

Relationship between preferences for control
over treatment decision making and
preferences for information among breast cancer patients

by

Thomas F. L. Hack

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presented to the University of Manitoba
in partial fulfillment of the
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Master of Arts
in
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A thesis submitted to the Faculty of Graduate Studies of
the University of Manitoba in partial fulfillment of the requirements
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MASTER OF ARTS

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FOREWORD

Patient:It's very hard. It's very depressing. It's very...I cry, and I try not to believe I have it - that I have cancer and I...I just think "Well it can't be. It's not true. I'm well." And then I have my cry and..."No, it is true." I...who knows...today, tomorrow, the day after.

Clinician: So it's hard to-

Patient: (patient began to cry at this point)...to watch the sun rise...to watch the sun set....

Clinician: Really try to make the most of each day.

Patient: Yes I am.

Clinician: And try to appreciate-

Patient: Yah, I do. I love my flowers.

Clinician: It seems that you find nature quite calming for you.

Patient: Yes, you see the birds. You see the...you never notice these things when you're well. Really...I never...I never...the sun came up...the sun set...but now all these things...watch the sun rise...oh, it's so beautiful...you watch the sun set...you see the flowers...you see the things grow...you see the birds...watch the birds....I watch the...like everything...nature...the squirrels in the trees and...just sit there and watch them. And just try and...

Clinician: It's wonderful.

Patient: Yes...it's just beautiful.

Clinician: I guess sometimes it takes a life-threatening disease to be able to stop and-

Patient: Yes-

Clinician: take a look and appreciate the beauty around us-

Patient: Yes, that's true...very true.

ABSTRACT

This study examined the relationship between cancer patients' preferences for involvement in making treatment decisions and their preferences for information about diagnosis, treatment, treatment side effects, and prognosis. These two variables have been shown to be related to Taylor's (1986) construct of psychological control. Thirty-five stage I and II breast cancer patients, recruited from the medical oncology and radiation oncology clinics at St. Boniface General Hospital and the Manitoba Cancer Treatment and Research Foundation, participated. Preferences about treatment decision making and information were assessed using card sort procedures. Following the administration of the card sort procedures, a semi-structured interview was conducted to provide patients with an opportunity to elaborate on their decision making and information preferences. Wilcoxon's rank sum tests, Kruskal-Wallis ANOVA tests, chi square analyses, and a content analysis of patient transcripts indicated that patients who wanted to play an active role in treatment decision making also desired detailed information. The relationship between role preference and information preference was not as clear for passive patients. Five of seven hypotheses were statistically significant. Patient preference for involvement in treatment decision making was significantly related to patient information preferences

with respect to a) degree of diagnostic detail desired, b) preference for receipt of a taped versus written copy of the diagnosis, c) preference for the type of verbal label attached to the illness by the physician, d) preference for number of treatment alternatives proposed, and e) degree of detail desired regarding treatment procedures. Patients felt it was not necessarily better to play an active or passive role, and that not all patients should be given the same kind and amount of information regarding their illness and treatment. The results are discussed in terms of a) the utility of Taylor's construct of psychological control and theory of cognitive adaptation, b) limitations of the study, and c) the recommendation of an approach to the provision of information to breast cancer patients by oncologists.

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INTRODUCTION

Cancer is a life-threatening disease that takes hundreds of thousands of lives each year. Advances in medical technology have produced several radiation and drug therapies that impede the spread and growth of cancer cells in the body. Although beneficial in prolonging life, these treatments are not effective in curing all types of cancer and a substantial number of cancer patients must therefore come to terms with impending death.

Psychological distress has been hypothesized to compromise host resistance, and there is a growing body of literature that suggests that psychological variables can contribute to the progression and containment of certain tumors (e.g., Levy, 1984). In a review article, Borysenko (1982) concluded that four discernible psychological variables are related to a poor cancer prognosis. These include a) difficulty in regulating the expression of anger, b) helplessness, c) depression, and d) unresolved anxiety.

The overview of research studies suggests that psychological functioning and host resistance to disease may be functionally related. However, the relationship between psychological functioning, stress, immunocompetency, hope, and health is complex and poorly

understood. The purpose of the proposed thesis research was not to develop a detailed account of this multifaceted relationship. However, if one is to argue that there is a relationship between physical health status and psychosocial functioning, an understanding of any mediating variable(s) in this relationship is fundamental.

It should be emphasized that the relationship between psychological functioning and disease progression is not unidirectional. While psychological functioning may contribute to an individual's health status, Psychological functioning can, nevertheless, be influenced by a cancer patient's physical status. Even though psychological functioning can impact upon one's physical health, it is undoubtedly true that medical interventions account for an even greater proportion of the variance in disease containment. For patients who are striving to adjust to their cancer illness and possible death, an understanding of the impact of both medical and psychological interventions on patients' adaptation to their illness is worthy of study. Researchers in psychosocial oncology should take into consideration the interaction between medical and psychological interventions as they influence both physical health and psychosocial status.

Psychological control

There is evidence to support the notion that a loss of psychological control can contribute to anxiety, depression, helplessness, and suppressed immunity. Psychological control may be defined as the belief that one can predict what will occur in their surrounding environment and that one can modify that environment to produce change that is fundamental to successful adaptation (Taylor, 1986). This definition is reminiscent of Bandura's (1977) concept of self-efficacy. According to Bandura, efficacy is the belief that one can successfully execute the behaviors necessary to produce desirable outcomes or to cope with undesirable ones. An understanding of the concept of psychological control may be critical to understanding the impact of the health care environment on a cancer patient's physical health and psychosocial status.

Psychological control, which is of primary importance under stressful or life-threatening circumstances, has been divided into four types of control by Taylor (1986): Cognitive, behavior, decision, and information. Cognitive control is defined as thinking about an aversive situation to reduce the negative implications of that event. For example, cancer patients who use visual imaging of white

knights to impede the spread of cancerous cells are exhibiting cognitive control. Behavior control is defined as the execution of an action that can serve to reduce the unpleasantness of a situation. By providing cancer patients receiving chemotherapy with medication they can ingest if their side effects (nausea, vomiting) become severe, the patient is provided with behavioral - or instrumental - control. An individual has decision control to the extent that he or she can choose from alternative courses of action. Allowing cancer patients to participate in the formulation of treatment decisions provides them with decision control. Information control is achieved when an individual obtains knowledge of an aversive event. By providing detail about possible side effects associated with chemotherapy, a cancer patient is given information control.

Within the health care system, there are many situations in which the different forms of psychological control may operate simultaneously. For example, by providing a cancer patient with a list of alternative cancer treatments from which to choose, the patient has increased information control and decision control. Taylor (1986) believed that beneficial effects of psychological control had their origin in the cognitive and behavioral changes that an

individual could make once psychological control is developed.

Taylor (1983) developed a cognitive-based theory of adjustment to threatening events. Much of the evidence used in developing the theory was gathered from observations of breast cancer patients. Briefly, the theory maintains that psychological adjustment to a life-threatening situation is based upon a) developing meaning out of the situation, b) maintaining a sense of mastery or control over the situation, and c) maintaining self-esteem through self-enhancing evaluations. The second of the three components of psychological adjustment, i.e., the mastery component, closely resembles Taylor's (1986) construct of psychological control, while the remaining components may be considered as cognitive elements that foster adaptive psychosocial functioning.

Many cancer patients maintain mastery over their illness by believing they can control the spread of cancer in their body, or that their physician or treatment will control the spread of cancer. Cognitive techniques such as meditation, imaging, self-hypnosis, are used to maintain mastery over one's cancer. These cognitive techniques are examples of Taylor's concept of cognitive control. Cancer patients may also gain a sense of mastery by acquiring information about

their illness and its treatment. Thus, information control is an aspect of mastery. Finally, by playing an active role in making treatment decisions, a sense of mastery can be developed. This corresponds to Taylor's concepts of decision and behavior control.

The medical information that is provided to cancer patients by health care professionals impacts upon patients' psychological control over their health. Although medical information and other kinds of information may be provided to the patient by members of the patient's social support network, the focus of the present research is information communicated to cancer patients by health care professionals, particularly physicians. While nurses, social workers, psychologists, and pastoral care workers may provide patients with important information, most patients feel, for example, that physicians help them adjust to their illness by providing them with illness and treatment information while nurses assist them by providing emotional support rather than information (Frank-Stromborg & Wright, 1984). To the extent that a cancer patient perceives that their information needs and preferences have been satisfied, psychological control over health may increase. Psychological control over health may decrease if desires for information are not satisfied.

Information needs and preferences of cancer patients

Several empirical studies have been conducted to a) determine the information needs of cancer patients, and b) measure cancer patients' satisfaction with information received from health care professionals as well as the quality of care provided to them. These articles will be reviewed with attention given to four critical components of the health care experiences of cancer patients: a) receiving the cancer diagnosis, b) formulating the treatment regimen, c) managing treatment side effects, and d) receiving the prognosis.

Many studies have been conducted to explore the best method by which physicians should disclose a diagnosis of cancer and provide illness information. Although most studies report that a majority of cancer patients want to be informed of their diagnosis (Gautam & Nijhawan, 1987; Henriques, Stadil, & Baden, 1980; Kelly & Friesen, 1950), there are studies that indicate a substantial number of patients wish to remain uninformed of their diagnosis (Jones, 1981; McIntosh, 1976).

There are some patients for whom receiving the cancer diagnosis provides information control, in particular, and psychological control in general insofar as they feel more able to adapt to living with cancer knowing they indeed

have cancer. Gautam and Nijhawan (1987), in their assessment of 100 radiation therapy outpatients from India, found that 71% of the 48 patients who were aware of their cancer diagnosis were satisfied about having received their diagnosis and stated that the diagnosis served to increase a) treatment compliance, b) ability to accept reality, c) capacity to plan for the care of dependants, and d) incentive to satisfy unfulfilled wishes prior to death. Ten percent of the 48 patients who knew their diagnosis felt they should not have been told, while 19% were indecisive.

For other cancer patients, psychological control - especially cognitive control - may be fostered by remaining unaware of their diagnosis (Jones, 1981). It seems that by remaining uncertain about their diagnosis, these patients can sustain feelings of hope for a positive health outcome (McIntosh, 1976). It may not be adaptive for these patients to come to terms with knowing they have cancer, particularly if it is a virulent type with limited probability of survival. For this reason, patients who are unaware of their diagnosis may not want to receive additional information about their illness and may report that they are satisfied with information they have received (Chesser & Anderson, 1975).

The question of whether or not cancer patients want to be informed of their diagnosis has typically been addressed with a retrospective research design. In these studies, the reactions of patients to whom the diagnosis had previously been discussed are studied. One of the more glaring weaknesses of this retrospective approach is that patients' self-reported desire for diagnostic information may be influenced by prior knowledge of their diagnosis. For example, a cancer patient may, prior to having their diagnosis disclosed to them, report that they do not want to receive their diagnosis so that they can maintain hope in a positive health outcome. Given that this patient is subsequently informed of their diagnosis, feelings of hope in a health outcome that arise out of not knowing the diagnosis are no longer possible. To regain psychological control and feelings of hope, this individual may strive to reconstruct their memories of past health care experiences so that these experiences can be positively regarded. In doing so, the patient may report that they wanted to be told their diagnosis.

McIntosh (1976) examined the illness information preferences of 74 patients with undisclosed malignant cancer. Upon admission, 64% of patients suspected they had cancer, 24% had discerned their diagnosis, and 12% did not

suspect they had cancer. Only 32% of patients who suspected they had cancer desired confirmation of their diagnosis. Eighteen percent of those who knew their diagnosis wanted information about their prognosis. The corresponding percentage for those who suspected they had cancer was 13%. Not a single patient wanted to know whether they would live or die or when they would probably die. They preferred to receive a progress report that explained the extent of disease progression. These findings may not be generalizable to cancer patients within the Canadian health care system because the subjects were patients from Scotland and the health care experiences of patients from Canada and Scotland may be different.

Patients were also given the option of receiving the details of their diagnosis in a study by Jones (1981). Forty-nine percent of 183 patients with inoperable bronchial carcinoma wanted to receive their diagnosis while 51% did not want to be told. Those who asked to receive their diagnosis were later asked if they regretted having asked. Of these 49%, only one regretted having asked for their diagnosis. Of the 51% who did not want to know their diagnosis, 42 later behaved in a manner that lead the researchers to believe that the patients were aware they had cancer. Perhaps the psychological control of these

latter patients would have been threatened if the researchers had decided to disclose the cancer diagnosis to them.

Physician preferences for disclosure of information

While there appear to be subgroups of cancer patients that vary in their preferences for diagnostic information, physicians have also been found to differ in their preferences for disclosing information to patients. The percentage of physicians that inform patients of their cancer diagnosis ranges from less than 40% (Holland, Geary, Marchini, & Tross, 1987) to 98% (Novack, Plumer, Smith, Ochitill, Morrow, & Bennett, 1979). There appears to be a trend toward increased disclosure of the cancer diagnosis. In a study conducted almost three decades ago, Oken (1961) found that almost 90% of physicians generally withheld a cancer diagnosis from their patients.

Criteria often used to decide whether or not to disclose the diagnosis include several patient and physician variables. Patient variables include a) illness severity/stage of illness, b) educational level, c) age, d) wishes of family members, e) emotional status, and f) requests for diagnostic information (Hardy, Green, Jordan, & Hardy, 1980; Hardy & Hardy, 1979; Holland et al., 1987; Novack et al., 1979; Oken, 1961). Physician variables

include a) years of medical experience, b) age, c) quality of medical training, and d) area of medical specialty (Greenwald & Nevitt, 1982; Hardy et al., 1980; Hardy & Hardy, 1979).

Many studies that have addressed disclosure of the cancer diagnosis have failed to acknowledge the cultural specificity of communication between patients and their physicians. Holland et al. (1987) sampled 1-7 oncologists from each of 20 countries and found that the percentages of oncologists that informed the patient of the cancer diagnosis ranged from over 80% in Sweden and New Zealand to less than 40% in Africa, France, and Spain. Ninety percent of respondents believed that a move towards more open disclosure was occurring in their country. The reasons for increasing disclosure included a) increased demands for information by patients and b) more open communication between patients and physicians.

In their examination of physicians' attitudes towards disclosing illness information, Greenwald and Nevitt (1982) found that 81% of physicians believed that patients should be informed of their diagnosis and 41% agreed that patients prefer not to be informed of their health status. Twenty-six percent of physicians experienced difficulty when talking to cancer patients, which suggests that there may

be a subgroup of physicians who refer cancer patients to other physicians, not because they lack technical expertise, but because they are uncomfortable when communicating with these patients.

Although most physicians agree that patients should be informed of their illness, physicians differ in the manner by which they disclose the diagnosis of cancer to patients. Some physicians avoid using the word "cancer" when conveying the diagnosis because of the negative images and feelings they believe some patients imply from the word. These physicians, instead, use words such as "tumor", "mass", "malignancy", or "growth". The three most commonly used words to describe the diagnosis are "tumor", "malignancy", and "cancer" (Hardy et al., 1980; Hardy & Hardy, 1979). There are physicians who will use the word "cancer" when initially disclosing the diagnosis but, when providing prognostic information, avoid using this term. Ray, Fisher, and Wisniewski (1986) discovered that there are three main approaches to the provision of information that are adopted by surgeons. These include a) discussing cancer in an optimistic manner, b) discussing the illness but avoiding the words "cancer" and "malignancy", and c) openly discussing cancer. Physicians from different countries may have a bias for particular words used to

convey the cancer diagnosis. Newall, Gadd, and Priestman (1987) found that physicians used the word "cancer" to relay the diagnosis to 98% of patients while physicians from England used euphemisms such as "growth" and "tumor" for over one-third of patients.

McIntosh (1976) found that patients with undisclosed malignant cancer who wanted to know their cancer diagnosis interpreted their physician's euphemisms for cancer as evidence that they indeed had cancer. Those patients who did not want to know their diagnosis interpreted their physician's euphemisms as evidence that they did not have cancer. In the study conducted by Newall et al. (1987) in which the use of euphemisms to describe the diagnosis was more prevalent among English physicians, American patients desired additional information about their illness while English patients were content with the amount of information received. One may hypothesize that the English patients did not want to receive additional information because they, like the Scottish patients in McIntosh's (1976) study, were interpreting their physician's euphemisms as evidence that they did not have cancer. By avoiding illness information, these patients may have been able to avoid discovering they had "cancer", thereby enhancing psychological control and maintaining hope for a

positive health outcome. Given that the American patients knew that they had "cancer", psychological control may have been enhanced by learning as much about their illness as possible.

