is that these individuals were enabled to get the information they needed to feel more involved in the decision making process. Strull, Lo, and Charles (1984) studied a group of hypertensive patients and concluded that better assessment of individual preferences for information, discussion, and decision making authority may result in enhanced patient participation in decision making. These conclusions were supported by Greenfield et al. (1985) who found that providing a group of ulcer disease patients with detailed information and encouraging them to participate in decision making resulted in them being more involved in the patient-physician interaction, and assuming a more active role in decision making. Robinson and Whitfield (1985) also reported that a group of surgery patients



gained a more accurate understanding of the suggested treatment when they were encouraged to ask the physician questions about the treatment recommendations.

A second explanation is that men in the intervention group were encouraged to assume a more consumerist approach in treatment decision making. Current support for medical consumerism is based on the assumption that most people desire some degree of control over treatment decisions, and that exercising such control will have a positive influence on their survival and quality of life (Degner & Aquino-Russell, 1988). However, there is no empirical evidence to support the assumption that such activism is effective for all people. Indeed, several investigators have suggested that an individualized approach may be both more appropriate and more effective (Degner & Beaton, 1987; Degner & Sloan, 1992; Forrow et al., 1988). Encouraging these men to take more responsibility in decision making than they prefer may be yet another approach to prescribing roles in health care.

Still another explanation is that wives and/or other family members provided the men with the extra support and confidence they needed to assume a more active role in treatment decision making. Men in the intervention group were encouraged to bring their wives and/or a family member to the treatment consultation for support. The literature has shown that spouses and/or significant others play an important role in providing support to the cancer patient (Jassak, 1992; Kesselring et al., 1986; Rose, 1990; Ward et al., 1991), and assistance in treatment decision making (Dermatis & Lesko, 1991). LaBrecque et al. (1991) reported that the presence of a family member in a patient-physician interaction resulted in the physician spending more time with the patient and providing more information. Empirical studies are needed to examine the influence wives and/or other immediate family members have on the extent to which these men participate in treatment decision making and the treatment choices that are made.

The majority (55%) of men in this study believed they had achieved their preferred role in treatment decision making. This finding is in contrast to Degner et al. (1996) who

reported that only 42% of women with breast cancer believed they had achieved their preferred role in treatment decision. Although this study used the same measure of decisional preferences as was used in this study, the methodology was different and some of the men in this present study had received the information intervention. Men in this study were asked to select the one statement that best described the role they assumed in treatment decision making six weeks following the initial interview, or after their treatment decision had been made. Women in the study conducted by Degner et al. (1996) were further from time of diagnosis than the men in this study, and the women were asked to identify their preferred then assumed role at the same interview retrospective of the stage of treatment protocol. It is unknown if time since diagnosis, difference in methodology, or gender caused the discrepancy.

Men in the control group (63.3%) were more likely to assume their preferred role in decision making than men assigned to the intervention group (50%). The intervention enabled 37% of these men to assume a more active role than they had preferred. It is also important to note that the small number of men in the intervention group (13.3%) who assumed less decisional control than they wanted, had all preferred an active role and assumed a collaborative role. These findings clearly demonstrate that the intervention did empower these men to be more active in treatment decision making.

## **5.2 Secondary Study Outcomes**

### **Anxiety and Depression**

Previous researchers (Fallowfield et al., 1990; Morris & Royle, 1988) have found that cancer patients who are given the opportunity to participate in treatment decision making have lower levels of anxiety and depression relative to patients who are not given a choice. The results showed men in the intervention group did indeed have significantly lower state levels of anxiety at six weeks however, levels of depression were similar for the two groups initially and at six weeks. Tattersall et al. (1994) also reported that providing

cancer patients with an audio tape and letter outlining the medical consultation did significantly decrease levels of anxiety but had no effect on levels of depression.

One explanation for this finding is that age had an effect on levels of anxiety and depression. Spielberger (1983) reported that although trait scores remained constant with age, there was a negative correlation between age and state scores for both men and women. This explanation was supported by Edlund and Sneed (1989) who conducted a study with newly diagnosed cancer patients to examine whether emotional responses to a cancer diagnosis differed among adult age groups. Their findings were able to demonstrate that while the youngest group (< 50 years of age) experienced the most distress in learning of their diagnosis, the oldest group (> 70 years of age) experienced significantly less psychological distress than all other age groups. Perhaps older individuals rely on their past life experiences to cope with a diagnosis of cancer. Although a diagnosis of prostate cancer may not be perceived as controllable, these men may perceive it as manageable, and the feelings of managing the problem may give rise to feelings of efficacy. Further research is required to examine the psychological impact of a cancer diagnosis on older patients with respect to how this affects their participation in medical decision making and quality of life following treatment.