Given that there may be differences between any particular patient and their physician with respect to the extent to which the use of euphemisms for the word "cancer" are preferred in diagnostic- or prognostic-related discussions, it would be useful to determine, prior to disclosing the cancer diagnosis, which patients would prefer to be told they have "cancer" and which patients would prefer that a euphemism be expressed. By doing so, patient preferences for information could be more easily satisfied by a physician who respects the patient's preferences. The implication for the patients' psychosocial functioning, of having this information need satisfied by physicians, is worthy of study.

Patient-physician communication and patient satisfaction

Few studies have attempted to evaluate, according to some predetermined criteria, the degree of completeness of communication between health care professionals and cancer patients. A collaborative research team known as GIVIO (1986) examined the content of physicians' written reports and rated the thoroughness of diagnostic information

provided to breast cancer patients. The written reports indicated that diagnostic information was thorough for 48% of patients, while physicians acknowledged that communication with patients was thorough in 62% of cases. Patients who were younger, well educated, and who were in the early stages of disease progression were more likely to receive complete information. The primary reason mentioned for failing to provide complete information was the supposed psychological problems of the patient.

There are many studies whose findings indicate that cancer patients have unanswered questions regarding their illness and its treatment (Derdiarian, 1984; Messerli, Garamendi, & Romano, 1980; Mitchell & Glicksman, 1977; Morris, Greer, & White, 1977). Lloyd, Parker, Ludlam, and McGuire (1984) found that 35% of 40 cancer patients were dissatisfied with illness and/or treatment information provided to them by physicians. Of these dissatisfied patients, those who wanted to hear their diagnosis felt that it had not been explained to them in sufficient detail. Similarly, Henriques et al. (1980) interviewed 58 cancer patients after they had been informed postoperatively about their cancer diagnosis and found that approximately 20% of patients were dissatisfied with information they received about their illness and with the

approach of the physician. Newall et al. (1987), however, found that 93% of patients reported being well-informed about their treatment. In contrast, in a study of the information needs of 60 cancer patients, Derdiarian (1984) found that additional information about the diagnosis, treatment, and prognosis was desired by 80%, 90%, and 90% of patients, respectively.

After having observed 118 instances of physicians disclosing the results of patient's biopsies, Taylor (1988) reported that in only 13% of cases did physicians inform the patient of their uncertainty about the best way to treat the disease. It seems likely that physician reluctance to express uncertainty stems from a belief that patients will use such information to make attributions of physician incompetence. In a review of the factors that influence the communication of information between cancer patients and physicians, McIntosh (1974) reported that although many physicians believe that withholding information from patients will prevent them from becoming alarmed, worried, or anxious, studies have shown that a majority of patients have a preference for more information than they currently receive from medical personnel.

Variables that influence the amount and type of information that physician's provide to their patients

include a) the physician's personal philosophy, b) the philosophy and demands of the clinical setting, c) the patient's age, personality, and social class, d) the physician's perception of what the patient wants and needs to know, and e) the patient's desire for, and ability to understand, information (McIntosh, 1974). Some physicians believe that providing patients with detailed information is inappropriate because the information may negatively affect patients and cause them to become depressed. The results of a survey of 170 physicians from eight countries (Taylor, Shapiro, Soskolne, & Margolese, 1987) showed that 81% of physicians felt that patients might be adversely affected by informing them of the uncertainty of the effectiveness of two cancer treatments.

The results of a study by Cassileth, Zupkis, Sutton-Smith and March (1980a), however, suggested that the belief that patients may be adversely affected by detailed information is unwarranted. The authors found that patients who desired detailed information about their treatment reported higher levels of hope, as measured by the Beck Hopelessness Scale (Beck, Weissman, Lester, & Trexler, 1974), than patients who wanted little or no information. A limitation of this study was that the authors did not control for the kind and amount of

information provided to patients. Therefore, the extent to which information may have contributed to reports of hopefulness could not be determined.

Recognizing the lack of research exploring the information needs of cancer patients, Dodd and Ahmed (1987) measured the preferences for cognitive information (i.e., desire to ask questions and be informed about treatment decisions) versus behavioral information (i.e., desire to play an active role in one's medical care) for 60 cancer patients at the beginning of radiation therapy and at the completion of treatment approximately 5.5 weeks later. These constructs of cognitive and behavioral information resemble Taylor's (1986) constructs of information control and behavior control, respectively. The results showed that patients preferred cognitive information at both interviews, and that the preference for cognitive information decreased over the course of radiation therapy.

There are demographic differences with respect to information preferences of cancer patients. For example, Cassileth et al. (1980a) found that young, white, and well educated patients desired more treatment information from health care professionals than did older, black, and poorly educated patients. Patients who wanted detailed information - positive and negative - were younger than

those patients who wanted minimal or only positive information.

Not all cancer patients may desire more illness information than they receive. Miller and Mangan (1983) found that desire for illness information was dependent on the patient's generalized tendency to seek out information in times of threat. A scale designed to classify patients as a monitor or a blunter was administered to forty gynecologic patients at risk for cervical cancer. Monitors are individuals who search for information under times of threat while blunters distract themselves from information under threatening circumstances. Half of the monitors and half of the blunters were given a videotape to prepare them for the operation. The remaining patients were given minimal information. Blunters experienced less psychophysiological arousal when they were given minimal information while monitors were less aroused by an increased level of information. The results suggested that cancer patients may be less agitated if provided with an amount of information that matches their coping style.

As with the diagnosis, physicians differ in the kind and amount of prognostic information they provide to cancer patients. Over a period of three years, Taylor (1988) was a participant observer of 118 meetings of patients and

physicians during which the results of the patients' biopsies were disclosed. In only 10% of disclosures did the physicians provide a realistic and specific prognosis using terms the patient could understand. An unsubstantiated prognosis was provided in 30% of the interactions, and in 45% of cases a prognosis was not provided. Taylor (1988) noticed that two communication styles were prevalent among the physicians. Experimenter-like physicians used medical terminology, statistics, and the results of published studies when explaining the diagnosis, while therapist-like physicians used euphemisms, fewer statistics, and the results of clinical experience rather than published studies.

In an examination of 82 patients beginning radiation therapy and 78 patients who had been receiving radiation therapy for some time, Cassileth, Volckmar, and Goodman (1980) found that all but 13 patients knew their diagnosis. A significant proportion of those patients who did not know their diagnosis were being treated palliatively rather than curatively. Only 50% of patients who received, or would be receiving, radiation therapy expected to be cured, while almost one-third of palliative care patients believed they might be cured. It is surprising that a substantial number of palliative care patients were unaware of their cancer

diagnosis and that they were being prepared for death rather than treated curatively. It is unclear whether patients' inaccurate reports of the form of care they were being administered (curative vs. palliative) arose from a lack of treatment information or, for those being treated palliatively, from an attempt to maintain cognitive control over their health by employing denial. The former alternative is not implausible given that less than 30% of new patients were satisfied with the treatment information they received, 50% of relatively knowledgeable patients reported lacking treatment information, and only 55% of new patients understood the process of radiation therapy.

The dissatisfaction that patients express with respect to interactions with physicians may arise, in part, out of a lack of understanding of the information and advice provided by physicians. Patients and physicians may assign different interpretations to information that physicians provide to patients, and Cassell (1988) argued that physicians should provide information to patients to reduce the uncertainty surrounding their illness, to increase the patient's ability to assume control of their care, and to strengthen the patient-physician relationship.

To improve the manner by which physicians communicate with patients, Ley, Whitworth, Skilbeck, Woodward, Pinsent,

Pike, Clarkson, and Clark (1976) encouraged physicians to provide instructions and advice early in the interview, clearly organize and emphasize all information, use short words and sentences, and provide detailed information rather than general conclusions. The intervention resulted in more information being recalled by patients, and comprehension of information was shown to be positively related to satisfaction and compliance. It is possible, therefore, to develop and implement interventions that produce positive effects for the patient. To the extent that these interventions impact positively on the psychological control of patients, one may hypothesize that the psychosocial status and medical status of patients may be enhanced.

In summary, while the majority of cancer patients indicate satisfaction with the kind and amount of medical information received from health care professionals, a significant number of patients are dissatisfied with the amount and kind of information they receive. A substantial percentage of cancer patients wish to be informed of their diagnosis and the majority of physicians satisfy this need. A substantial percentage of physicians, however, avoid using the word "cancer" or "malignancy" when disclosing the diagnosis or providing illness information, preferring to

employ euphemisms such as "tumor" and "growth". Some patients prefer to receive ambiguous information, e.g., euphemisms for the word "cancer", regarding their diagnosis and prognosis. For these patients, the uncertainty attached to ambiguity allows them to maintain hope in a positive health outcome. Although patients and physicians disagree on the effects of disclosure on patients' compliance with treatment regimens and psychological distress, the results of these studies suggest that communication skills of physicians can influence patient responses including satisfaction, recall of information, and treatment compliance and that these communication skills can be modified to produce desirable effects on patient functioning.

Control over treatment decision making

Research shows that cancer patients differ regarding their preferred level of involvement in making treatment decisions. Traditionally, patients have played a passive role in treatment decision making. However, as increasing numbers of physicians are adopting a more open communication style with patients, and as the paternalistic style of medical practice is replaced with a more consumer-oriented philosophy, patients are beginning to play a more active role in formulating their treatment regimen.

Research that examines patients' preferences for involvement in treatment decision making will now be reviewed.

In an examination of the medical and demographic characteristics of patients who wish to play/not play an active role in their medical care, Blanchard, Labrecque, Ruckdeschel, and Blanchard (1988) found that 92% of patients wanted to receive as much information as possible, and 69% wanted to participate in treatment decision making rather than have their physician make the decisions. Patients who desired an active role in making decisions tended to be younger, not married, and have a prognosis of less than three months or greater than one year. Those who preferred that the physician make the decisions were more likely to be male, married, have lung cancer with a prognosis of three months to one year, and have low functional status. Patients who desired greater involvement in treatment decision making were more involved in actual decision making, perceived themselves as being more involved, and were less satisfied with the quality of patient-physician interaction. Physicians were more likely to discuss test results with patients who wanted to actively participate in their medical care. This study may be criticized for using crude measures of information

preferences and control over treatment decision making. With respect to information preferences, no attempt was made to differentiate between preferences for diagnostic, treatment, and prognostic information needs. Rather, patients, indicated whether they wanted to receive a) as much information as possible, b) only positive information, or c) only information necessary to properly care for one's health. With respect to preferences for treatment decision making control, no attempt was made to differentiate between patients who wanted to collaborate with their physician and those who wanted to play a more active role.

Degner and Russell (1988) examined a) whether cancer patients prefer to retain, share, or relinquish control over treatment decision making, and b) whether patients prefer to delegate decision making responsibility to their physicians or family members. The method used to measure preferences for decision making responsibility was more refined than the method used by Blanchard et al. (1988). The results indicated that patients wanted to be included in treatment decision making and that they were reluctant to allow family members to make those decisions. Patients preferred to share control with their physicians and would rather delegate decision making responsibility to physicians than to family members.

Like Blanchard et al. (1988), Cassileth et al. (1980a) found that younger patients preferred to play a more active role in treatment decision making. In addition, well educated patients preferred to be more involved than those who were poorly educated. Those who preferred to be actively involved in the treatment decision making process and those who preferred more information about their treatment reported the highest level of hope. In turn, the degree of hope reported by patients was highest for those patients whose prognosis was positive. Given that high levels of hope are positively related to psychological control, it may be desirable to encourage patients to play an active role in treatment decision making if they desire to play this role. Other benefits that appear to be gained by playing an active role include increased knowledge of medical problems and higher treatment compliance (Carter, Inui, Kukull, & Haigh, 1982).

Ende, Kazis, Ash, and Moskowitz (1989) found that patients tend to prefer that their physicians make treatment-related decisions. Like Blanchard et al. (1988) and Cassileth et al. (1980a), younger patients wanted more control over treatment decision making than older patients. However, the measures used to measure patient preferences for decision making responsibility and information

preferences were weak. Scores from several items were pooled to derive a final score representing the degree of decision making control that was preferred. Unfortunately, these items were quite unique and may not have represented a single, underlying dimension. Therefore, pooling these items may be considered inappropriate. The content of many of the information items was general and may not have reflected valid and specific information needs.

Physicians may have preferences with respect to their patients' degree of involvement in medical decision making. Merkel, Rudisill, and Nierenberg (1983) found that physicians were more fond of patients who had been instructed, prior to their interactions with physicians, to express medical and emotional concerns and to ask questions regarding their illness and its treatment. Physicians have been found to be less satisfied with patient-physician interactions in which the physician used many facilitative remarks and played an active role (Weinberger, Greene, & Mamlin, 1981).

Robinson and Whitfield (1987) found that patients of inexperienced physicians asked more questions and provided more comments about their treatment than did patients of experienced physicians. The implication is that physicians should encourage patients to contribute to treatment-

related discussions if they believe it is important for patients to play an active role in making treatment decisions. If physicians fail to do so, patient involvement may decrease as physicians become more experienced.

To enable a cancer patient to play an active and effective role in treatment decision making, it may be necessary for the patient to have a sufficient amount of illness- and treatment-related knowledge. For example, before a cancer patient can evaluate alternative treatment options, that patient may require information about the probability of success and side effects associated with each treatment alternative. An understanding of the information preferences of these patients may be a necessary first step in the development of interventions to equip patients with information minimally necessary to make a knowledgeable contribution to the decision making process.

In an examination of cancer patients' perceptions of various aspects of their illness and its treatment, and possible areas of misperception between patients and physicians, Mackillop, Stewart, Ginsburg, and Stewart (1988) found that 16 of 48 patients who were being treated palliatively believed that they were being treated

curatively, and less educated patients were more likely than well educated patients to misinterpret the intent of their treatment. Regarding perceptions of treatment outcome, the physicians believed that 32% of patients had a 50% or more probability of being cured, while 68% of patients believed they had a 50% or more probability of being cured. Less educated patients were more likely to believe they may be cured than were highly educated patients. While 46% of patients were at least 50% certain that their treatment would prolong their lives, physicians reported that they were at least 50% certain that the lives of only 12% of patients would be extended. The patient's understanding of whether their treatment was curative or palliative correctly matched the physician's perception of the patient's understanding in 66% of patients. Assuming that the perceptions of physicians are closer to the truth, these findings suggest that a substantial percentage of cancer patients, particularly those who are less educated, overestimate the degree to which they will benefit from their treatment. These patients may lack information that is an important aspect of a) playing an active role in treatment decision making, and b) adapting well to their illness. Alternatively, they may have been given ambiguous

information allowing them to formulate optimistic expectations, or may have been using denial.

In a study conducted by Muss, White, Michielutte, Richards-II, Cooper, Williams, Stuart, and Spurr (1977) to discern cancer patients' knowledge of their chemotherapy regimen after procedures for informed written consent had been implemented, the results revealed that patients lacked an understanding of the drugs they were receiving, the side effects of those drugs, and the purpose and goal of the treatment regimen. The authors concluded that informed consent procedures do not provide sufficient information to enable patients to participate effectively in treatment decision making. Findings from other studies support the general finding that informed consent forms are poorly understood by a substantial number of cancer patients who sign them (Cassileth, Zupkis, Sutton-Smith, & March, 1980b; Morrow, 1980; Morrow, Gootnick, & Schmale, 1978).

The studies examined above suggest that cancer patients are more likely to play an active role in decision making if they are a) young, b) female, and c) well educated. It should not be assumed however, that patients who play an active role are better off physically or psychologically relative to patients who wish to give treatment control to their physicians. The relationship between degree of

involvement in treatment decision making and medical and psychosocial status is not well understood. As well, there is not a clear relationship between degree of involvement in decision making and psychological control. Indeed, there is not even a clear relationship between preference for involvement in decision making and the degree of actual involvement. Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, and Till (1989) found that for 77% of 52 patients, there was agreement on preference for active involvement in decision making and degree of actual involvement in decision making. Most of the patients for whom there was a lack of congruence reported that their desired level of involvement was less than their actual degree of involvement. Although the data indicated that patients who preferred an active role in decision making were actually more active in seeking information, 63% of patients who were highly active in seeking information preferred either no or minimal involvement in decision making.

Rationale for proposed thesis

Some researchers have concluded that physicians should provide their patients with additional information during medical interactions. Others however, have concluded just the opposite. In a review of empirical methods that have

been used to discern what information physicians should provide to patients, Tuckett and Williams (1984) stated that evidence for the effect of various information-providing interventions on the functional status of patients can only be interpreted with confidence if the methodology developed to measure and represent the exchange of information in patient-physician interactions are derived from a theoretical framework. Another factor that influences the confidence associated with information-providing interventions is the reliability and validity of the method. If different methods of presumably similar constructs produce different results across studies, then perhaps what is truly being assessed is largely "method variance".

Prior to specifying the kind and amount of information that physicians should provide to patients, researchers need to a) be aware of the various kinds of information that physicians provide to patients and b) develop a reliable and valid methodology for measuring the presence of these particular forms of information-providing (Tuckett & Williams, 1984). Many empirical examinations of information needs and satisfaction, as well as many of the aforementioned studies that have isolated aspects of psychological functioning to examine their effect on health

status are fraught with methodological weakness and/or are not based on a strong theoretical foundation. For instance, there are disparities in reports of satisfaction among cancer patients. Given that most of these studies have used measures of satisfaction for which the psychometric properties have not been substantiated, the extent to which the disparities in patient reports of satisfaction reflect true differences in satisfaction, differences in the instruments of measure, or response bias, is not clear.

Additional research is needed to explore how information preferences may differ across cancer patients. Specifically, there is a lack of quantitative and qualitative data describing the kinds of patients that share similar information preferences. If subgroups of patients that share information preferences can be identified, clinicians and researchers will be able to develop interventions a) for the provision of this information by health care professionals, and b) to assist patients in obtaining this information for themselves.

In the literature review presented above, four illness phases - diagnosis, treatment, side effects, and prognosis - were reviewed with respect to patients' preferences for information within each of them. The review of studies

that examined preferences for involvement in treatment decision making identified three types of involvement that vary in the degree of control preferred by the patient. Relinquishers are those patients who wish to give decision control to their physician (i.e., passive involvement), retainers are those who wish to make their own treatment decisions (active involvement), and sharers are those who wish to collaborate with their physician in the decision making process. In the following hypothetical case scenarios, the health care experiences of an active, passive, and collaborative client are provided with respect to the four illness phases:

An "active" patient - Mary Taylor is a well educated 40-year-old high school teacher. Mary sat anxiously in her physician's office waiting for him to arrive and disclose the results of her diagnostic evaluation. While seated there, she pondered the several questions she had prepared for the physician. Mary wants as much information as possible regarding her illness, including the amount of cancer and the location of the cancer in her body. If Mary indeed has cancer, she wants to be informed of this so that she can begin to consider various treatment options. Mary wants to have final say regarding any proposed treatment and she realizes that specific information is needed so

that she can make informed decisions. If Mary does have cancer, she will want the physician to provide her with all possible treatment alternatives so that she can weigh the alternatives and choose a treatment that will best satisfy her needs. She wants to know about the potential side effects and degree of risk associated with her treatment. Mary wants her physician to be honest with respect to the likelihood of surviving the cancer.

A "passive" patient - Louella Parsons is a 65-year-old housewife who has a grade 8 education. Louella sat anxiously in her physician's office waiting for her to arrive and disclose the results of her diagnostic evaluation. While seated there, she thought she would feel better if the physician didn't tell her she had "cancer". Louella hopes the physician will not give her a lot of details she won't be able to remember. Louella hopes the physician will have an idea of what treatment she might need and give her any necessary prescription or medical tests. Louella has no questions for the physician. Louella expects the physician to make all of the treatment decisions.

A "collaborative" patient - Anne Murphy is a 50-year-old legal secretary who has some college education. Anne sat anxiously in her physician's office waiting for him to

arrive and disclose the results of her diagnostic evaluation. While seated there, she hoped that she would be able to understand what her physician told her about her illness. Anne feels that the best way to get better is to work together with the physician to arrive at decisions. Anne wants to receive information about the illness, and wants the physician to provide her with more than one treatment option.

The purpose of the present study was to conduct a qualitative and quantitative examination of the relationship between cancer patients' preferences for medical information and preferences for involvement in making treatment decisions. If it could be shown that the three degrees of desired involvement in treatment decision making - active, passive, and collaborative - have unique, although not necessarily mutually exclusive, information preferences, physicians might be better able to furnish patients with information that matches patients' unique preferences for information. By heeding patient preferences for both involvement in treatment decision making and preferences for information, one might expect any consequent impact on psychological control to be favorable. A thorough exploration of this relationship was, therefore, worthy of research.

The proposed study was similar to that conducted by Cassileth et al. (1980a), Blanchard et al. (1988), Sutherland et al. (1989), and Ende et al. (1989), in that patient preferences for information and degree of participation in their medical care were assessed. However, the proposed study improved upon the earlier studies in several ways. First, the proposed study used a more sensitive measure of preferences for involvement in decision making. Both Cassileth et al. (1980) and Blanchard et al. (1989) offered subjects only two possible alternatives, i.e., giving control to the physician or participating in the decision making process. This instrument, therefore, did not discriminate between patients who wanted to collaborate with their physician and those who wanted to retain control. The measure used in this study provided patients with five alternatives. Second, unlike the present study, the information preferences questionnaire did not address the manner by which patients wanted physicians to provide them with information.

In the present study, patient preferences for control over making treatment decisions were measured with a card sort procedure developed by Degner and Russell (1988). An advantage of this measurement tool is that it was developed

out of a theoretical framework referred to as unfolding theory (Degner & Russell, 1988). According to unfolding theory, a single underlying psychological dimension underlies an individual's selection from a given set of alternatives. In this case, the underlying psychological dimension is preference for control over treatment decision making. Unfolding theory has other advantages with respect to its application to data collection. Using a two-alternative forced-choice format, subjects actively lay out their preferred order of alternatives. This approach, therefore, is more motivating for subjects than paper-and-pencil measures or direct questioning procedures. Unfolding theory allows for a more precise measure of preference to be obtained because the entire ordering of alternatives (i.e., 120 possible orders of five cards reflecting 120 varying degrees of role preference) can be analyzed rather than the most preferred alternative that is the product of many other measures.

To measure information preferences in the present study, the researcher developed a card sort procedure consisting of a series of short vignettes. Given that the vignettes represent events along a multidimensional continuum, relative to the vignettes of the treatment control card sort procedure which are hypothesized to represent events

lying on a unidimensional continuum, the preference orderings were not amenable to examination based on unfolding theory. Rather, a qualitative analysis of this data was conducted.

To the extent that empirical studies of the impact of psychosocial interventions on health outcome have not acknowledged the degree of impact that medical interventions exert upon medical health status, these studies lack clinical significance. Most researchers would support the statement that health care research must be clinically significant in addition to being statistically significant. In this context, clinically significant research may be defined as research that shows that a clinical intervention produces a positive change, or forestalls a negative change, in the cancer patient's medical or psychosocial status.

In addition to being statistically and clinically significant, however, health care research must be of practical significance insofar as any findings should lend themselves to recommendations that can be built into the existing structure of the health care system. An advantage of the present study is that it was designed from the perspective of patients' interactions with health care professionals, primarily their oncologist. Therefore,

clinically significant findings lend themselves to the development of recommendations that are feasible given the sociopolitical structure of the health care system.

Development of hypotheses

In general, if a cancer patient expresses a preference for active involvement in treatment decision making, i.e, a retainer of decision control, that individual is hypothesized to want more medical information than a patient who wishes to relinquish decision making authority to their physician. There are three hypotheses that were developed from this premise. These hypotheses are related to the receipt of information about the diagnosis, treatment, and side effects of the treatment.

First, the degree of technical detail preferred by patients in the disclosure of their diagnosis was hypothesized to be a function of preference for involvement in treatment decision making. Those who wished to play an active role were expected to desire more detail about the nature and severity of their illness than those who wished to play a passive role.

Second, the degree of technical detail preferred by patients in their physicians' provision of treatment options was hypothesized to be a function of preference for involvement in treatment decision making. Those who wished

to play an active role were expected to desire more detail than those who wished to play a passive role.

Third, patient preference for information about all possible treatment side effects and how to remedy them was hypothesized to be a function of preference for involvement in treatment decision making. Those who wanted to play an active role were expected to want more information about treatment side effects than patients who wanted to play a passive role. This is not a trivial matter since most cancer chemotherapy produces profound side effects (e.g., hair loss, nausea, vomiting).

If patients desire a high degree of personal control over the selection of their cancer treatment, one would expect them to prefer that the physician provide them with information about all possible treatment options. In addition, these patients will probably want to be informed of the degree of risk associated with all of the treatment options. Patients who want their physicians to control the selection of their cancer treatment may prefer that their physician provide them with a description of only the optimal treatment or with no information at all. It was hypothesized, therefore, that patient preference for full disclosure of all available treatment options and the degree of risk attached to each option is a function of

preference for involvement in decision making. Patients who wanted to play an active role were expected to want to be informed of all available treatment alternatives and the degree of risk associated with them while patients who wanted to relinquish control to physicians would want to be left uninformed, or informed, without a degree of risk attached, of the treatment that the physician has decided to administer.

Although research has examined patient demand for information and satisfaction with information received, few articles have attempted to discern the optimal means by which to provide illness- and treatment-related information to clients. Reynolds, Sanson-Fisher, Poole, Harker, and Byrne (1981) tested the hypothesis that patient preferences for additional information could be facilitated by asking them if there are specific aspects of their illness and its treatment about which they want to be informed. Compared to control patients who were not asked if they had specific information needs, providing additional information to the experimental patients, at their request, produced greater recall of information. Furthermore, the experimental patients were provided with either a tape-recorded or written copy of the interaction during which they received their diagnosis. Providing a tape-recording of this

meeting did not produce greater recall relative to patients who received a written copy of the interaction.

In the above study, it is possible that psychological control may have been enhanced in the experimental patients who desired to play an active role in making treatment decisions. Given the assumption that patients who wish to retain control over treatment decision making desire a considerable amount of illness- and treatment-related information, it was hypothesized that patient preference for receiving a tape-recorded copy or written copy of the diagnosis is a function of preference for involvement in treatment decision making. Those patients who wanted to retain control were expected to be more likely to prefer a tape-recorded or written copy of their diagnosis relative to patients who wished to relinquish control. These latter patients were expected to not want a copy of the diagnosis.

The findings of some of the studies reviewed above indicated that there are a subset of patients who want to remain uncertain about their diagnosis and prognosis (McIntosh, 1976; Newall et al., 1987). For these patients, McIntosh (1976) concluded that uncertainty may allow feelings of hope for a positive health outcome to be maintained. For patients who wish to have diagnostic and prognostic information fully explained to them, uncertainty

is not desirable and may threaten feelings of psychological control. Past research has not discerned whether patients who wish to play active/passive roles also wish to be certain/uncertain about their prognosis. To shed light on this question, cancer patients were asked whether they wanted to receive the best possible prognosis from their oncologist, the most likely prognosis, or the worst possible prognosis. It was difficult to formulate a directional hypothesis with respect to the relationship between patient preference for prognostic information and preference for involvement in treatment decision making. However, this relationship was examined because of the implications of this relationship on the oncologist's provision of prognostic information to patients.

Given that passive patients are expected to prefer minimal information about their illness and treatment, these patients are also expected to prefer that their physician provide them with the best possible diagnosis. Active patients, who are expected to desire detailed information so that they can obtain the knowledge necessary to assist the physician in the formulation of a treatment plan - are hypothesized to prefer that their physician inform them of the most likely prognosis. This hypothesis is based on the assumption that receiving a realistic

prognosis will facilitate effective decision making by active patients, and that receiving the best possible diagnosis will provide hope and relieve anxiety in passive patients.

Given that patients who prefer uncertainty also prefer to hear euphemisms for the word "cancer", it was hypothesized that patient preferences for euphemisms for the word "cancer" would be a function of preference for involvement in decision making. Patients who wanted to play an active role were expected to want their physician to use the word "cancer" while patients who wanted to relinquish control were expected to prefer hearing terms such as "malignancy", "tumor", or "mass".

The research lends support to the belief that females, younger patients, and well educated patients are more likely to prefer active involvement in treatment decision making than patients who are male, older, and poorly educated. Excluding sex, the two variables - age and educational status - and illness severity will be treated as independent variables in the proposed study. The research examining the variables of age, educational status, and illness severity were discussed above and will now be briefly summarized.

In selecting age as an independent variable, it was assumed that older patients hold more conservative attitudes towards health care than younger, and therefore more liberal, patients. Patients with liberal health attitudes were thought to be less likely to conform to the existing patriarchal nature of health service delivery. Younger patients, therefore, were hypothesized to prefer a more active role in treatment decision making and desire more detailed information than older patients.

Patients who are poorly educated are hypothesized to prefer that their physicians make treatment decisions because they lack knowledge that is essential for making informed treatment decisions. Well educated patients are more likely to have more illness-related knowledge or, at least, have the ability to determine the kind and amount of information they need to make informed, rational decisions. Therefore, well educated patients were expected to prefer an active role in making treatment decisions.

The relationship between illness severity and preference for involvement in decision making is hypothesized to be more complex. It may be that patients who have a positive prognosis believe they have psychological control and therefore wish to be active in making treatment decisions. As a patient's prognosis worsens, however, the patient's

psychological control is threatened and the patient may come to believe that intervention by the physician is necessary if they are to become healthy. If the prognosis continues to worsen, such that the patient believes they will not survive, the patient may wish to have control over treatment decisions because, realizing their impending death, their focus is no longer quantity of life but rather quality of life. Psychological control can thus be maintained if the patient can adapt to their illness in a manner that improves their quality of life. Therefore, one would expect that patients whose illness severity/prognosis is relatively favorable or relatively unfavorable would want to play a more active role in treatment decision making than patients whose prognosis is comparatively average. Given that all patients in this study will have a favorable prognosis, it is hypothesized that the association between illness severity and preference for involvement in treatment decision making will not be significant.

Overview of design and method

The purpose of this research was to conduct an examination of the relationship between cancer patients' preferences for involvement in making treatment decisions and preferences for medical information. The subjects were

35 Stage I and II breast cancer patients accrued from the oncology and radiotherapy clinics at St. Boniface General Hospital, and from the Manitoba Cancer Treatment and Research Foundation. Patients were asked to volunteer for the study if they fell within 2 to 6 months of having received their cancer diagnosis. Patient preferences for control over treatment decision making were assessed using a card sort procedure developed by Degner and Russell (1988). A card sort procedure developed by the present researcher was used to assess information preferences. Nurses from the oncology unit reviewed the card sort procedures to ensure they reflected valid health care experiences and concerns of cancer patients as well as the kind of information that oncologists provide to patients. Following the administration of the card sort procedures, a 20-minute semi-structured interview was conducted with the patients to allow them an opportunity to a) share their health care experiences and concerns with the researcher and b) elaborate on their role and information preferences. The data was analyzed by applying correlational methods to the quantitative data and performing a content analysis of the qualitative data.

Summary of hypotheses

i. Diagnosis

1. The degree of technical detail preferred by patients in the disclosure of their diagnosis is positively related to preference for involvement in treatment decision making.

2. Patient preference for receiving a taped copy or written copy of the diagnosis is positively related to preference for involvement in treatment decision making.

3. Patient preferences for euphemisms for the word "cancer" is negatively related to preference for involvement in treatment decision making.

ii. Treatment

4. Patient preference for disclosure of the major treatment options and the degree of risk attached to each option is positively related to preference for involvement in treatment decision making.

5. The degree of technical detail preferred by patients in the physician's description of treatment procedures is positively related to preference for involvement in treatment decision making.

iii. Side effects

6. Patient preference for information about all possible side effects and how to remedy them is positively related to preference for involvement in treatment decision making.

iv. Prognosis

7. Patient preference for receiving prognostic information is related to preference for involvement in treatment decision making such that active patients want to be informed of the most likely prognosis while passive patients want to be given the best possible prognosis.

METHOD

Subjects

The subjects were 17 stage I and 18 stage II breast cancer patients aged 32 to 83 and consecutively accrued from the oncology and radiotherapy clinics at St. Boniface General Hospital, Winnipeg, Canada, and the Manitoba Cancer Treatment and Research Foundation, Winnipeg, Canada. Only those patients who were between 2-6 months post-diagnosis and able to read and speak English were asked to volunteer for the study.

Two months post-diagnosis was selected as the minimum time acceptance criterion to ensure that all patients had begun their cancer treatment. At two months post-diagnosis most breast cancer patients have commenced treatment. There was only one patient that was more than two months post-diagnosis who had yet to commence treatment. Although this patient was sampled, her data was not included in subsequent analyses.

Another reason for the two month post-diagnosis acceptance criterion is the finding that many breast cancer patients experience psychological distress upon hearing their diagnosis and the researcher did not want to heighten existing levels of distress in these patients. Patients appear to be less distressed after having had sufficient time - approximately two months - to adapt to knowing they have cancer and to adapt to their treatment regimen and consequent side effects.