A second explanation is that a type II error may have occurred given the limited sample size. It is believed that a larger sample was required to support the hypotheses that men who received the empowerment intervention would have significantly lower levels of anxiety and depression at six weeks, than those men who were in the control group. Another reason may be that the answers on the measurement scales were influenced by factors such as: disease-related symptoms (nocturia), previous medical conditions, health status of spouses, different stages of treatment protocol at six weeks, and severity of side-effects being experienced at six weeks. Still another reason may be that asking men to complete the STAI and CES-D forms at each measurement time proved to be too difficult a task for this particular group of men. Further methodological research is required to

develop a short measurement tool that would accurately capture the psychological status of older cancer populations. Specifications of such a scale would be as follows: able to be completed at home and returned by mail, one page in length with large print, and easy to read (grade 6 level). This would be a particularly challenging task given the varied educational levels and health status' of this older subgroup.

### **Personal Control in Patient-Physician Relationship**

The PCQ was used in this study to measure the men's levels of perceived control in the patient-physician relationship. Participatory control explains how patients can maintain control in a situation such as a medical treatment consultation for prostate cancer. It is based on the need for patients to relinquish some control and to recognize that physicians do have more knowledge and expertise to respond to the medical situation. If the interaction between the patient and physician facilitates the patient being involved in his/her care, a trust is developed. This trust in the physician allows the patient to give the physician permission to undertake his professional functions while the patient still maintains control over the situation (Grifone, 1989).

Although the majority of men reported having a high degree of personal control in the patient-physician relationship, men in the control group did have higher scores overall. It was hypothesized that men who received the intervention would have higher levels of personal control in the patient-physician relationship if they assumed more decisional control however, this was not proven. One explanation for this finding is that almost two-thirds of men in the control group were able to assume their preferred roles in decision making whereas, 37% of men who received the intervention were assuming more decisional control than originally preferred. Blanchard et al. (1988) also found that cancer patients who preferred a more active role in decision making were slightly less satisfied with their level of involvement in the interaction with their physician. Perhaps assuming more responsibility in decision making has a negative effect on the degree of control cancer patients experience in the patient-physician relationship.

Still another explanation for this finding is the PCQ lacks discriminant validity. Borgiel et al. (1989) reported that the PCQ is strongly correlated with a measure of satisfaction with one's physician ( $r = .54, p < .001$ ). If the PCQ is interpreted in this way, then men in the control group were more satisfied with their medical care than men who received the intervention. However, this finding is in contrast to Greenfield et al. (1985) who reported a group of ulcer disease patients had similar levels of satisfaction with medical care despite their assumed decisional role and amount of information received. Further studies are required with this and other cancer populations to reexamine the relationship between decisional control, satisfaction with medical care, and perceived personal control in the patient-physician relationship.

### **5.3 Patients' Evaluation of intervention**

The results showed that the audio tape was used mainly as a means to review information discussed at the initial medical treatment consultation and/or to share information with other family members. This result is consistent with the findings of previous investigators (Hogbin & Fallowfield, 1989; Johnson & Adelstein, 1991) who also found that providing cancer patients with an audio tape of the initial treatment consultation assisted in communication of illness-related information to family and assisted in recall of information discussed. Previous investigators have also found that providing an audio tape of the consultation decreased levels of anxiety in a group of patients with advanced carcinoma (North et al., 1992), and women prior to treatment for breast cancer (Hogbin & Fallowfield, 1989). Similarly, men in this present study who received the audio tape also had significantly lower levels of state anxiety six weeks after the treatment consultation. In contrast, Tattersall et al. (1994) and McHugh et al (1995) reported that providing cancer patients with an audio tape of the initial consultation did not have any significant effect on levels of psychological distress at four weeks.

The majority of cancer patients do not have the knowledge or skills to know what information they require to be involved in treatment decision making. Reviewing the

question list was found to be an efficient way of introducing men to the type of information they might need to discuss with their physician. Information on advance of disease, likelihood of cure, and types of treatment available were the three preferred categories of information identified prior to the initial medical treatment consultation. These information needs were the same as previously reported by Davison et al. (1995) with a group of men newly diagnosed prostate cancer (0 to 6 months), and replicate the findings of two recent studies of women newly diagnosed with breast cancer (Beaver et al., 1996; Degner et al., 1996). These findings provide further support to the hypothesis that information needs may be similar for newly diagnosed cancer patients. Further research needs to be conducted with these men to identify their information needs at various points of their illness trajectory. Time points should include: referral from general practitioner to urologist for diagnosis, pre-treatment consultation (0 to 3 weeks post-diagnosis), post-treatment (6 to 12 months), and follow-up care (greater than 12 months).