Six months post-diagnosis was adopted as the maximum time acceptance criterion because it was important to assess patients preferences with respect to diagnostic and treatment decision making information as close as possible to the actual time of diagnosis so that a more reliable indication of these preferences could be obtained. In addition, the 2 - 6 month time frame was adopted to enable sampling of a fairly homogeneous patient population.

Primary tumors are commonly described according to a four-stage clinical-diagnostic classification scheme. A Stage I tumor is 2 cm or less in its greatest dimension, while a Stage II tumor exceeds 2 cm but is less than 5 cm in its greatest dimension. A Stage III primary tumor is more than 5 cm while a Stage IV tumor can be of any size but also lies in direct extension to the chest wall or skin

but not to the pectoral muscle. Stage I and Stage II patients were chosen for this study because patients are more likely to have a Stage I or II primary tumor at the time of initial diagnosis.

Seventeen patients were receiving chemotherapy, 16 patients were receiving radiotherapy, 1 patient was receiving both chemotherapy and radiotherapy, and 1 patient was receiving hormonal therapy. Of the 17 patients receiving chemotherapy, 4 were also receiving hormonal therapy. Three of the 16 patients receiving radiation therapy were also receiving hormonal therapy.

All patients who were asked to participate in the study agreed to do so. Two patients were not asked to participate. One of these patients was blind, a factor that would hinder their ability to perform the card sorting procedure. The other patient was experiencing difficulty adapting to her life with cancer. This latter patient was asked a few months later to participate. The patient agreed to do so but was not recruited for the study because the targeted sample size had been reached.

Materials

To discern patients' preferences for control over treatment decision making, a card sort technique developed by Degner and Russell (1988) was used. Patients were

provided with five cards comprised of written statements and an illustrative drawing, and were asked to sort the cards according to their preferred choices. The statements varied in the degree of treatment control afforded the patient and the order of the cards indicated the degree to which a patient wishes to relinquish, retain, or share control over treatment decision making. The five cards are presented in Figure 1.

To discern patient preferences for information, cards were prepared in a similar manner to those developed to study preferences for treatment decision making control. For each of the hypotheses, a number of cards were presented to the patient to sort according to their preferred order. These cards, developed to examine information preferences for each of the hypotheses, are presented in Figure 2.

A 20-minute semi-structured interview was conducted with each patient to review their responses to the card sort procedures and to gather information about their health care experiences. A copy of the interview guide is presented in Appendix A. Necessary medical and demographic information, i.e., patient's date of birth, stage of cancer, and treatment regimen, were obtained from the

Figure 1. Treatment decision making role preference cards.

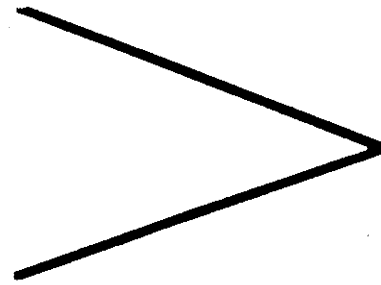
I prefer to make the final selection about which treatment I will receive.

I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.

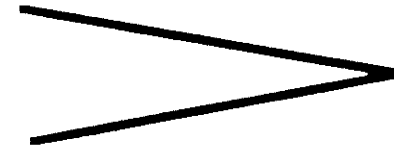
I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion

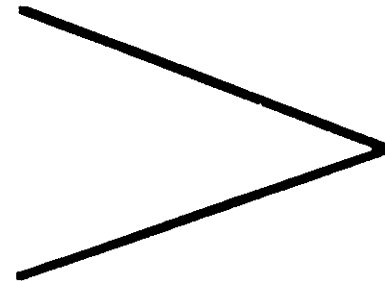
I prefer to leave all decisions regarding my treatment to my doctor.



**Active
Role**



**Collaborative
Role**



**Passive
Role**

Figure 2. Information preference cards.

Extent of diagnostic detail

"I want a detailed explanation of my diagnosis, including the type of cancer, location of cancer (by showing me my X-rays and having the location of illness illustrated on a plastic model of the human body), and extent of disease progression"

"I want a brief explanation of my diagnosis, including a short description of the type of cancer, location of the cancer, and extent of progression"

"I want to hear my diagnosis, but do not want it explained to me"

Copy of diagnosis

"I would like to receive a tape-recorded copy of the physician telling me my diagnosis"

"I would like to receive a written copy of my diagnosis prepared by my physician"

"I would not like to receive a tape-recorded copy of the physician telling me my diagnosis or a written copy of my diagnosis prepared by my physician"

Illness descriptors

"I would like my physician to use the word 'cancer' when describing my illness"

"I would like my physician to use the word 'tumor' when describing my illness"

"I would like my physician to use the word 'malignancy' when describing my illness"

"I would like my physician to use the word 'mass' when describing my illness"

"I think it is best for my physician not to place a name on my illness"

Treatment alternatives

"I want to be informed about the major treatment alternatives available to me and the degree of risk associated with each alternative"

"I want to be informed about the single best treatment for me and the degree of risk associated with it"

"I want to know as little as possible about my treatment"

Treatment procedures

"I want a detailed explanation of the purpose and procedures associated with my treatment"

"I want a brief explanation of the purpose and procedures associated with my treatment"

"I do not want the purpose and procedures of my treatment explained to me"

Treatment side effects

"I want an explanation of all possible treatment side effects and how to remedy them"

"I want an explanation of the most likely treatment side effects and how to remedy them"

"I don't want an explanation of possible treatment side effects and how to remedy them"

Prognostic information

"I want to be told what the best possible outcome is regarding my health"

"I want to be told what the worst possible outcome is regarding my health"

"I want to be told what is the most likely outcome is regarding my health"

patient's file. At the completion of the patient interview, the researcher asked the patient to specify the highest grade of education they had received.

Procedures

Prior to sampling patients, the researcher met with five nurses and administrators from the oncology unit at St. Boniface General Hospital and eight nurses and administrators from the oncology unit at the Manitoba Cancer Treatment and Research Foundation. The purpose of the meeting was to explain their participation in the study, and to have them review the card sort procedures to ensure that they reflected valid health care experiences and concerns of cancer patients as well as the kind of information that oncologists provide to patients. As a result of these two meetings, the following card was added to hypothesis #3: "I would like the physician to use the word "mass" when describing my illness".

Given that the purpose of the proposed research was not that of refining the psychometric properties of the card sort measures, it was felt that the meetings with the oncology nurses and administrators were sufficient to enable the commencement of data collection. Therefore, the proposed pilot work with 4 - 8 patients to refine the information preferences vignettes and the administration of

the clinical interview and card sort procedures was abandoned. If, during the administration of the measures to the first four patients, the researcher had found that modifications to the measures or data collection procedures had been necessary, the refinements would have been made and the data from these four patients would not have been included in subsequent analyses. Given that no modifications were necessary, the data from all patients were included in the analysis.

Prior to the researcher's meeting with the patient, the patient was briefly informed as to the nature of the study by one of the nurses at the clinic. It was felt that the nurse, rather than the researcher, should have initial contact with the patient because it was thought that those patients who were reluctant to participate in the study would feel more comfortable telling the nurse, rather than the researcher.

Data collection was conducted from July 9, 1990 to November 26, 1990. Given the often busy schedules of the oncologists, the researcher met with some patients prior to their meeting with their oncologist and other patients following their meeting with their oncologist. Some of the patients came to the cancer clinic to receive treatment and did not meet with their oncologist.

The card sort procedures and the interview were conducted in quiet rooms at St. Boniface General Hospital and at the Manitoba Cancer Treatment and Research Foundation. Upon meeting the patient, the researcher introduced himself to the patient, explained the nature of the study, and provided the patient with a brief written description of the purpose of the study on a consent form to be signed and returned. A copy of the consent form is presented in Appendix B.

The cards used to measure patient preferences for control over treatment decision making were presented to the patient in pairs and the patient was asked to indicate which of the two cards they prefer. This process continued until all the cards were ordered according to the patient's preferential ranking. The order of presentation of the cards was fixed so that order effects would be held constant across subjects. The order of cards was as follows: CARD B, D, C, A, E.

To measure the procedural reliability of this card sort procedure, the first two cards that were presented to each patient were the following:

- I prefer to make the final selection of my treatment after seriously considering my doctor's opinion. (CARD B)

- I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion. (CARD D).

By administering the card sort procedure in this manner, rather than the established procedure (CARD A followed by B, C, D, E), it was intended that the researcher would be able to see whether the distribution of role preferences matched that of previous studies.

It became clear during the administration of the treatment decision making card sort procedure that approximately one-fourth to one-third of the patients did not have a clear sense of the meaning of the card sorting task. For these patients, the researcher ceased using the card sorting format and asked the patients to glance at all five cards and rank order them.

A semi-structured interview was conducted with each patient following the administration of the card sort measures. The purposes of the interview were to a) explore the information needs of the patient and the reasons why the patient needed this information, b) explore the amount of treatment control that the patient desired and that which the patient believed their physician wanted them to have, c) discover the kind of information that the patient wanted to have/avoid to satisfy their desired degree of

involvement in treatment decision making, d) have the patient provide examples of the kinds of patients who should play an active/passive role and be given different kinds/amounts of information, and e) provide an opportunity for patients to talk about their experience with cancer in a supportive context.

The semi-structured interviews were scheduled for approximately 20 minutes and each of the card sort measures required approximately five minutes to administer. The total time required of each patient was approximately 30 minutes.

All data-gathering sessions with patients were audio-taped to facilitate the data analysis. To protect the confidentiality of the data, the audio-tape and all written data were stored in a locked room when not being used by the researcher, and all tapes were erased after having been transcribed.

Patients were interviewed after they received their diagnosis. It would have been desirable to interview the patients before they received their diagnosis - at the time of biopsy. The logistics of the oncology unit, however, did not make this feasible. A retrospective examination, therefore, of preferences for information about the diagnosis was conducted.

Data reduction and analysis

The patient's responses to the treatment decision making card sorting procedure were recorded in a proximities matrix. This matrix indicates the preferred card selected by the patient for each of the ten forced-choice events, and provides useful information with respect to the dimensionality of the role preferences construct.

Age, educational status (less than grade 10, grade 10 or 11, high school graduate, some college, college graduate), and illness severity (Stage I or II), served as independent variables in this study while preferences for control over treatment decision making and preferences for information were treated as an independent or dependent variable depending on which other variable was included in the statistical test.

Given the small sample size and the fact that approximately one-third of the role preference data could not be unfolded along the unidimensional construct of treatment decision making preference, an ordinary least squares approach to the ANOVA was not performed. The small sample size also precluded the calculation of a log-linear ANOVA. Statistical analyses were carried out with Wilcoxon's rank sum tests, Kruskal-Wallis ANOVA procedures, and 2X2 chi square tests.

The relationship between treatment decision making role preference and each of the information preference variables was analyzed using Wilcoxon rank sums tests, Kruskal-Wallis analyses of variance (ANOVAs), and chi square tests. These tests were also used to examine the impact of other variables such as age, education, and illness severity on the role and information preference variables, and to examine the relationships among the information preference variables. The statistical procedure chosen to examine the significance of the relationships between variables depended on both the measurement characteristics of the variable (i.e., categorical, ordinal) and the sample size restrictions of specific statistical tests.

Depending on the statistical test that was used, the role preference variable was reduced in three different ways. For the Wilcoxon rank sum tests and the Kruskal-Wallis analyses of variance, the role preference variable was divided into six levels representing varying degrees of preferential involvement in treatment decision making: active-active, active-collaborative, collaborative-active, collaborative-passive, passive-collaborative, and passive-passive. These six levels were determined by the patient's two most preferred choices in the card sort procedure. To this end, cards A and B were considered "active" cards,

card C was the "collaborative" card, and cards D and E were "passive" cards. For example, a patient whose top two cards were C and B would be considered a collaborative-active patient. By organizing the role preferences variable in this manner, the number of patients categorized into each of the six levels were as shown in Table 1. The most common role preference ordering was that of collaborative-passive. This card combination was observed in 37% ($n = 13$) of patients.

Chi square tests were limited to the 2 X 2 variety because of insufficient patient numbers. Therefore, in chi square tests that examined role preferences, patients were classified as either active or passive. Patients whose preferred card was a or b were classified as active patients, those who preferred cards d or e were considered passive patients, and those who preferred card c were classified as active or passive depending on whether their second most preferred card was card b (active patient) or card d (passive patient). Table 1 also shows the number of active and passive patients classified in this manner. Forty-three percent of patients were classified as active while 57% were passive.

TABLE 1
 Dichotomized, trichotomized, and heximensional
 representations of treatment decision making role
 preference

	Number of Patients	%
Active	15	43
Passive	20	57
Total	35	100

	Number of Patients	%
Active	8	23
Collaborative	20	57
Passive	7	20
Total	35	100

	Number of Patients	%
Active-Active	2	6
Active-Coll.	6	17
Coll.-Active	7	20
Coll.-Passive	13	37
Passive-Coll.	5	14
Passive-Pass.	2	6
Total	35	100

In some cases the meaning of statistically significant relationships could not be clarified by the information provided in a 2 X 2 contingency table. In these situations a trichotomized representation of the role preferences variable proved fruitful. This was arrived at by considering the patient's most preferred card. Active patients preferred card a or b, collaborative patients chose card c, and passive patients chose card d or e (see Table 1). When categorized in this manner, 23% of patients were active, 57% were collaborative, and 20% were passive.

A content analysis was performed on the information obtained from the patient interviews. This analysis was performed by adapting the procedures outlined by Riemen (1986). First, the tape recordings of all patient interviews were transcribed. Second, significant statements were set in bold type in each of the transcripts. Third, these bold face statements were re-read and prevalent themes were identified.

RESULTS

The data provide strong empirical support for the hypothesis that preferences for treatment- and illness-related information are a function of a patient's stated preference for involvement in treatment decision making. Overall, the findings suggest that patients who desire an

active role in deciding their treatment desire more detailed information about their medical care than patients who would prefer a more passive posture. Five of the seven hypotheses that were developed were statistically significant. Prior to examining each of these hypotheses, the relationship between role preference and age, educational status, illness severity, and treatment regimen will be reviewed.

An examination of the relationship between treatment decision making role preference and age, education, illness severity, and treatment procedure indicated that decision making role preference was significantly related to only one of these variables - education. The Wilcoxon's rank sum test performed on these two variables indicated that patients who had graduated from high school were significantly more likely to prefer an active role than non-high school graduates, the latter of who preferred a passive role ($z = 2.60$, $p < .01$, one-tailed). The corresponding strength of association measure (eta) for this relationship was .446. A two-way chi square test on the relationship between education and role preference (see Table 2) was also significant (chi square(1, $N = 35$) = 5.30, $p < .05$), adding further support for the hypothesis that desire to play an active role in deciding upon one's

course of treatment is positively related to educational status.

As expected, the relationships between role preference and each of illness severity and treatment regimen were not statistically significant. Contrary to expectation, the relationship between role preference and age was also not significant. It was expected that older breast cancer patients would be more likely to prefer a passive role relative to younger patients who were expected to desire active involvement in their treatment. The failure of the strength of this relationship to reach statistical significance can not be attributed to a homogeneous sample with respect to age. There was sufficient variation in the ages of the patients to eliminate this possible influence of attenuation.

In addition to the statistical tests relevant to the formal hypotheses of this study, one other strength of association measure was statistically significant: Illness severity (i.e., tumor stage) and treatment regimen (chi square(1, N = 31) = 5.46, $p < .05$). Patients with a Stage I tumor were more likely to be receiving radiation treatment while chemotherapy was the more likely treatment for their Stage II counterparts. This may be explained by

TABLE 2

Contingency matrix for role preference and educational status

	High School Graduate	Not High School Graduate	Total
Active	12	3	15
Passive	7	13	20
Total	19	16	35

the fact that Stage I tumors are often treated with radiotherapy because clinical trials have not yet definitively demonstrated that chemotherapy increases chance of survival in Stage I women.

The hypotheses of interest - with their associated statistical findings - and sample excerpts (where available) from patient transcripts will now be successively presented. This will be followed by the results of the content analysis of those portions of the patient interviews that explored treatment decision making and information preferences in general.

Hypothesis 1 - Treatment decision making control and diagnostic detail

As predicted, the degree of technical detail preferred by patients in the disclosure of their diagnosis was positively related to preference for involvement in treatment decision making. A Wilcoxon's rank sum test was statistically significant ($z = 2.219$, $p < .05$, one-tailed), indicating that active patients prefer to receive a detailed diagnosis of their illness while passive patients prefer either a brief diagnosis or no diagnosis at all (see Table 3). The eta value for this relationship was .380. Of the 11 passive patients who stated a preference for a

TABLE 3

Contingency matrix for role preference and preference for diagnostic detail

	Detailed	Brief or No Info	Total
Active	13	2	15
Passive	9	11	20
Total	22	13	35

brief diagnosis or no diagnosis, only three patients preferred not to receive their diagnosis. Of the two active patients who wanted to receive either a brief diagnosis or no diagnosis at all, both wanted a brief diagnosis. The data thus indicate that only 3 of 35 patients preferred not to receive their diagnosis.

Further examination of the contingency table provided in Table 3 shows that although passive patients desired either brief or no diagnostic information, there were nine passive patients who wanted to receive a detailed diagnosis. Therefore, the data suggest that one can reliably predict that active patients desire a detailed diagnosis but this high degree of predictive ability breaks down for passive patients.

The following is a sampling of patient opinions with respect to receiving their diagnosis:

Active patients

I find that each person should be told if they have cancer or not, rather than vague things or nothing at all...because then they are not given a chance to fight or survive if they want to....the oncologist should say the person has cancer but I think the oncologist should...not just show the bad aspect of the disease but should also let the patient know that he can handle...and it's his own decision to survive and fight his disease.

...my feeling was always they were going to tell me. They were going to call me in a room and tell me. This is because of...what has been in my life before...I know they have different ways here. They have all over the place...but I find I would have preferred if I had been asked to come into a room...just for the doctor to tell me...but I don't like to be told this lying in a hospital bed...then, I push it away...cause I find I have enough things going right now...I like to sit down, be dressed, and sit down and get bad news. I don't like to get bad news when I'm in a night gown...

Passive patient

I don't think I would like to be left in the dark. I would like to know...if they called it everything else but what it was and led me to believe I had something else, I'd feel very deceived. I wouldn't care for that at all...when you have something you've got to know what it is and then you can work with it.

Hypothesis 2 - Treatment decision making control and receipt of a copy of the diagnosis

The hypothesis that patient preference for receiving a taped or written copy of the diagnosis is a positive function of preference for involvement in treatment decision making was confirmed. A Kruskal-Wallis one-way analysis of variance (ANOVA) revealed that active patients expressed a preference for a written copy of their diagnosis while passive patients preferred either a written

TABLE 4

Contingency matrix for role preference and preference for a copy of the diagnosis

	Written	Taped	No Copy
Active	13	2	0
Passive	9	3	8
Total	22	5	8

copy of their diagnosis or no copy at all (chi square(2, N = 35) = 5.99, $p < .05$). The eta value for this relationship was .437.

Closer scrutiny of the contingency matrix in Table 4 shows that both active and passive patients preferred a written copy over a taped copy of their diagnosis, and that all active patients indicated that they wanted a copy of their diagnosis either in written or taped format. Therefore, the results indicate that active patients would like to receive a written copy of their diagnosis, while passive patients would prefer either a written copy or no copy at all.

The following is an excerpt from a patient interview regarding preference for a taped copy of the diagnosis:

Passive patient

There's no need. As I say, I will always remember exactly what he said....it's in here (gesturing to brain). I remember his words and I remember the look on his face, so I would neither need a video presentation of it or anything because my memory will...serve me.

Hypothesis 3 - Treatment decision making control and illness label

It was hypothesized that patient preference for a euphemism rather than the word "cancer" would be negatively related to preference for involvement in treatment decision

making. That is, active patients were expected to indicate a preference for their physician to use the word "cancer" when speaking with them, while passive patients were expected to prefer that a euphemism for "cancer" be spoken or that no descriptive term be used by physicians when referring to their illness. To analyze the data pertaining to this hypothesis, two Wilcoxon's rank sum tests were performed. First, this statistical procedure was applied to the role preference data using "cancer" as one category and all the euphemisms (i.e., "malignancy", "tumor", and "mass") and the non-descriptive term option in the second category. Second, a similar analysis was performed on the role preference data using "cancer" and "malignancy" as one category and the remaining euphemisms and non-descriptive term option in the other category. Both of these analyses were statistically significant: ($z = 1.95, p < .05$, one-tailed) and ($z = 2.29, p < .05$, one-tailed), respectively. The eta values associated with these two analyses, respectively, were .334 and .393. A Wilcoxon's rank sum test was performed on the role preference variable using "cancer" as the first or second most preferred choice in one category and "cancer" as the third, fourth, or fifth most preferred choice in the second category but this analysis failed to reach statistical significance.

The number of active and passive patients who preferred the descriptive terms as categorized above are presented in Table 5. From these two contingency matrixes, it may be concluded that virtually all active patients prefer that their physician use the word "cancer" or "malignancy" to describe their illness while approximately 75% of passive patients prefer that a euphemism for the word "cancer" be used. Note that only 1 patient (passive) preferred that no descriptive term be attached to their illness by their physician, and that three patients (all passive) ranked "cancer" as their least preferred option.

The following are excerpts from the patient interviews with respect to the word used by the physician to describe the patient's illness:

Active patients

He said that there was a problem. Well, when you know there is a problem you associate it right away with cancer, but I had to hear it. I had to hear the word because I couldn't say that word to myself. I couldn't say I had cancer to begin with. So I had to hear it from the doctor...that I had cancer...and then I could say I had cancer.(first choice - "cancer")

I don't know...if you say "cancer" you know it's serious. I mean, you might as well think about it seriously...if you call it a malignancy, well, you know, that's not so bad...but when you hear it's cancer, you know, it is serious and that you have to act on it....(first choice - "cancer")

TABLE 5

Contingency matrix for role preference and preference for a verbal descriptor for the illness

	"Cancer" or no label	Euphemism or no label	Total
Active	10	5	15
Passive	5	15	20
Total	15	20	35

	"Cancer" or "Malignancy"	"Tumor" "Mass" or no label	Total
Active	14	1	15
Passive	10	10	20
Total	24	11	35

Self-denial is a big part of it because I know it was self-denial with me. I said "No, this isn't cancer", you know, "I'm feeling too good for this". You know, right after the operation I recovered so very quickly...I felt really good and then I said "No, this can't be cancer" but these treatments have made me realize that it is cancer, because, you know, when you go through these treatments it kind of shocks you. (first choice - "cancer")

He told me when they tested - "It was cancer". And I said fine...I knew it was...either it was or it wasn't. (first choice - "cancer")

I think that many people are too afraid of the word. It's just the word itself...you just feel - well, you're doomed if you've got it, and if you understand more about it you'll know it isn't so. It's just one of many illnesses and not necessarily the worst maybe. (first choice - "cancer")

Passive patients

I'm not crazy about the word...put it that way. I mean it's not a nice...I use it...I do use it. I'm using it more everyday but you don't run around telling everybody "I've got cancer"....all your friends know...friends have been terrific...but...the cancer word...it's a scary word because, you know, many outcomes that haven't been too good. I've had a lot of people in my family that have died of cancer. So, I'm not too crazy about using the word. I use it, but...it's not in my daily vocabulary if I can help it. I don't avoid it. (first choice - "malignancy"; "cancer" was second choice)

...she probably equates the word "cancer" with death, obviously. I mean it's something that she can't even grasp, you know, to use that word. And, of course, for myself, I always use it because that's what it is...and it's...there's treatment

for cancer and there's hope for cancer, and it's...your attitude is the main thing.(first choice - "cancer")

...when you first hear it <"tumor"> it's not so dramatic as being thrown at the word "cancer". It's the biggest frightening thing, you know? I think if they use the word "tumor" first...you got a tumor, okay, then you know that anyway...I think it's easier to...I don't know...you have to face the facts if it is cancer....Well, to use the word "malignancy"...it was malignant...that word "cancer" has become such a big C...it's a very frightening word.(first choice - "tumor"; "cancer" was fifth choice)

I guess it's just a scary word....I'd rather him tell me it's a malignant tumor or...whatever...other than the word "cancer".(first choice - "mass"; "cancer" was fourth choice)

...the first time they will tell you "cancer"...it's so shocking....So if they use maybe first "mass"...it's not so shocking...so maybe "mass" is a more appropriate word to use first...(first choice - "mass"; "cancer" was fifth choice)

People hear the word "cancer" and they just freak. It's terminal.(first choice - "mass"; "cancer" was fourth choice)

I talk to anybody about it...I mean if anyone says anything to me about it, yah, I'll talk about it. It's something that nobody else can help. It's a disease like chicken pox. It's worse than that but, you know, it's something that can happen to anybody and everybody. Yah, it's something that should be talked about. It's not a closed closet anymore, I think, not like it was then.(first choice - "cancer")

Hypothesis 4 - Treatment decision making control and treatment alternatives

The hypothesis that patient preference for disclosure of the major treatment options and the degree of risk attached to each option is positively related to decision making role preference was confirmed. A Wilcoxon's rank sum test on the data showed that active patients wanted their physician to provide them with all treatment alternatives and the degree of risk attached to each alternative, and passive patients also preferred to hear about all the available treatment options ($z = 3.299$, $p < .001$, one-tailed). The eta value for this relationship was .566. Given the large number of passive patients who wanted to be informed of the major treatment alternatives (see Table 6), the patients were categorized as active, collaborative, and passive, for further analysis. Also in Table 6, this trichotomized version reveals that all active patients wanted complete information about all of the major treatment alternatives, while passive patients preferred to hear about the single best treatment or hear nothing at all. Of the five passive patients, only one indicated that they did not want to hear about their treatment.

TABLE 6

Contingency matrix for role preference and preference for information about treatment alternatives

	Major	Best or None	Total
Active	15	0	15
Passive	13	7	20
Total	28	7	35

	Major	Best or None	Total
Active	8	0	8
Collaborative	17	3	20
Passive	2	5	7
Total	27	8	35

The following is an excerpt from one of the patient interviews with respect to desire for information about treatment alternatives:

Active patient

I felt I had to know it all so that I could make a proper judgment for myself - what kind of treatment I wanted, and I...just felt that I had to know it all. If I didn't know what was going to happen to me or what alternatives I had, then it wasn't a positive thing for me.

Hypothesis 5 - Treatment decision making control and treatment procedures

The degree of technical detail preferred by patients in the physician's description of treatment procedures was shown to be positively related to role preference. A Wilcoxon's rank sum test indicated that active patients want detailed information about their treatment procedure, while passive patients cannot be so clearly categorized as desiring detailed or brief information about their treatment procedure ($z = 2.385$, $p < .01$, one-tailed). The eta value for this relationship was .409.

Role preference has again been dichotomized and trichotomized (see Table 7) for the reader to gain a clearer understanding of the information preferences of the patient sample. The data suggest that all active patients

TABLE 7

Contingency matrix for role preference and preference for information about treatment procedures

	Detailed	Brief or None	Total
Active	15	0	15
Passive	14	6	20
Total	29	6	35

	Detailed	Brief or None	Total
Active	8	0	8
Collaborative	17	3	20
Passive	4	3	7
Total	29	6	35

want detailed information about their treatment procedure, the majority of collaborative patients want detailed information, and passive patients (as presented in the trichotomized contingency matrix) are evenly divided among wanting either detailed or brief/no information. Only one patient (passive) indicated that they want to receive no information about their treatment procedure.

The following excerpt from a patient interview pertains to desire for information about the side effects associated with treatment:

Collaborative-Passive patient

Because he was saying something to me that I wasn't sure if I was understanding, and if I was understanding it the way I thought it was, it was a side effect that I had never heard of before and I wanted to know "Yah, could this be happening to me or is it very unlikely"...and then I got talking to my own oncologist last week and he said "No", he couldn't have been saying what I thought he was saying. But I had him repeat it twice and I came out with the idea that I knew what he was talking about and yet, needless to say, I didn't.

Hypothesis 6 - Treatment decision making control and treatment side effects

The hypothesis that patient preference for information about all possible side effects and how to remedy them is a positive function of preference for involvement in treatment decision making was not supported by the data.

The contingency matrix presented in Table 8 suggests that the failure of this hypothesized relationship to reach statistical significance may be attributed to a ceiling effect, i.e., the majority of patients, both active and passive, desire detailed information about the side effects associated with their treatment.

There was one passive patient who preferred to receive no information pertaining to treatment side effects. This is the same patient who preferred to receive no information about treatment alternatives (hypothesis 5) and treatment procedures (hypothesis 6).

Hypothesis 7 - Treatment decision making control and prognosis

The relationship between role preference and preference for receiving prognostic information was not statistically significant. As shown in Table 9, for each subgroup of active, collaborative, and passive patients, there were slightly more patients who preferred to hear the best possible prognosis with respect to their illness than there were who wanted to know of the best possible health outcome. Table 9 does not include the data of one active patient who preferred to hear the worst possible health outcome.

TABLE 8

Contingency matrix for role preference and preference for information about treatment side effects

	Detailed	Brief or None	Total
Active	14	1	15
Passive	16	4	20
Total	30	5	35

TABLE 9

Contingency matrix for role preference and preference for prognostic information

	Most Likely Outcome	Best Outcome	Total
Active	3	4	7
Collaborative	8	12	20
Passive	2	5	7
Total	13	21	34

Content Analysis

The purpose of the content analysis was to collect a qualitative data base to facilitate understanding with respect to the relationship between treatment decision making role preference and information preference. To this end, these constructs were discussed with the patient sample. Several themes were drawn out of these discussions and are presented below.

i) Treatment decision making role preference

Patients who preferred an active role in treatment decision making indicated several reasons for wanting to do so. Active patients stated that because it is their body and their life that is being altered by the cancer, they have a personal right/responsibility to have the final say about the type of treatment they receive. Patients frequently used the word "control" when articulating why they wanted to play an active role. These patients said that it is important to have control over one's body, health, and life, and that it is necessary to be, at least, treated as an equal by the physician if their sense of control is to be fostered. Playing a role that is subordinate to that of the physician would threaten their control. Patients indicated that having control over treatment decision making allows them to maintain a

fighting spirit or positive attitude which, in turn, they believe to be beneficial in combatting their disease.

Passive patients felt that treatment control is best left in their physician's hands because the physician has the knowledge to make the best possible treatment decision. For this reason it is important to place faith and trust in your doctor. Passive patients expressed discomfort with the thought of having to make their treatment decision and identified the physician's input as instrumental to an effective decision making process. Having identified the importance of the physician's knowledge and expertise, passive patients indicated that they want their physician to keep them informed of their treatment plan. Some of these patients stated that they want their physician to consult them after having formulated a treatment plan.

The following excerpts from the patient interviews provide a sampling of the reasons why patients prefer a particular decision making role posture. There was some variability of responding in that a few active patients responded in the manner of passive patients and some passive patients wanted to be a major contributor to the decision making process. The words of the majority of patients, however, echo the foregoing themes:

Active patients

Basically, it's a matter...that it's my body...it's my decision, it's my life. I'm the one whose going to have to live it right or wrong, you know....I prefer to have an active role in making decisions that will effect my physical health, my quality of life, and eventually when and where, if possible, I'm going to die from it....I would never have just allowed someone to say "Now this is what we are going to do" and let them get away with it without asking a lot of questions.

I think because I had to have a positive attitude and if I didn't know what was happening to me...I think that's a lot to do with the cure of it...is your attitude, and because I felt I had to know it all so that I could make a proper judgment for myself - what kind of treatment I wanted, and I...I just felt that I had to know it all....I'd rather go for the positive at this point than the negative because I think it's better for me...for my overall mental...as well as physical....

Well, just in case my doctor might have prescribed a very light treatment and I felt I wanted to have more aggressive treatment, to make sure if I had any more cancer that the chemo will destroy it.

I think everyone has a personal right to make decisions for themselves. You can collect...you can get expert advice on the subject but the ultimate decision should be your own.

Because I think it's up to me to decide what is best for me...after consulting, after reading maybe, asking for more consultation with different doctors like I did when I was given my diagnosis - I asked for another opinion...and then I decided to go for surgery, but ahh...I think it's up to me as a patient, as a person, to decide what I want to do with my life. If I don't want treatment it's up to me....I could have refused treatment...I was tempted to

refuse treatment....I think it's important to keep that control over my life, over my health, and...what is going to happen to me. I like control in other areas and I think this is the most important area of my life.

Collaborative-Active patients

I find if I'm in control...if I make a decision with the doctor...I can fight better with my cancer...if I can have some control then I'm more willing to fight, therefore, to heal better.

I don't want the doctor to be way up here and me to be way down there. I like to...I mean I know I can't be on the same level as the doctor but I like to...would like to communicate with him as to treatment....I just don't want to say to him "Well, just do what you have to do and I'll go along with that and not ask any questions"....I'm just nosy. I'm basically a nosy person....I mean I put all my trust in the doctors but I still want to know what's going on.

I possibly couldn't know all the things that the oncologists know about cancer, and I like to...interact with my surgery, therapy...for them to give me their input on what could be done or can be done....I am a very independent person, I think....I find it bothers me...it really troubles me if I can't...if I'm not given space...to be independent. But I do like their input....I don't like the passive role.