#### **5.4 Sources of Information**

It has been suggested that patients who prefer a more active role in treatment decision making may require different types and amounts of information than do patients who are concerned primarily with coping with the effects of the treatment(s) and disease (Degner & Sloan, 1992). Men in the intervention group were found to be more active in seeking information than men in the control group. Seventy per cent of men who received the intervention sought information from two or more sources whereas the majority (53%) of men in the control group did not seek information from any other source. Several other investigators (Cassileth, Zupkis et al., 1980; Hack et al., 1994; Sutherland et al., 1989) have also found that a positive relationship exists between decision making and identified information needs in cancer patients, with those preferring more active roles in decision making desiring more information. The results of this study suggest that information seeking may not be dependent on the preferred role, but it may depend on how much

assistance health care professional give these men to get the information they want, that determines whether they seek out and utilize other resources.

The three main sources of information used by men in this study were as follows:

1. talking to someone with prostate cancer, 2. general practitioner and/or other specialist, and 3. family and friends. Men in the intervention group were told that if they wanted, their physician would put them to contact with other prostate cancer patients currently being seen at the clinic. Men in the intervention group sought out other men with prostate cancer because it provided them with the opportunity to openly discuss the pros and cons of various treatment options, and to find out how other men coped with the side-effects. Men in the control group talked mainly to friends and neighbors that had prostate cancer, or in many cases prostate disease. Providing men with guidance on the types of information they may need, assisted them to seek out and ask more appropriate questions of men with prostate cancer.

The second most frequent source of information used was the mens' own general practitioners and/or other specialists. All men were told by their physicians to get a second opinion if they wished, and they were readily referred to radiologists and/or other urologists. Many of the men reported that they had made an appointment with their own general practitioner to discuss their treatment options and to get his/her opinion. They did this because many considered their practitioners as trusted friends. More men in the intervention group asked for second opinions. Perhaps this was an indication that they were adopting a more consumerist approach to their care. Receiving written and/or verbal information from family and friends was the third source used by both groups. Sons and daughters were very active in seeking out information and sending it home to their fathers. Some of these sources included the Internet, books on prostate cancer, commercially sold video tapes on prostate cancer, and video tapes of television talk shows that discussed prostate cancer. Wives reported that they phoned the Manitoba Cancer and Treatment Foundation, and Canadian Cancer Society for information.

## 5.5 Study Recommendations

### Research

There is a need to replicate this study with a larger sample of men, and other newly diagnosed cancer populations. Suggested changes to the methodology used in this study would include: 1. nurse researcher being present at patient-physician consultation to observe the interaction and know what treatment options were offered; 2. meeting with patients in the intervention group and their significant others after the consultation, to discuss the information they received at the consultation; 3. measuring information comprehension of all patients at four months; and 4. measurements of state anxiety, depression, and personal control in the patient-physician relationship at four months following initial consultation instead of six weeks. The latter change is necessary because many of the men had just started or had their treatment, and it is believed their responses may have been different at four or six months.

This chapter has identified several research questions that need to be addressed with this patient population. Further research is required to:

1. Determine if the extent of decisional control is dependent on the point of time in the illness trajectory at which role preference is measured;
2. Identify predictors of role preferences of men newly diagnosed with prostate cancer;
3. Examine the influence wives and/or other immediate family members have on the extent to which men with prostate cancer participate in treatment decision making and the treatment choices made;
4. Examine the psychological impact of a cancer diagnosis on older male cancer patients with respect to their participation in medical decision making and quality of life following treatment;
5. Develop a tool to measure the psychological status of older cancer populations;



6. Identify information needs of men with prostate cancer at the time of referral from their general practitioner to the urologist, pre-treatment consultation (0 to 3 weeks post-diagnosis), post-treatment (6 to 12 months), and follow-up (greater than 12 months);
7. Reexamine the relationship between decisional control, satisfaction with medical care, and perceived personal control in patient-physician interactions with this population, in addition to other cancer populations;
8. Determine if it is the preferred role, and/or health care professional assistance (for example, showing patients how to seek out the type of information they need) that has an effect on the amount of information desired; and

### **Practice**

The potential benefits of implementing this intervention in the clinical setting are striking. The results show that it is possible to empower men newly diagnosed with prostate cancer to assume a more active role in medical decision making by assisting them to get the information they feel they need. Simply providing these men with written information was not sufficient to increase their decisional control. It may also be necessary for physicians to offer written information to patients in unmarked envelopes to ensure their informational and confidentiality needs are being met. Assessment of information needs using a prepared question list was found to be an effective way for patients to identify the type and amount of information they wanted to have. The written information and audio tape of the medical treatment consultation also provided these men with a source of information they could review and share with their family. Provision of information using these three strategies would be easy and economical to implement in any busy community clinic setting.

Current health care is being judged in terms of cost effectiveness and outcomes obtained with available resources. The quality of health care delivered is not dependent on

the number of sophisticated procedures that are performed, but rather on how well it enhances the quality of life of the population it serves. The current emphasis in cancer care is on cure, and often the ability to function following treatment is overlooked. The sharp increase in prostate cancer, diverse screening practices of general practitioners, and variation in medical treatment, makes the evaluation and promotion of decisional control a pressing issue with this group of men. The Control Preferences Card Sort has proven to be a reliable method of accomplishing this goal. This measurement tool could also be incorporated into any clinical setting to assess the extent to which individuals want to be involved in deciding which cancer screening procedures they wish to have. It would also serve to introduce men to the different ways they can participate in deciding which treatment would enable them to maintain the quality of life they desire. The card sort would also prove useful in decision analysis, which is a quantitative research technique that can factor patients' values and preferences into decisions about the usefulness and cost-effectiveness of treatment strategies.

Clearly, a multi-disciplinary approach is required to provide the type of care these men require at the time of diagnosis. Although patient-centered medicine has been advocated by patients' rights groups since the early 1960's, only recently has it received more attention. Patient-centered medicine has been defined as "health care that is closely congruent with and responsive to patients' wants, needs, and preferences" (Laine & Davidoff, 1996, p. 152). In patient-centered cancer care, all health care professionals would work together to ensure patients are informed and supported in a way that allowed them to participate in health-related treatment decisions. Patient-centered cancer care also involves determining the type and amount of information, and decisional control each individual wants. Physicians and nurses in community clinic settings have a major role in the implementation and delivery of this type of care.

Recognition of psychological distress in newly diagnosed patients is a crucial aspect of cancer care, but oncologists often fail to detect general distress and to identify those

patients with psychological disorders severe enough to warrant intervention (Ford, Fallowfield, & Lewis, 1994). Clinical psychological evaluations should be considered as an integral part of cancer care however, this may not be realistic given the number of cancer patients being diagnosed annually and the number of available clinical psychologists. Nurses, as members of the multi-disciplinary team, must be aware of the need to refer those patients who require clinical assistance, to the appropriate professionals.

The optimal and most cost-effective mode of delivering this type of multi-disciplinary cancer care would be if all men were screened for prostate cancer and diagnosed at one site. This type of "one-stop shopping" would provide men access to a group of specialists who would provide them with information on available treatment options, and the pros and cons of each. A proposal for such a program is currently being considered in Manitoba. It is believed that if such a program is shown to be effective with this group of men, similar programs could be developed for other cancer populations using a similar protocol. Perhaps the biggest threat to the development of such a program would be that costs drive health care decisions, and it is unknown if such a program would be more cost-efficient than the current method of delivery.

### **5.6 Conclusions of Study**

This is the first experimental study that has provided a group of newly diagnosed prostate cancer patients with self-efficacy information, and measured assumed decisional role as the primary patient-outcome. Although older male cancer patients have previously been stereo-typed as passive recipients of care, the findings of this study have demonstrated that if they are informed and included in treatment decision making, they are able to assume a more active decisional role. Since the medical management of prostate cancer is so highly controversial, physicians need to incorporate patients' values of outcomes achieved or the treatments endured. This empowerment intervention is capable of assisting these men to take a more active role in deciding which treatment option is best for them. Further research is needed to measure the longitudinal effect of their treatment

choices on outcomes such as quality of life and functional status. Further study is also required to determine if a similar type of intervention could be used by general practitioners to assist these men decide if they want to be screened for prostate cancer. A carefully designed research program is required to deal with these important research issues, and ensure these men receive a high quality of health care.

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**APPENDIX A****CONCEPTUAL AND OPERATIONAL DEFINITIONS**

**Self-efficacy Information** was defined as information which would enable an individual acquire the knowledge he required to participate in making his medical treatment decision. Self-efficacy information was provided by the following collective intervention: encouragement of individuals to include spouses/significant others in information sharing sessions and treatment consultation with physician; encouragement to read a package of written information on prostate cancer, and showing patient where he could find information he wanted to have; provision of opportunity to have treatment consultation with physician audio taped; provision and discussion of a written list of questions individuals could ask their physician at the initial treatment consultation; and encouragement of individual to participate in the treatment decision making process to the extent he was comfortable.

**Empowering Experience** was defined as a transactional process whereby an individual believed his self-efficacy was enhanced through the provision of self-efficacy information, and he was able to assert personal control over factors affecting his health (Bandura, 1986; Conger & Kanungo, 1988; Gibson, 1991). These secondary study outcomes were indexed by the individual's subjective response to the State-Trait Inventory Scale, Centre for Epidemiologic Studies Scale, and Participatory Control Questionnaire.