I prefer that my doctor and I share responsibility for deciding because I didn't want to just...I wanted to know a little more about it before I made my final decision....I did more inquiries then decide with my doctor....I would like to make the final decision with my doctor after I've discussed it with somebody else besides...not just my doctor.

...it is my body that's involved in this, and...I like to have a sense that I have some control over what's happening to me when I'm in a situation like this, especially because it's a situation where you do give up a lot of control, and by...making decisions in co-operation or conjunction with a doctor who has the information that I need to have to make those decisions it allows me to maintain a sense of control or autonomy but still have the information I need to make an informed decision...So...I think it has to do with having a sense of control over your own body....

Collaborative-Passive patients

...he explains everything to you and he tells you what he thinks would be the best thing for them to do for you...so you kind of mull it over and if you think it's okay you go along with the doctor.

...I don't want the doctor to take the full responsibility. I want to have a...choice in that, but I want to know what all the choices are....I don't want to feel afterward that my doctor didn't have any input but by the same token I want to know that I've had some input as well....it was the doctor who did the actual surgery that I felt gave me a share in the decision as to whether it be the lumpectomy or the mastectomy...I don't really feel as though I had any choice in treatment...it is the doctor in here who made that decision.

I have great faith in my doctor. I had good doctors looking after me...they have all the information...much more than myself, and I think a patient has to, just, have good faith in their doctors...I would like him to...relate to me and explain everything and not keep me in the dark, and the more I know...the better off I feel I am....I feel once they tell you what's happening and you understand your doctor, it's good to go with him because you cannot

make these big decisions. You don't know what the cobalt machine does, how much it's gonna do for you, what it's gonna do for you...you have to leave this in the hands of your doctor...I'm a person that believes in people and ah...I wouldn't want to say I want this or that because I don't know if that's what would be good for me.

...he or she is educated in this field so I automatically trust the doctor...and I don't have the knowledge, or whatever, that they have so...that's what you see a doctor for....so you feel you are participating so your doctor isn't like a dictator...you're sharing in what's going on....I think a person doesn't feel as alienated if they're sharing. I think if the doctor were just to tell you "A, B, or C. We're going to do this or that"....I think I would feel treated as a child.

I wanna know what's going to happen. But I don't want to make that decision alone....I want to take part in that decision but I don't want him to decide, in case it's something I don't agree with....I prefer to be involved even though I let my doctor, in this case, do most of the decision...but I was so caught off guard...but I'm happy with the decision I made....I didn't really have any choice actually. So I had to take his word for it. You have to take...you have to believe in your doctor too.

I prefer the doctor's opinion but I would still like to ask what he had in mind, what I would prefer or suggest, you know, but I would more than likely go with...the doctor's recommendation....but at the same time you just don't want to be left in the dark- to be told "This is what's going to happen". It's important for you to be involved in some way....it just makes me feel better to have a say in something, especially when it's my body that their talkin' about....but I don't think I would

be able to do better than the doctor's diagnosis and treatment.

Probably because I feel more comfortable with it, knowing that he wants to share the fact that I have cancer...that we can just talk about it together....I'd like to know what the doctor has to say and I feel more comfortable with him giving a decision that I can base my decision on....a mutual kind of decision. I think it's much easier for the patient....I like to know what's happening.

Well, sometimes I don't agree with what they're going to do and I'd like to have a word in what, you know...what decisions somehow...to have some say in the matter. I'd don't like to just let them have blank decisions to do what they like with me....But I would listen to the doctor and want to know why he is doing this and that sort of thing to me without just taking his word for everything.

I feel you discuss it with the doctor...he explains the possibilities of different things happening and...suggests a treatment, and then we can discuss that and...decide which is best for me.

I put my trust in the doctor and he'd know what's best for me. After all, he's had all these studies about all this....not knowing too much about any of this I just felt he would know what's best for me or best for the type of cancer that I have....Well, it's just that I didn't know what to ask. I was asked too, have I any questions, and I didn't have any questions because I didn't know...what was I supposed to ask.

I prefer that my doctor is responsible for deciding the treatment....I don't want to decide just for myself. I want to hear first the opinion of my doctor.

Because when it's got to do with you, you don't want to feel like someone else is taking control of your life.

Passive patients

He knows more about it than I do, so, I mean I think he should have...the final decision as to what is going on....I'd like to know what is going to be happening but I don't know anything about it so...he's got - not the right - but he's got more information to know what's right....but I also want some say in it....I wouldn't want to just sit back and ask nothing and know nothing...I like to know what's going on.

Well, he's the one that knows it all.

Because I feel the doctor knows what he's doing and I have full confidence in my doctor. Therefore I listen to him and that's why I decided on that...I gave my opinion too.

...I guess I think the doctor knows a lot more than I do...about my problem. But I like him to listen to me and what I think too....I've trusted them right from the beginning...

Because they obviously are the people who are most knowledgeable about it all and...I wouldn't know what kind of decision to make....They have the training and the experience and they're the ones who know what has to be done....I wouldn't know how to make a decision about it. I have to rely on them....If you have any faith in your doctor then you let him decide what to do....I don't want to know the bad things that can happen. If they're going to happen, they're going to happen anyway. I don't want to know all about them, and I just rely on my doctor to do what has to be done at the time....So the less I know the happier I am.

I think the doctor would know what was best to do for me....I suppose it would help if you had read up on it but I still think the doctor would be the one to decide what treatment you have.

ii) Patient perceptions of their physician's prescribed role

The patients were asked whether they had a sense of the kind of role (i.e., active or passive) that their physicians wanted them to play with respect to treatment decision making. The patient transcripts suggested that the majority of active patients believe their physician wants them to play an active role in their care. Passive patients were equally likely to believe that their physician wanted them to adopt a more active role as they were to believe the physician would prefer that they adopt a passive stance. There were a minority of active and passive patients who did not have a sense of the role their physician would like them to play. Excerpts from the patient interviews are presented below:

Active patients

...he expects me to make decisions about my treatment...he told me what treatment was available and it was my decision whether I wanted to accept it or not....he didn't force anything on me.

I think he'd prefer me to ask the questions. That's one thing I've found here; that there wasn't any silly question that you could ask. Everything was a serious question because it involved you...so I don't hesitate to ask any

questions no matter how trivial they might seem....they want you to have a little control over what is happening to you. But also, I've found that they take a cue from you...

I had three visits with him before I made the decision to go through with this program so I imagine that he would rather I participate in it I guess. I don't know really...

I have very much a sense that he's more than willing to answer any questions that I have...I know when I went the first time and he explained about the radiotherapy, he was very thorough in explaining it and more than willing to answer any questions that I had. So I get a sense very much that he wants you to understand what's going on and to ask questions if you don't understand.

No, we hardly ever talk about it. We did the first day when I was in and really not that much....They don't really have time to chat because they're in and out so fast.

...if I recall the first meeting that I had with him...and I had to make a decision as to whether to go standard or protocol...I remember him telling me that it was my decision only...so I guess in some ways he wanted me in control of the decision I was making and it was not his decision.

....maybe doctors don't like the patients asking questions - so many questions, but let them place themself on that bed....what's going through a patient's mind...is this right, is this wrong?...you ask questions to a doctor...you know how you want to know these things? And maybe the doctors think well...it's too much from patients.

I know he's got my best interests at heart but I just get the feeling that maybe he would like me to not ask questions...just sort of sit back....He's very busy.

...no, I don't really have a sense....I get the sense that it's probably up to the patient - how many questions they ask and that sort of thing.

Passive patients

Well, he asks questions so I'm sure he has...both of us having something to do with the treatment. Like the way he speaks...he doesn't just tell me and that's it.

Not really. I don't have much to do with my physician, really. I see him maybe two minutes here and there and that's about all.

The medicine oncologist, he likes to be the one in control of everything.

...he always tells us "Now, don't make up your mind just on a spur of the moment". He says "You go home and you think it over and next time you come and see me we'll talk about it"....he never tells us he wants us to make up our minds right then and there.

I think he wants to know how I feel, what I want to do and...I saw the doctor this morning, and...he kind of asked me questions and let me ask questions....He kind of seems to know what I can take and what I can't take.

In his position and everything...he knows it all.

I think a more active role in...letting him know how you're feeling, how you're responding to treatment. I'm sure that must help him...absolutely.

iii. Which patients should play which type of role?

The patients were asked whether they felt that some patients should make their own treatment decisions while other patients should leave treatment decision making in the hands of the physician. This question was asked to a greater proportion of active patients because there were some passive patients for whom this question seemed inappropriate. The researcher felt that there were passive patients whose efforts to cope with their illness might be threatened if they were to contemplate the implications attached to their consideration of the active role (i.e., if they felt they were not a "good" patient because they had not endorsed the active role).

The majority of active and passive patients that were surveyed stated that there was no best role that a cancer patient could adopt. There was one active patient who felt that all cancer patients should play an active role, and one passive patient who believed that all patients should have their treatment decisions decided upon by their physician. All other patients felt that the best role (i.e., active or passive) for a patient to play depended on the particular circumstances and coping style of the patient.

The patients voiced several explanations as to why patients adopt different role postures with respect to

treatment decision making. These explanations included a patient's inability to play an active role given mental infirmity, a lack of education, and difficulty in accepting they have cancer. For these reasons, it was felt that patients need, and benefit from, an oncologist who can make decisions on behalf of the patient. Other explanations provided included the amount of faith that a patient has in their physician, the patient's will to live, and the manner by which the patient has coped with other threatening situations in the past.

Active patients

...there are people who, when confronted with the words "cancer" of any kind or some major illness, are likely to retreat and sit there and wring their hands and..."Why me", "Why Now", this sort of thing...and maybe procrastinate to the point where they would die before they had to and in that case I think that other members of their family and/or their doctor should step in and take a more active role and say "We are going to do this now, we are not going to wait until later. We are going to do it and take care of it", and sort of lead them by the hand through it if they have to....there are some people that are incapacitated mentally when confronted with this. To a certain extent it's their personality...probably the way they've confronted other things in their life.

...I think it just depends on the person. I guess maybe some people...can't accept what's going to happen to them...it's bad enough that you've got cancer without knowing that...you're going to have surgery or whatever treatment you have.

I think the patient should make their own decisions...

...you're just fooling yourself, I think, if you're just playing a passive role....It's better to be passive for some people because some people, maybe, couldn't handle it. I mean, maybe it's hard to cope with it at first...I think it's personality...a lot of it.

I think it would depend on the patient. For myself, I can't hide my head in the sand and pretend that it's not happening...but maybe somebody else doesn't feel that way. They'd just as soon think "Well, I've got this problem, you deal with it, fix me up so I'm okay, and let's just get on with it." And I feel that way too...like I want them to fix me up, I want to get back on with my life sort of thing and not have this hanging over my head. But at the same time I have to live with myself and I worry a lot about things and it's usually about things that I don't know something about...I worry about the possibility of things that could happen, so if I ask him questions and find things out, it helps me.

I guess it depends on the individual...a person sort of approaches it differently and I think it's an individual preference.

I think it's just an individual decision that has to be taken...I'm concerned about myself and if the system is such that I can make my own treatment decisions...great, but everyone else decides what they want to do. I think it's better to...to fight. I think it is a better surviving mode and...approach but it's their decision...it's not mine to decide....I think it's part of their personality and it's how much they want to hang on in life. I think it's a matter of life or death and if you want to hang on. If you have a surviving approach where you fight hard and

if you want to let go and die then just let go and die. So I think it's a matter of personality and what the person is going through in his life at the moment...and that...makes him decide to fight, make decisions, control or just "I let go and I don't want to go on and the doctor makes the decisions for me".

Someone who is maybe a real passive person like - "Take over...I'm in your hands and do whatever and I don't want to know about it" - I think would have to be a sort of laid back, passive person.

It probably depends on the patient....Or maybe just don't have the energy to, or feel they don't have the confidence in themselves to go ahead and learn more and maybe have to take a role in it. I guess it varies with people...how much faith they put in their doctor. You almost think of the doctor as a magician who can just take you over and do everything. So, that could be a reason for playing a passive role if you feel that way.

Passive patients

...perhaps because some people might have more of an understanding of what's going on. Some people, maybe, are perhaps very poorly educated...that they would have no idea at all what's going on and in that case I feel the doctor should certainly be making their decisions but that's just my own opinion.

It could depend on the patients...some patients want to take part...they should be given the option. But if they don't want to take a role in it, well then that's their decision.

Clinician: Do you think some patients should play a more active role in treatment decision making while other patients should play a more passive role?

Patient: No.

Clinician: Because all patients should play a passive role?

Patient: Yah, that's right.

iv. Information needed to address present concerns

Patients were asked if there were any decisions they were facing in their life and what information they needed to address these concerns. Approximately one-half of the sample did have questions with respect to the treatment of their illness for which they were in need of information. Some of the patients indicated they had no questions because once their treatment had been decided upon there were no more questions to consider asking. Other patients stated that the only treatment-related decision they were facing was that of deciding whether or not to continue treatment. Several patients mentioned at some point in our discussion that they could not think of any questions to ask their physician while they were speaking with him during their weekly visit but that as soon as they left the physician's office their minds were flooded with concerns and questions that were anxiety-provoking.

The concerns for which patients had formulated questions varied greatly, encompassing issues such as treatment procedures, side effects associated with the treatment, and prognosis. Excerpts from the patient interviews pertaining to the information needs of patients are presented below. Rather than present excerpts from active patients and then

passive patients, excerpts are presented for those patients who had information needs:

Patients with questions/information needs

Well, the only thing about my treatment is...I would like to know how the machines work.

...I'd like to know a bit more about...what kind of cells is the chemo destroying? This part here I don't understand.

I'm already wondering to myself....Are there any instances when they say "Well come next Tuesday morning...oh ho, this isn't quite enough. We'll give you another"....I'm curious as to how an oncologist decides what number of treatments for what patient for what type of cancer. But that's just a curiosity...but I would still like to know...

"What is it in my blood that was cancerous?", "Why did my system pick that up?" That's my question. I don't know if anyone can give me an answer.

...if I get sore breasts from radiation I want to have some cream ready to put on me...that's my only concern that I can think of at the moment.

Well, right now all they can give you is statistics and stuff and you kind of want to know what's going to happen in the future...but they can't give you that.

"How do we know this is working?"... I've been having blood tests all the time but do we really know the chemo's working...

I would like to know...they were supposed to be taking pictures while they were giving me the treatment....they did it

twice and they haven't done it again since...

v. Should all patients be given the same information about their illness and its treatment?

Almost all patients stated that the kind and amount of illness- and treatment-related information that physicians should provide to patients depends on the type of patient with which the physician is engaged. There was only one active patient who stated that all patients should be given the same information.

Patients indicated that there are four considerations involved in deciding whether to provide a patient with information. First, there are some patients who don't want to be informed about their illness and their wishes should be respected. Second, there are patients who can not manage the information perhaps due to a lack of education or the utilization of an avoidant coping style such as denial. For these patients, it may be useful to notify family members of the patient's health status. Third, several patients stated that personality differences across patients influence the extent to which they desire information. Fourth, patients mentioned that either illness severity or the post-diagnosis time duration may alter a patient's desire for information. That is, patients with a poor prognosis or those who have been recently diagnosed may be less wanting of information

because it threatens their coping effort and increases psychosocial distress.

The following are excerpts from the patient transcripts with respect to the amount and kind of information that should be provided by physicians to their patients:

Active patients

Well, ideally I suppose they should but if they can't deal with it then maybe they shouldn't.

I suppose it varies really...their personality...maybe they would rather not know so maybe it's up to the doctor to sort of look at his patient and see what they're like.

I think some people need to know a lot more than others do and want to know a lot more and others, maybe, don't want to know as much.

I think it depends on the period of time whether...you give the information early on or later on.

Some people say "What I don't know won't hurt". I feel that...what I don't know I don't have control over...

Collaborative-Active patients

I think the oncologist should...sense which person he has in front of him. I think there has to be some psychology here...of knowing how to provide the information...I find that each person should be told if they have cancer or not, rather than vague things or nothing at all...because then they are not given a chance to fight or survive if they want to...the oncologist should say the person has cancer but I think the oncologist should...not just show

the bad aspect of the disease but should also let the patient know that he can handle...and it's his own decision to survive and fight his disease.

I feel the doctors should be very open to patients...like tell 'em....I don't think they should keep anything from patients.