**Empowerment in Treatment Decision Making** was defined as a transactional process whereby an individual believed he had sufficient information to participate or become more involved in deciding which medical treatment was best for him. This main behavioral outcome was indexed by comparing the individual's subjective response to the Control Preferences Scale prior to receiving the self-efficacy information, and then six weeks post treatment consultation.

**APPENDIX B**  
**EMPOWERMENT MODEL**

**Provision of Self-efficacy Information**  
**(To a Group of Men Newly Diagnosed With**  
**Prostate Cancer)**



**Empowering Experience**  
**↓ Anxiety and ↓ Depression**  
**(Measures- STAI and CES-D)**  
**↑ Personal Control in Patient-Physician Relationship**  
**(Measure- PCQ)**



**Empowerment in Treatment Decision Making**  
**↑ Participation in Treatment Decision Making**  
**(Measure- CPS)**



## APPENDIX C

### CONTROL PREFERENCES SCALE

The following choices were found on separate cards, and presented to participants as outlined in the methodology section.

1. I prefer to make the final selection about which treatment I will receive.
2. I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.
3. I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
4. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.
5. I prefer to leave all decisions regarding my treatment to my doctor.

Choice 1 or 2 indicates an active role.

Choice 3 indicates a collaborative role.

Choice 4 or 5 indicates a passive role.

**Preferred role in treatment decision making** refers to the involvement the patient wishes to have in treatment decisions made regarding the type(s) of medical treatment(s) he will receive.

**Assumed role in treatment decision making** refers to the role the patient was actually assuming in treatment decisions made regarding the type(s) of medical treatment(s) he received.

**Active role in treatment decision making** refers to the patient making the final decision on the treatment he received, after consideration of the doctor's opinion.

**Collaborative role in treatment decision making** refers to the patient and doctor sharing responsibility for deciding which treatment was best.

**Passive role in treatment decision making** refers to the patient preferring the doctor to make the final treatment decision after considering his option, or leaving all treatment decisions up to the doctor.

## APPENDIX D

## STATE-TRAIT ANXIETY INVENTORY

## Self-Evaluation Questionnaire (Form X)

Developed by C. D. Spielberger, R. L. Gorsuch, &amp; R. Lushene

IDN \_\_\_\_\_ Date \_\_\_\_\_

**Directions:** A number of statements which people have used to describe themselves are given below. Read each statement and then **circle the appropriate number to the right of the statement to indicate how you feel right now**, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

**Part One: State Anxiety** (example of scale on form)

	Not at All	Somewhat	Moderately	Very Much So
1. I feel calm.....	1	2	3	4
2. I feel secure.....				
3. I am tense.....				
4. I am regretful.....				
5. I feel at ease.....				
6. I feel upset.....				
7. I am presently worrying over possible misfortunes...				
8. I feel rested.....				
9. I feel anxious.....				
10. I feel comfortable.....				
11. I feel self-confident.....				
12. I feel nervous.....				
13. I am jittery.....				

- 14. I feel "high strung".....
- 15. I am relaxed.....
- 16. I feel content.....
- 17. I am worried.....
- 18. I feel over-excited and "rattled".....
- 19. I feel joyful.....
- 20. I feel pleasant.....

**Directions:** A number of statements which people have used to describe themselves are given below. Read each statement and circle the number to the right of the statement to indicate how you generally feel. There are no right or wrong answers. Do not spend too much time on any one statement but **give the answer which seems to describe how you generally feel.**

**Part Two: Trait Anxiety** (example of scale on form)

	<b>Almost Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Almost Always</b>
21. I feel pleasant.....	1	2	3	4
22. I tire quickly.....				
23. I feel like crying.....				
24. I wish I could be as happy as others seem to be..				
25. I am loosing out on things because I can't make up my mind soon enough.....				
26. I feel rested.....				
27. I am "calm, cool, and collected".....				
28. I feel that difficulties are piling up so that I cannot overcome them.....				
29. I worry too much over something that really doesn't				

- matter.....
30. I am happy.....
31. I am inclined to take things hard.....
32. I lack self-confidence.....
33. I feel secure.....
34. I try to avoid facing a crisis or difficulty.....
35. I feel blue.....
36. I am content.....
37. Some unimportant thought runs through my mind  
and bothers me.....
38. I take disappointments so keenly that I can't put them  
out of my mind.....
39. I am a steady person.....
40. I get in a state of tension or turmoil as I think over my  
recent concerns and interests.....

## APPENDIX E

## CENTRE FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE

## CES-D Scale

IDN \_\_\_\_\_ Date \_\_\_\_\_

**Instructions for questions:** Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

1. Rarely or none of the time (less than 1 day)
2. Some or a little of the time (1-2 days)
3. Occasionally or a moderate amount of time (3-4 days)
4. Most or all of the time (5-7 days)

---

	Rarely or None (less than 1 day)	Some or Little (1-2 days)	Occasionally or Moderate (3-4 days)	Most or All (5-7 days)
During the past week:				

---

1. I was bothered by things  
that usually don't bother me.      1                      2                      3                      4
2. I did not feel like eating;  
my appetite was poor.
3. I felt that I could not shake  
off the blues even with help  
from my family or friends.
4. I felt that I was just as  
good as other people.
5. I had trouble keeping my  
mind on what I was doing.
6. I felt depressed.

7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people dislike me.
20. I could not get "going".

## APPENDIX F

## PARTICIPATORY CONTROL QUESTIONNAIRE

\*\*Revised for this study

IDN \_\_\_\_\_ Date \_\_\_\_\_

Please circle the number that best describes your answer.

1= Strongly Disagree-----&gt; 7= Strongly Agree

1. Your doctor understood the concerns you had about your illness.

1    2    3    4    5    6    7

2. Your doctor listened carefully when you were describing your treatment concerns.

1    2    3    4    5    6    7

3. You were able to work with your doctor to arrive at a treatment decision.

1    2    3    4    5    6    7

4. During the meetings with your doctor, you felt free to ask questions about your illness.

1    2    3    4    5    6    7

5. You were satisfied that your doctor had explained the possible treatment choices with you before you made a treatment decision.

1    2    3    4    5    6    7

6. The doctor discussed the tests and medical procedures with you in a way that gave you a sense of control.

1    2    3    4    5    6    7

7. The doctor encouraged you to become involved in your health care.

1    2    3    4    5    6    7

8. You and your doctor openly discussed available options regarding your treatment.

1    2    3    4    5    6    7

9. The doctor acted as if you had an important and significant part to play in the treatment of your illness.

1    2    3    4    5    6    7

10. The doctor gave you the opportunity to discuss symptoms you were experiencing as a result of your treatment, and gave you information on how to cope with these symptoms.

1    2    3    4    5    6    7

11. The doctor acted as if you were to be passive and just do what you were told by him.

1    2    3    4    5    6    7

12. The doctor made you feel you had a working partnership with him in understanding the best possible care of your illness.

1    2    3    4    5    6    7



13. The doctor was as receptive to your concerns as you were receptive to his opinions about your illness.

1      2      3      4      5      6      7

**APPENDIX G**  
**QUESTIONNAIRE**

**Part One (To be completed by investigator at first interview)**

Date: \_\_\_\_\_

1. IDN: \_\_\_\_\_

2. Physician (circle): (1) M (2) L

3. Group (circle): (1) E (2) C

4. Preferred Role in Treatment Decision Making: At this time, what role do you wish to play in making a treatment decision? Please select the card that best describes the role you prefer. (a) preferred (order) \_\_\_\_\_

**Complete STAI then CES-D Scales**

5. Family/Significant Others present at interview:

(1) Spouse (2) Common-law (3) Son or Daughter (4) Other relative (5) Friend (6) Alone

6. Age at last birthday \_\_\_\_\_

7. Education (years completed): \_\_\_\_\_

8. Marital status: (1) Married (2) Common Law/Cohabiting (3) Widowed (4) Divorced  
(5) Separated (6) Never Married

9. Employment status: (1) Full-time (2) Part-time (3) Retired

10. Place of residence: (1) Urban (2) Rural

11. Time before consultation (in days): \_\_\_\_\_

**Part Two: (To be completed by investigator at second interview)**

Date \_\_\_\_\_

1. Length of time since first interview (weeks): \_\_\_\_\_
2. What role do you feel you played in making your treatment decision? Please select the statement that best describes the role you assumed. \_\_\_\_\_ (from completed mail-out form)
3. Did you have a pelvic lymph node dissection, and if so what were the results?  
(1) Yes/Positive (2) Yes/Negative (3) No (4) Unknown
4. Treatment chosen:  
(1) Orchiectomy (2) Radical Prostatectomy (3) Radiation (4) Hormone (5) Watchful Waiting (6) Alternative (7) Hormone and Orchiectomy (8) Hormone and Radiation
5. Treatment received:  
(1) Orchiectomy (2) Radical Prostatectomy (3) Radiation (4) Hormone (5) Watchful Waiting (6) Alternative (7) Hormone and Orchiectomy (8) Hormone and Radiation
6. Did you read the information in the package given to you? (1) Yes (2) No  
If no, why? \_\_\_\_\_  
\_\_\_\_\_
7. What other sources of information did you use to help you make a treatment decision?  
(1) Friend/relative (2) Talking to someone who has prostate cancer (3) Television/radio  
(4) Newspaper (5) Medical Journal (6) Other Doctors (7) None
8. Have you met and discussed any of the information you received with other men who were in this study? (1) Yes (2) No

**For Men in Intervention Group:**

9. Please rank in order of importance which method you found most helpful to get the information you wanted to make a treatment decision (1 being the highest, and 3 being the lowest).