Patient: I think maybe some patients couldn't handle knowing everything, do you know what I mean? Like that might really bother them....But that's up to them....that's something that you would have to get settled with your physician or oncologist, or whatever, right from the beginning....I think in this field that the physicians/oncologists...have to be sensitive to that...and I would hope that they would...find out...I was just thinking back...I was told...what was going on, mind you my diagnosis, my prognosis was excellent but if it wasn't, I don't know if I would have wanted to know. Maybe not everything...So, it's hard to say but, yah, some people maybe should not be told...be up to them.

Clinician: It's important then to ask them-
Patient: Yah, I would think so...or, maybe not ask them. Maybe ask their family....cause if your sitting there and the doctor says to you "Well, do you want to know or do you not want to know."....then you're kind of going "uhh"...maybe in a round about way. Maybe go through the family or something, instead of coming right out and asking the person.

I believe that everyone should be given...some might need a little longer time to be told...see the doctor more times and go at it slower.

Well, some people I think can't take all of it.

Well, I think it depends on the kind of person and it also depends on how you...process information....one of the

things that I sense is that there seems to be a philosophy that people can only handle X amount of information at a time...they dole it out to you in little bits and you never quite can get the whole picture. So, what happens is you have this series of appointments and you anticipate the next appointment...about what they're going to tell you and...the thing would be to do is to ask the person "Are you a small picture person or a big picture person?" If you're a big picture person they give you the whole thing. If you're a small picture person then they can give you little bits of information as you go along through the system.

Collaborative-Passive patients

But I think one person or maybe two or three people in the family should know what's going on so that...say they go and visit somebody in the hospital and this person looks just terrible and they don't know what's really wrong and if they knew the circumstances they'd know "Well, this is what can be expected." See...even if the patient doesn't know...but someone should know that is close to the person.

I think it depends on the person's personality.

...in our country I think everybody should get the same amount of treatment and the same amount of information, certainly. I don't think there should be different levels of information given to anybody and, actually, if people are slow or, say, from a different type of society, I think it probably takes longer to explain. I think, maybe, repetitious explaining to some people, and I think they should know. But then there's people that don't want to know....So there's different types of people who want different types of information as well.

I think they should be well informed....it depends on each individual...how strong you are and how positive you are.

Oh, I suppose it's the patient really. If they want to know about themselves...what's going on. Some of them don't want to know...

I guess it depends on the patient but also the extent...of the cancer they have. But, as I say, it's difficult to answer for someone else isn't it, when you feel a certain way yourself. I like to know exactly where I'm going. But ah...I guess there are a lot of people that kind of are afraid of it.

It probably depends on the patients themselves because some patients can handle things better than other people. Other people want to know everything. Some people don't want to know. It would depend on the person and the doctor.

Passive patients

I think everybody should know what's...I say everybody should know - no, that's wrong. Probably some people can't take it....not everybody handles it the same way....I don't think everyone can cope with it, can handle it. They probably can handle it in little doses but I don't think everybody wants to know everything the same as I do. Everybody is different.

Depends on the patient....I think he should tell you the truth, shouldn't he? They do tell the truth as a rule, don't they? They don't hide...like...when I was examined, right away they told me. They gotta tell you, am I right?

I suppose it depends on the patient, on what attitude they take toward their illness, whether it's good for them to know everything or no.

In their responses to the question regarding the amount of information that should be provided to patients, many patients indicated that it is important for the physician to be sensitive to the role preferences of their patients and the amount of information that their patients might want to receive. This became apparent after speaking with the first five or six patients. The remaining patients that were interviewed, therefore, were asked whether the oncologist should strive to ascertain whether they have an active or passive patient seated in their office and whether the patient wants to receive detailed information or not. A sampling of excerpts pertaining to this portion of the patient interview are presented below:

Active patients

Yah, I think so because we all have our own personalities. Some people are much stronger than others so I think that makes a lot of difference...

Yes, I think they should be sensitive to the patient...how they feel...I find for myself...I see this one doctor and they give me all this information and I see another doctor and I get all this information and I find...I have not had training in this and I cannot possibly absorb all the words and all the terminology that's used....

I think that probably just happens...because they give you so much information to begin with...you don't know what questions to ask to begin with because it's all so new...you only know what

questions you need to ask after they've sort of told you what's going to happen and what could happen...what treatment you can have...it all just boils down to the person and what they want to know.

...first of all they should probably ask the patient "Do you want to know the whole full extent and everything"...and then let the patient decide...how much they want to know...

Passive patients

I think when you talk with people...you get a sense of where they're coming from. In doesn't take long to get to know a person as to how they feel, and if you get the feeling that they want to know, I think that an oncologist's duty is to let them know.

I think he should be aware of what the patient wants...that's part of his job too. To realize whether they just want to be passive and listen or whether they want to play a role.

I think they sort of sense as to what the patient is like though too, don't you think so? I think they sense this right away because if the patient asks a lot of questions...or insists on it, they tell them about it. I'd imagine the doctor would do that already.

...I think it's up to the oncologist to kind of gauge how much information he gives out first and then your reaction to it...or tell him how much more you can take and how much little...how little you want to know. If you want to know more you will ask more questions.

Absolutely. The doctor has to know his patient. Sometimes the patient does not give out as they should...

I think so, because when I first went down to the cancer clinic there were two doctors there...they told me absolutely everything...I didn't want to know. I know they thought they had to give me the information so I'd know what I was going into but I heard so much about cancer and the different types and the different treatments and the ones that worked sometimes and sometimes don't and all this that it depressed me. I would rather just have them say "Well, you've got this kind of cancer and we're going to do this treatment."....I'd like to be asked how much I want to know before they tell me....Some people just have to know everything that could possibly happen and all the different treatments and that. Some people are like that but I'm not. I bury my head in the sand....some people are terribly interested in all the different treatments...some people...enjoy hearing about all these different medical treatments and what can be done and what can't be done and all that but not me. I just want them to fix me up and that's it.

vi. Perceptions of health care providers

Throughout the data collection period, several patients offered their opinion with respect to the care provided for them by health care professionals - particularly medical and radiation oncologists. A sampling of these comments are presented below, to provide the reader with a sense of the satisfactions and frustrations experienced by breast cancer patients as they proceed through the health care system. The comments were numerous and varied, and only a sampling are included. Given the diverse nature of the comments, no attempt has been made to summarize the

material. Although some of the comments are critical of the care provided to the patients, it is not necessarily the case that the experiences of the patients are unique to patients at the cancer centers that were surveyed. That is, similar comments might be obtained if the patients were drawn from other cancer clinics throughout Canada. Note that portions of the transcripts that include names of hospital staff are excluded, as are any statements the researcher felt might identify a patient or health care professional.

Active patients

...a lot of credit goes to the radiation department here. They have a certain knack of making people feel relaxed....it would have been a lot more helpful for both me and my roommate if you had a continuity of nursing staff. I guess I was in ten days and we had the same nurse twice. We had a different nurse every day.

I think that should be re-emphasized with the oncologist, that positive attitude towards life...towards fighting the disease and making changes in the patient's life if he has to make changes to fight better. I think this is an aspect that perhaps the oncologist is not dealing with because it's not scientific enough probably....the person has a disease but the person is not a disease and I think...if there was a human aspect to the department of oncology...there is a human aspect but it's always scientifically related to the treatment ...symptomology, etc....I think the mind and the body are so closely related that I think it would be very important that there be a team of

psychologists...psychotherapists that are directly in the department...like having offices in their department. There is social work but there should be more to this department than doctors, nurses, social workers.

....maybe doctors don't like the patients asking questions - so many questions, but let them place themselves on that bed....what's going through a patient's mind...is this right, is this wrong?...you ask questions to a doctor...you know how you want to know these things? And maybe the doctors think well...it's too much from patients.

I don't want the doctor to be way up here and me to be way down there. I like to...I mean I know I can't be on the same level as the doctor but I like to...would like to communicate with him as to treatment....when I have to...have my check-up with my oncologist, I prefer to have it with his nurse...I know he's got my best interests at heart but I just get the feeling that maybe he would like me to not ask questions...just sort of sit back...but his nurse is great....He's very busy....it's good that I have his nurse to talk to. Otherwise I think it would probably bother me.

...all the radiologists here seem to be very, you know, I haven't asked a lot of questions but they give me the impression they'd be more than willing to answer any questions. They always explain exactly what they're doing and exactly what to expect from the machines...

So I had asked the oncologist about it the first meeting and he just avoided the whole question and it was like such a fast meeting and he was like out the door and I never got the answer, and so I walked around for many weeks thinking that pregnancy meant, you know, imminent death....I think that the whole area of

breast cancer and treating patients has to be rethought in the light of feminism. Like that just hasn't entered the medical community at all, and I think that has to do with issues of control and information and all of that stuff. I think that the medical profession perhaps, because it has been largely male dominated and it's very old in traditional professions, still has aspects and vestiges of sexism that will take a long time to...

Passive patients

Dr. _____ was my oncologist. I had a nice meeting with him at the beginning and he explained everything in detail, and I felt confident when I went.

...if I am his patient I would like to see him more...the one resident I have seen I had such terrible time understanding...I had him repeat and even when he repeated I could not understand what he was talking about....I felt it was my prerogative to say "Hey, I'd like to speak to my own oncologist", and I heard him laughing in the background but he came in and he talked to me, you know, like laughing at the fact that I couldn't understand

...they've all been fairly good...given me what kind of information I need to know.

Oh, I definitely think he certainly has a feel for the patient and, you know...definitely.

At the moment I'm not very happy with my doctor...perhaps I shouldn't say that....I don't get my answers....Well that didn't seem quite the right answer to me and I didn't know how to approach him to get any more information out of him....the technologists - the ones who give me the treatments - they're fine. They will tell me anything sort of thing they're going to do...but this doctor...I'm not satisfied with him at all actually and the way he

handles things. He won't tell me what's going on. He just looks at me. He doesn't look at my operation scars or anything to see if it's burning or anything like that. You'd think they would have a look at it but he doesn't. He just looks at my face and doesn't offer any information at all.

...we did come and talk with him for an hour...and he did show me the results of the biopsy which I was glad to see, you know...one and one-half centimeter and...it was explained - the size of it...and that was fantastic.

Summary of Results

The results indicated that active patients desire detailed information about their illness and its treatment. Passive patients, however, were often as equally likely to want detailed information as they were to want minimal information. Educational status was a statistically significant variable in that patients who were high school graduates tended to prefer an active role while patients who did not finish high school tended to adopt a more passive posture.

Both active and passive patients indicated that a written copy of their diagnosis was preferable to a taped copy. With respect to the word patients want their oncologist to use when referring to their illness, all but one of the active patients indicated that either the word "cancer" or "malignancy" was preferred. Passive patients preferred that a euphemism for "cancer" be used.

The content analysis revealed that active patients wish to play such a role because it affords them control over their body, health, and life. Passive patients said they wanted their oncologist to formulate treatment decisions without their assistance because they lack the knowledge and expertise of an oncologist. Active patients, and to a lesser degree passive patients, had a sense that their oncologist would like them to play an active role in their medical care by asking questions and contributing to the decision making process.

The majority of active and passive patients stated that neither the active nor passive role is a superior role to play, and that the best role for a particular patient depends on the patient's circumstances and coping style. The majority of active and passive patients also agreed that not all breast cancer patients should be given the same amount of information about their illness and its treatment. They indicated that a patient may not want information depending on the following patient variables: a) educational status, b) personality, c) coping style, and d) illness severity.

DISCUSSION

The results provide evidence for a relationship between patient preference for involvement in treatment decision

making and preference for illness- and treatment-related information. There appear to be three distinct groups of breast cancer patients with respect to these two variables. First, there is a group of active patients who want to receive detailed information about their illness and its treatment. Second, among the passive patients there is a subgroup who, like the active patients, want to receive detailed medical information, and there is a subgroup who desire minimal information.

The data suggest that understanding a patient's role preference can assist health care professionals in the provision of information to these patients. Moreover, the data suggest that when role preferences are defined as either active or passive using the card sort procedure, this statement is more reliable for active than for passive patients. The division of the role preferences construct into active, collaborative, or passive categories indicated that both active and collaborative patients desired detailed information while passive patients were equally likely to want information as they were to not want information. Due to insufficient sample size, however, chi square analyses for 3X2 contingency matrixes could not be conducted to confirm these observations statistically. Despite this limitation, the contingency matrix data

suggest that future studies of role preference must go beyond an examination of active and passive roles and, using a larger sample size, consider patients who wish to work in collaboration with their physician.

Given the limited sample size, it may be questioned whether breast cancer patients were adequately represented in this study with respect to the proportion of active, collaborative, and passive patients within the larger population of Stage I and II breast cancer patients. The proportion of active (23%), collaborative (57%), and passive (20%) patients obtained in this study is dissimilar to that reported by Degner and Sloan (1990) and Sutherland et al. (1989) in their role preference data collected from patient samples in Canada. The participants in the present study clearly wanted a more active role. Degner and Sloan (1989) reported that active patients comprised 12% of their sample, 29% were collaborative patients, and 59% were passive patients. Sutherland et al. (1989), in their Canadian sample of cancer patients, found that 10%, 27%, and 63% of patients, respectively, wanted to play an active, passive, and collaborative role. These findings are similar to those reported by Degner and Sloan (1990).

There are several possible explanations for the discrepancy between the proportion of patients preferring

various role postures found in the present research and in those reported by Degner and Sloan (1990). The first is methodological, specifically, the role preferences card sort procedure in the present study was administered differently than in Degner and Sloan's (1990) work. In this study, the first pair of cards that were presented to all patients were always Cards B and D:

CARD B - I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.

CARD D - I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

In Degner's research, the first pair of cards presented to the subjects were not necessarily B or D. In both cases, each card was paired with every other card, according to the requirements of the unfolding method.

Cards B and D were the first two cards administered in the present study because prior studies of patient involvement in treatment decision making suggest that most patients want to be at least minimally involved in making treatment decisions but don't want to be solely responsible for formulating their treatment decisions. Indeed, this was found to be the case in the present study in that only

one patient chose either Card A or E as their most preferred choice.

Although the card sort procedure was administered differently in this study, this fact does not adequately explain the discrepancy between the present data and that of Degner's. It is difficult to conceive of how this minor administrative alteration could produce such a dramatic change in findings. Three other possible explanations exist: a) the academic status of the researcher, b) the restricted sample size, and c) the type of cancer in the patient sample.

Nursing staff were commonly used to administer the role preference card sort procedure in the research by Degner and associates while in the present study a student served as interviewer. It is possible that in the former studies, patients were reluctant to indicate that they wanted to play a more assertive role in their care for fear that they may be perceived as challenging the professional expertise of their care-givers which, in turn, might reduce the quality of care provided for them. This possibility should be tempered by the results of the content analysis which indicated that patients often describe the nurses as the health care professionals with whom they feel most comfortable.

Second, given that only 35 patients were sampled, it may be argued that the proportion of active, collaborative, and passive patients obtained is not representative of the actual proportion of stage I and II breast cancer patients that fall into these categories in the larger population of breast cancer patients. Future studies should sample a greater number of patients to validate the representativeness of the results in the present study.

Finally, the sample in the present study was comprised of women with breast cancer. In the research of Degner and associates and Sutherland et al. (1989), the samples were comprised of cancer patients with varying disease sites. Degner and Sloan (1990) reported that females with reproductive cancer desired a more active role in treatment decision making than any other class of cancer patient. This fact may best explain the disproportionate number of active patients found in the present study.

In the process of developing the role preferences card sort procedure, Degner and Russell (1988) borrowed from unfolding theory and conducted an unfolding analysis on their data. Unfolding analysis is useful because it allows a researcher to ascertain whether a construct is unidimensional. In their pilot study, Degner and Russell (1988) found that 59 out of 60 patients could have their

card sort preferences unfolded using unfolding analysis. In a subsequent study conducted by Degner and reported in Degner and Sloan (1990), it was possible to locate two-thirds of the patients on a unidimensional continuum of treatment decision making control.

Coombs (1976) argued that as long as 50% plus 1 of the patients in the sample can be unfolded, the data support the existence of a unidimensional construct. Thus, the studies reported in Degner and Sloan (1990) support the existence of a unidimensional role preference construct according to Coomb's requirement. The purpose of this line of discussion is not to argue the dimensionality of the role preference construct. Rather, the fact that one-third of patients had card sort rankings that could not be unfolded raises the question of what thoughts were passing through the minds of these patients while they were proceeding through the card sort procedure. That is, given that their rankings did not illustrate the existence of a unidimensional construct, what constructs did they believe were being measured by the procedure? This is of particular importance in the present study in which approximately two-thirds of patients were able to complete the card sort procedure without difficulty while the remaining one-third of patients encountered difficulty with

the procedure. At one point, when they gazed upon two cards placed in front of them they became confused, shared a look of perplexity with the researcher, and admitted that they were not certain as to what the cards were "getting at". Do these patients represent the same one-third of patients for whom Degner found it impossible to unfold the preferential rankings along the dimension of interest? Alternatively, do these patients think about treatment decision making along a different dimension?