- (1) Question List \_\_\_\_\_
- (2) Tape Recording \_\_\_\_\_
- (3) Written Information Package \_\_\_\_\_

10. (i) Did you have your treatment consultation with the physician audio taped?

(1) Yes (2) No

(ii) If no, why did you decide not to have your consultation audio taped?

- (1) Did not feel was necessary
- (2) Felt uncomfortable asking doctor to get it audio taped
- (3) Forgot
- (4) Physician said not necessary

**If answered yes to 10 (i), continue.**

(iii) Approximately how many times did you or a family member/friend listen to the tape?

\_\_\_\_\_

(iv) How did you use the tape?

- (1) Listened to at home to review what had been said
- (2) To share information with family
- (3) To help make a treatment decision
- (4) Not used
- (5) #1, #2, and #3
- (6) #1 & #2
- (7) #1 & #3
- (8) #2 & #3

11. Did you use the question list to help you decide what questions to ask your doctor?

(1) Yes (2) No

If no, why? \_\_\_\_\_

\_\_\_\_\_

12. Treatment started at time of second interview? (1) Yes (2) No

**APPENDIX H**  
**CONSENT FORM**

I understand I am being asked to participate in this study that is looking at different ways of giving information to men newly diagnosed with prostate cancer to assist them in making treatment decisions. This study has been approved by the Faculty of Nursing Ethics Committee at the University of Manitoba and the Winnipeg Clinic Ethics/Access Committee.

I understand this study is being conducted by Joyce Davison, who is a registered nurse and a doctoral student in the Faculty of Graduate Studies at the University of Manitoba. I am aware that my name was given to her by my physician.

As a participant I know I will be assigned by chance to one of two groups each receiving information in different ways. I am being asked to meet with Joyce today which will take about 30 minutes to one hour of my time. I will be asked to sort some cards to find out how I wish to participate in treatment decision making and I will be asked to complete two forms to measure the emotions I am feeling. I also will be asked some questions about myself such as age, education, and marital status.

**At five weeks:** Joyce will phone me to ask me which treatment I have selected and how I felt about the information I received. She also will mail four forms to me in a self-addressed envelope. Three of these forms are the same as the ones that will be used at this interview. The fourth is a short form that will show how I felt about the information I received. The forms will take about 20 minutes of my time to complete. I understand I am being asked to complete these forms and mail them back to her within a few days.

I understand my participation in this study is voluntary, and if I choose not to participate it will in no way affect my medical or nursing care. If I decide to stop part way through either of the interviews, I will be free to do so.

I also understand my participation in this study will result in no direct benefits to me, but it may provide me with an opportunity to clarify some of the feelings and concerns

I might have about assuming different roles in treatment decision making and the information I receive. I also understand the only known risk of participating in this study is it may make me think about my illness and treatment, and that may be uncomfortable for me.

I have been assured my involvement in this study will remain strictly confidential, and the information I give will be kept in a locked filing cabinet. I understand only Joyce will know my identity, and the information I provide will be identified by a code number. The only people who will have access to the coded information are Dr. L. Degner (Advisor, University of Manitoba), and a designated statistician. I understand the information I give will not be destroyed for a minimum of ten years. I also understand the written report and any publication coming out of this study will describe group information and will not identify me in any way.

I have received an explanation of what the study involves, and had any questions I might have answered to my satisfaction. I am aware I can contact Joyce at (home), or Dr. Lesley Degner (study supervisor) at 235-3482 (office) St. Boniface Research Centre if I have any further questions about this study.

My signature below indicates I am informed, and I agree to participate as a volunteer respondent in the study as described in this consent form. I have been offered a copy of this consent form.

Date \_\_\_\_\_ Participant's Signature \_\_\_\_\_

Witness \_\_\_\_\_

I would like a summary of the study results mailed to me: 1. Yes 2. No

Mailing Address: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

## APPENDIX I

### WRITTEN INFORMATION PACKAGE

These various publications were approved by the urologists who practice at the clinic where the study was conducted. The written information package contained the following brochures and articles.

1. The Canadian Prostate Health Council:

- Prostate Disease: Important Information for Men (#6916)

- Prostate Cancer: A Patient's Guide (#6888)

- Prostate Specific Antigen: A Blood Test for the Early Detection of Prostate Cancer (#6112)

2. Zenica Pharma. (1992). Prostate cancer: What it is and how it is treated.

3. Bazinet, M., Chesley, A. E., Trachtenberg, J., Berger, E. R., & Shoham, S. (1990).

Cancer of the prostate: A desk reference for primary physicians. Key

Pharmaceuticals: Division of Schering Canada Inc.