The question of whether patients in the present study would have produced preferential rankings that could not be unfolded if they were encouraged to proceed with the card sort procedure following the point of confusion was not explored in this study. Sensing the patient's puzzlement, the researcher chose instead to lay all five cards in front of the patient and ask them to successively remove their preferred cards and place them in a pile.

Future research is needed to explicate the hypothesized construct of treatment decision making role preference. Several studies have used various means by which to examine role preferences, but the construct has not yet been conclusively determined as unidimensional. One might argue that the card sort procedure should be used in applied research to demonstrate its clinical utility and that

further theoretical analysis will a) show diminishing theoretical returns and b) represent less useful research given its non-applied focus. Even if this is the case however, the important point to be made is that one should only place as much confidence in the conclusions drawn from applied studies that utilize the role preference card sort procedure to the extent that one may confidently articulate the construct(s) that the procedure is measuring.

Future studies are needed to a) further investigate the relationship between treatment decision making role preference and other psychosocial variables and quality of life concerns, and b) explicate the dimensionality of the treatment decision making role preference construct. Given that it was necessary, in the present study, to place all five role preference cards in front of one-third of the patient sample, future studies that are not designed to address the theoretical foundation of the construct should abandon the forced choice technique and simply place all five cards in front of the patient as described above.

The results pertaining to the relationship between role preference and receipt of diagnostic information showed that three passive patients did not want to receive their diagnosis. Given that these patients were sampled after they had received their diagnosis, it was not possible to

ascertain, prior to receiving their diagnosis, whether they would like to receive their diagnosis. If it is indeed the case that few breast cancer patients do not want to receive their diagnosis, and if it could be demonstrated that not being informed of their diagnosis would be beneficial for them, then health care professionals may have to consider their policy regarding informing all patients of their diagnosis. In many cancer centers, it is considered unethical not to inform all patients of their diagnosis.

It is not surprising that the majority of cancer patients are highly anxious when they receive their cancer diagnosis, and health care professionals have sought to develop procedures for reducing this anxiety. Cancer patients often indicate that they do not remember what their physician told them in the consultation during which time their cancer diagnosis was discussed. If important information is being imparted to patients during this consultation, a procedure that would facilitate information recall would be beneficial for patients and physicians as well in the sense that less time would be demanded of the physician to repeat information to address patients' questions. The results showed that it may prove useful to provide active patients with a written copy of the diagnosis using the same wording expressed to the patient

when conveying their diagnosis. Reynolds et al. (1981) found that information recall was enhanced by furnishing patients with a written copy of their diagnosis. Given the fact that a) patients in the present study preferred a written copy over a taped copy of their diagnosis, and that b) Reynolds et al. (1981) found that information recall was no greater for patients who received a taped copy relative to those who received a written copy, providing patients with a written copy of their diagnosis would be more beneficial to patients than providing a taped copy.

The above discussion assumes that it is desirable for cancer patients to recall important information that their oncologists provide to them. An alternative view is that subjects need to deny and repress information at the time of diagnosis because the information is threatening and serves to increase their anxiety. If this is so, presenting cancer patients with information in a form that readily allows for the use of avoidant coping strategies may be respectful of their coping attempts and may decrease psychological distress.

The results indicate that both the role preferences and euphemism preferences card sort procedures are useful for determining the word that patients want physicians to use when referring to their illness. Almost all active

patients want their physician to refer to their illness as "cancer" or "malignancy". A majority of passive patients (75%) want their physician to call the illness a "tumor" or a "mass", or not refer to the illness at all. However, one hesitates to recommend the use of the card sort procedure for determining the word that physicians should use when disclosing the cancer diagnosis because if a patient is in a state of denial, the patient's current state of psychosocial distress might be exacerbated by informing them that an alternative reference term for the illness is the word "cancer". Perhaps the role preferences and euphemism preferences card sort procedures could be administered to those patients for whom the physician has previously used the word "cancer" when referring to their illness to ascertain whether these patients actually prefer the word "cancer" to that of a euphemism. Alternatively, the card sort procedure could be administered after treatment has commenced, as was done in this study. In addition, the patient could be asked to specify what word their physician uses to describe their illness, and the accuracy of their response could be validated by the oncologist.

The retrospective method of assessing patient preferences has been useful for integrating the areas of

information preferences and treatment decision making role preferences. However, there are drawbacks associated with the retrospective method. First, it should not be assumed that a patient's preferences for diagnostic information and information regarding treatment alternatives is identical to that which might be obtained prior to the patient's receipt of the diagnosis and prior to the formulation of a treatment plan. It would be useful to obtain the patient's preferences prior to these important events. This would be possible for the treatment alternatives card sort procedure. Indeed, there was a highly significant statistical relationship between role preference and preference for information about treatment alternatives. Active patients wanted to be informed of all treatment alternatives and the degree of risk associated with each alternative, while passive patients wanted to either be informed about the single best treatment and the risks associated with it, or hear nothing at all about the treatment they would be receiving.

The amount of diagnostic detail that a patient wants their physician to include in their discussions may be difficult to ascertain prior to the time when the physician discloses the diagnosis. If the patient is unaware that they have cancer, they may be unsure as to whether they

want detailed information upon hearing that they have cancer. This dilemma of not knowing what one wants to know about one's illness in the event that the illness is cancer is compounded by the fact that denial is a common response to being diagnosed with cancer. Perhaps a patient needs a period of time during which to overcome this period of denial before they can be responsive to details surrounding their diagnosis.

One should also not assume that preference for involvement in treatment decision making is a static phenomenon. It may be more reasonable to hypothesize that role preferences differ depending on factors such as illness severity and the amount of time that has elapsed since the diagnosis was delivered. Perhaps patients who respond to their illness with a relatively greater amount of denial may indicate they prefer a passive role because they do not feel able to contribute to the decision making process. Perhaps it is only as patients learn to accept their illness that they prefer a more active role in their care as they strive to cope with the disease and its implications. These are questions that should be addressed in future studies.

The theory of cognitive adaptation to life-threatening events developed by Taylor (1983) appears to have some

utility when it is applied to the dynamic constructs of treatment decision making control preference and information preference. The theory is useful in that it can explain why passive patients may or may not want information. For both subgroups of passive patients discovered in this study, the theory would predict that patients' preferences would serve to maintain the patient's feelings of mastery and control over their illness. For example, there may be a point during the illness when the patient feels more in control of their body and illness knowing the physician is going to formulate the important decisions that must be made for the patient to be cured. At another point in time, the patient may realize this sense of control in knowing that they are collaborating with their oncologist in the formation of important decisions that affect their health and their life.

Taylor's theory and the concept of psychological control are less useful in explaining the processes involved in a patient's decision to move from playing an active role to a passive one or vice versa, or from wanting illness- or treatment-related information to not wanting this information. What is needed is a theory that not only explains why a patient plays an active or passive role but also can explain when and why a patient moves from playing

an active to a passive role or vice versa. This theory would have to be temporal in nature, considering the important milestones in illness and treatment progression at which time the breast cancer patient faces important decisions about her health, body, life, and future, etc.

One would expect such a theory, regardless of its cognitive or behavioral theoretical and empirical roots, to incorporate the tenets of existential philosophy. Consideration of existential issues may be necessary to garner an understanding of the life of a suffering cancer patient. Taylor (1983) does, in her discussion of adapting to a life-threatening illness, include the existential issue of developing a sense of meaning out of the cancer experience. Specifically, Taylor discusses how breast cancer patients strive to establish meaning a) in their definitions for why they have cancer, and b) in the manner by which they restructure their life to cope with their disease. However, Taylor did not fully apply the theory in a manner that elucidates the critical stages in the progression of the life of a cancer patient, including points when decisions must be formulated regarding treatment, and when information may be useful to enhance a patient's understanding of their diagnosis, treatment, and prognosis.

When Taylor's theory is more fully developed, or when a new theory arises to encompass the foregoing areas of concern, researchers and clinicians working in the area of psychosocial oncology will be able to more fully understand a patient's need for illness- and treatment-related information as well as their need to be (un)involved in treatment decision making.

The results suggest that patients' preferences for the kind and amount of illness and treatment-related information they wish to receive are related to treatment decision making role preferences in a systematic manner. An implication of the results is that active patients should be encouraged to assert themselves in their care and be furnished with detailed information, and that passive patients should have their information preferences respected. To draw this implication, however, requires an acceptance of the assumption that role preference is a matter of patient choice and that it is no better to play an active or a passive role. Is it true that it is more adaptive for some patients to be assertive in their care while other patients are best left in the dark with respect to illness- and treatment-related information? Is there a threshold level for passive patients in that there is a

point beyond which playing a passive role is negative in its consequences for the patient?

Some health care providers and researchers may argue that all patients should be educated and encouraged to play an active role regardless of whether they prefer an active or passive role. Perhaps an even greater number of health care professionals might argue that a patient's role preference (active/passive) should be respected but that regardless of the extent of a patient's involvement in treatment decision making, all patients should be given complete information. One might ask whether a patient's quality of life, medical status, or psychosocial status is compromised if they are employing denial as a coping method. Is preference for minimal information a simple matter of patient preference or does it reflect a maladaptive avoidant coping strategy that should be targeted for change to afford a cancer patient a better life?

The foregoing questions need to be addressed in carefully designed research programs. Presently, the answers to these questions are formulated with value-driven reasoning rather than discovered using the objective scientific method. The answers to these questions are important because they often direct many of the behaviors

of health care professionals who must decide every day how much information to impart to a patient and how much detail to withhold. These are questions worthy of scientific exploration.

The results serve as strong evidence for providing detailed information to active patients. This may indeed be a wise choice. There are those who would argue that, whenever possible, a patient's expressed wishes for information should be respected and satisfied by health care professionals. Proponents of this line of reasoning would argue that it is in the best interest of the active patient to provide them with detailed information if they request such information. Others may counter argue, however, that research evidence does not conclusively indicate that active involvement by the patient is necessarily in the best interest of the patient.

Past studies have sought to explicate the relationship between preference for involvement in treatment decision making and outcome variables such as quality of life, medical health outcome, and indicators of psychosocial functioning. Several of these studies are fraught with design flaws, inadequate sampling methods, and measurement instruments with insufficient psychometric validation. One severe limitation associated with this research - and

psychosocial oncology research in general - is the difficulty encountered when deciding upon appropriate outcome variables against which to ascertain the effectiveness of an intervention. Quality of life, functional status, psychosocial status, disease outcome, immunocompetency, and other physiological states are all possible outcome variables. A related issue is whether the outcome variables are those that are of greater importance to physicians or to patients.

A discussion of the appropriateness of outcome-based psychosocial oncology research, and the limitations thereof, is beyond the scope of this paper. The researcher believes that it is not cost effective, in terms of the patient's well-being, to wait for the conclusions drawn from elaborate outcome-based research studies prior to implementing clinical interventions designed to satisfy patient preferences for involvement in their medical care and preferences for receipt of illness and treatment-related information. If a patient requests additional information, health care professionals should cater to these wishes unless they can bring forth empirical evidence suggesting that the provision of this information would compromise the patient's well-being.

It may be questioned whether there is a specific clinical intervention that can be recommended based on the findings of this study and prior research; an intervention that is feasible given the limited time resources of medical and radiation oncologists. The answer is yes. Several of the patients in this sample stated that they had unanswered questions about their illness and treatment, and that having the answers to these questions would reduce their anguish. These same patients, however, admitted to not asking their questions to the oncologist. There are several reasons to explain this failure to ask questions. First, these patients were uncertain as to whether their questions were important questions. Patients realized that they had only a limited amount of time to spend with their oncologist and didn't want to waste the oncologist's time with irrelevant questions. Second, patients hesitated to ask oncologists to repeat information because they did not want to appear stupid and/or inattentive. Third, patients did not want to appear stupid to the oncologist because they wanted their oncologist to like them. Fourth, patients were unsure of what to ask. Patients commonly reported that only after they left the oncologist's office did they think of questions to ask, and by the time they

were to see the oncologist again, they had forgotten their questions.

The following recommendation, coined by the researcher as the dual-solicitation approach to the provision of information to cancer patients by oncologists, has been developed based on the results of this study and prior research: Patients should be encouraged by oncologists to write their questions down on paper and bring their list of questions to their meeting with the oncologist. Oncologists should a) provide the patients with a rationale for recording their questions, b) encourage patients to not worry about whether their questions are important or not, c) ask to see the patient's list of questions during the next appointment, d) answer the patient's questions during the next appointment, and e) verbally praise patients for bringing questions to the appointment, and demonstrate understanding and acceptance of those patients who do not have questions. This approach is called the dual-solicitation approach because it calls for the oncologist to earnestly solicit questions from patients and asks the patient to formulate questions and solicit answers from their oncologist. It may not be so important that a patient brings questions to their appointment as it is for

a patient to realize that their oncologist is keenly interested in their questions and concerns.

There is empirical support for this recommendation beyond the findings of this study. Reynolds et al. (1981) found that cancer patients' preference for medical information was facilitated by asking them whether they wanted information about specific aspects of their illness and treatment. Experimental patients were shown to a) desire more information and b) have better recall for this information than control patients who were not encouraged to ask questions. In a study conducted by Merkel et al. (1983), experimental patients were instructed, prior to their interactions with physicians, to express medical and emotional concerns and to ask questions regarding their illness and its treatment. The results showed that physicians were more fond of experimental patients than control patients who were not given any instructions.

The findings of these two studies suggest that patients should be encouraged to ask questions and solicit information from their oncologist. The dual-solicitation approach a) requires minimal additional effort by oncologists, b) can be easily implemented, and c) demonstrates respect for patients' information preferences. In addition, this approach should prove to a) foster

increased patient understanding and recall of information pertaining to their illness and its treatment, and b) increase the quality of the patient-oncologist relationship as perceived by both the patient and oncologist.

To summarize, the results of this study show that a majority of cancer patients desire detailed information about their illness and its treatment. In addition, virtually all patients who indicate that they want to play an active role in treatment decision making want detailed information about their diagnosis and treatment. Further research is necessary to understand the discrepancy in information preferences of passive patients. Research is also needed to a) critically detail the advantages and disadvantages associated with adopting an active, collaborative, or passive role in treatment decision making, b) examine the dimensionality (i.e., construct validity) of the treatment decision making control preference construct, and c) more fully develop a theory of adaptation to life-threatening events that can explain the dynamic constructs of treatment decision making preference and information preference as they pertain to the breast cancer patient. Finally, the dual-solicitation approach to the provision of information to patients by oncologists

should be implemented and the benefits and limitations evaluated.

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Appendix A
INTERVIEW GUIDE

Interview Guide

Patient Name:

Date:

Interviewer:

Time:

Patient Demographics and Medical Information

Date of Birth:

Educational Status:

Diagnosis:

Current Treatment:

Questions

1. Why do you want - to make treatment decisions on your own? (active patient)

- your doctor to make the treatment decisions? (passive patient)

- to work together with your doctor to make treatment decisions? (collaborative patient)

2. How much control do you feel your doctor would like you to have over making treatment decisions?

3. Do you feel that some patients should make their own treatment decisions but that other patients should have their treatment decisions made by their doctor?

4. (If "yes" to question #3) What kinds of patients should make their own treatment decisions?

5. (Ask the patient to elaborate on any information card sort orders that were not as predicted by the hypotheses)

6. Are there any important decisions that you have to make right now with respect to your illness or treatment?

7. What illness or treatment-related information is most important to you right now?

8. Should all patients be given the same amount/kind of information regarding their illness and treatment or should the amount and kind of information depend on the circumstances of the patient?

Appendix B
PATIENT CONSENT FORM

PATIENT PREFERENCES FOR INFORMATION AND INVOLVEMENT IN
TREATMENT DECISION MAKING -
PATIENT CONSENT FORM

The present research is being conducted to acquire knowledge about the kind of illness and treatment information that breast cancer patients prefer to receive from their physicians, and the degree to which patients want to be involved in making treatment decisions.

In consenting to participate in this study, I understand that I will be shown a series of cards with statements on them about breast cancer and its treatment and that I will be asked to place the cards into my preferred order. I understand that my responses will be taped and then erased at the end of the study. Further, I understand that my responses will remain confidential and that my name will not be listed in any research paper that may be written for this study.

I understand that I am under no obligation to participate in this study, that I am free to withdraw at any time, and that my participation in this study will have no influence on my medical treatment.

Having understood the above conditions, I agree to participate in this study.

Date: _____

Signature: _____