## APPENDIX J

### LIST OF QUESTIONS

**This is a list of questions that may help you and your family members receive the information you need to assist you in deciding which treatment is best for you. You may find it helpful to use this list when you see your doctor to discuss treatment options.**

1. Considering the type and extent of cancer I have, as well as my age, lifestyle, and other factors, what treatment options are available?
2. Which treatment option(s) do you recommend?
3. What is the goal of treatment? (example: cure, shrink tumor so it can be treated by other means, extend life, reduce pain)
4. How many patients have you treated with this type of cancer in the last twelve months?
5. What types of doctors do you think will need to be involved in treating me?
6. Would it be helpful if I talked with someone who has had the type of treatment that I am considering?

**For each treatment option:**

1. Please explain what the treatment is.
2. What are the short-term and long-term risks?
3. What are the side effects? (example: temporary, long-term, delayed- those which may not occur until perhaps later)
4. What can I do to prevent or lessen the side effects?
5. How will the treatment option affect my other medical problems?
6. What side effects should I report to you during or after treatment?
7. How will the treatment affect my ability to work or perform other activities that are necessary or important to me?
8. Will the treatment hurt or be uncomfortable?
9. What can be done to prevent or lessen the discomfort?

10. How long will this treatment take?
11. How and when will you be able to determine if this treatment accomplishes its intended goal?
12. Will the treatment affect me emotionally or sexually?
13. What will my quality of life be like during and after treatment?
14. After the treatment ends, what medical care will I receive to determine whether the cancer recurs or spreads in the future?
15. Should I get a second opinion from another doctor?
16. How can I make plans to get help at home during my recovery, or help with care for my spouse?

**Additional Questions:**

**APPENDIX K**  
**STUDIES CONDUCTED TO DETERMINE CANCER PATIENTS'**  
**PREFERRED ROLES**

<b>Study</b>	<b>Suther- land et al. (1989)</b>	<b>Degner &amp; Sloan (1992)</b>	<b>Hack et al. (1994)</b>	<b>Davison et al. (1995)</b>	<b>Beaver et al. (1996)</b>	<b>Degner et al. (1996)</b>
<b>Type of Patient</b>	Various Cancers (N = 52)	Various Cancers (n = 428)	Breast Cancer (N = 35)	Prostate Cancer (N = 57)	Breast Cancer (n = 150)	Breast Cancer (n = 278)
<b>Gender</b>	67.3% Females 32.7% Males (10% prostate)	52% Males (31 % GU cancer); 48% Females (30.2% breast cancer)	Females	Males	Benign Breast (n = 200) Females	(Newly Diagnosed Group) Females

<b>Time Since Diagnosis (weeks)</b>	Not stated (Tx phase)	Mean 10.7	8 to 24 Weeks	Mean 9.42 <u>Subgroup</u> n = 22 1 Week	Mean 2.5 <u>Benign</u> (same day diagnosis)	< 24 Weeks
<b>Age (mean years)</b>	48.5 SD = 13.8	59 SD = 13.9	Not Stated	71 SD = 6.78 <u>Subgroup</u> n = 22 70.5 SD = 7.31	54.8 SD = 10.7 for Cancer 39.2 SD = 11.3 for <u>Benign</u>	56.05 SD = 12.4 < 50 (36%) ≤ 69 years 85.3% > 69 years 14.7%
<b>Education</b>	Not Stated	33% < Grade 10	Not Stated	55% < HS <u>Subgroup</u> n = 22 58% < HS	64% < HS for Cancer 44% < HS for <u>Benign</u>	40.6% < HS 59.4% ≥ HS

<b>Pref. Role:</b> <b>1. Active</b>	10%	Total 12%	23%	Total 19%	Cancer 20%	Total 22%
		<u>Subgroups</u> < 50 yrs 21% > 50 yrs 10%		<u>Subgroup</u> n = 22 14 %	<u>Benign</u> 23.5%	<u>Subgroups</u> < 50 yrs 31% 50-69 yrs 20% 70+ yrs 38%
<b>2. Collab- orative</b>	27%	Total 29%	57%	Total 23%	Cancer 28%	Total 44%
		<u>Subgroups</u> < 50 years 37% > 50 years 27%		<u>Subgroup</u> n = 22 36%	<u>Benign</u> 45.5%	<u>Subgroups</u> < 50 yrs 48% 50-69 yrs 44% 70+ yrs 38%

<b>3. Passive</b>	63%	Total	20%	Total	Cancer	Total
		59%		58%	58%	34%
		<u>Subgroups</u>		<u>Subgroup</u>	<u>Benign</u>	<u>Subgroups</u>
		< 50 years		n = 22	31%	<50 yrs
	42%	50%		21%		
	> 50 years				50-69 yrs	
	64%				36%	
					70+ yrs	
					48%	

Note: HS = High School; Pref. Role = Preferred Role.