

**DESIRE FOR CONTROL OVER HEALTH CARE IN MANITOBA WOMEN WITH A  
FIRST TIME DIAGNOSIS OF BREAST CANCER**

**by**

**Kaaren Ruth Neufeld**

**A thesis  
presented to the University of Manitoba  
in partial fulfillment of the  
requirements for the degree of  
Master of Nursing  
in  
the School of Nursing**

**Winnipeg, Manitoba**

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DESIRE FOR CONTROL OVER HEALTH CARE IN MANITOBA  
WOMEN WITH A FIRST TIME DIAGNOSIS OF BREAST CANCER

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A thesis submitted to the Faculty of Graduate Studies of  
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To my family - Ken, Bryan and Mark -  
and to my extended family  
for their love, support, and belief in my ability.

## ABSTRACT

This thesis is a descriptive study which addressed the research question: Is desire for control over health care the voice of a vocal minority or a phenomenon representing the majority of women facing breast cancer? Specifically, do these women desire active behavioral involvement in their health care, and are they seeking information about diagnostic and treatment procedures? The concept of control was conceptualized by incorporating two models of helping and coping described by Brickman and his colleagues with four patterns of control over treatment decision making described by Degner, Beaton and Glass. The Krantz Health Opinion Survey and Desire for Control scales were used to collect the quantitative data. The sample consisted of 43 respondents who were experiencing a first time diagnosis of breast cancer and who were within one year from initial diagnosis. The data were collected from 12 different settings.

A high desire for information was reported although this may not necessarily be evident from usual patterns of questioning behavior. Respondents were not prepared to assume responsibility for deciding "what is best" or "what procedures I should have" but most definitely wanted to "have a say" and to "influence" the care received. Joint control based on the assumptions of the compensatory model of helping and coping was the prevalent attitude. There was no support for the hypothesis that younger women desire greater control than older women. There was some support for an association between desire for control and extent of disease. Desire for control may be strongly affected by the situational factor of the nature of the illness. The small sample which was atypical of the target population prohibits any generalization of study results. Implications for nursing and further research are discussed.

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## CHAPTER 1

### Statement of the Problem

In the past, patients (and women in particular) relinquished their rights and responsibility for health into the hands of a health care professional who had the power to heal. However, as the long awaited cure for cancer remains elusive, women today are realizing that they are in effect pioneers in science's quest for a cure for breast cancer. A review of current lay and professional literature suggests that many women facing diagnosis and treatment for breast cancer are dissatisfied with the traditional medical model of service and are insisting in increasing numbers on sharing or assuming responsibility for control over their health care. It also suggests that they are seeking the services of health care providers who will give them honest and complete information regarding diagnostic procedures and treatment alternatives (Mast, 1984; Scott, 1983a; Wallis, 1983; Edsall, 1982a & b; Spletter, 1982; Kushner, 1981; Shapero & Goodman, 1980; Annas, 1980). However, the anecdotal nature of the literature and lack of empirical data leads one to question whether this desire for increased control is the voice of a vocal minority or a phenomenon representing the majority of women facing breast cancer.

Breast cancer is a major health concern for all Canadian women and creates a life crisis for many. Approximately 9,220 Canadian women are newly diagnosed with the disease each year (Canadian Cancer Society, 1983). As well, it will be diagnosed as the new primary site of cancer for an estimated 500 Manitoba women in 1985 (M.H.S.C., 1984; Statistics Canada, 1980). Although earlier detection is credited with bringing about longer life expectancy, mortality rates over the past forty years reflect no significant changes (McPherson & Fox, 1977). Cancer of the breast remains the leading cause of death in women from all causes between the ages of 35 to 54 years (Canadian Cancer Society, 1982).

A major impact of the diagnosis of cancer is a feeling of loss of control. The assaultive

nature of the disease and its treatment can quickly erode any sense of control over health that the woman may have had prior to diagnosis (Mast, 1984; Cromartin, 1983).

"My greatest problem - and I think that of many women with breast cancer, perhaps especially women undergoing chemotherapy - was regaining the sense that my body is my ally. My body had always been mine and great and super, and suddenly I had to make the intellectual effort to believe that my body and I were still on the same side - that my body had not become an opponent" (Edsall, 1982a, p. 85).

Literature on the psychosocial impact of breast cancer describes the experience as emotionally traumatic and initially disruptive of lifestyle patterns (Meyerowitz, 1980; Maguire G. P., Lee, Bevington, Kuchemann, Crabtree, & Cornell, 1978). Younger women report more adjustment difficulties than do older women (Jamison, Wellisch & Pasnau, 1978; Maguire P., 1975). Many women report that they would like more knowledge regarding their diagnosis, diagnostic tests, treatment, and resultant lifestyle changes (Reynolds, Sachs, Davis, & Hall, 1981; Morris, Greer, & White, 1977). Acquisition of this knowledge is vital for the woman who wishes to participate in the treatment decision making process. Although health care providers are reported as important sources of information (Mast, 1984), one study found that two-thirds of its subjects identified lay literature and family and friends not associated with health care as their primary source of information concerning treatment options (Greiner & Weiler, 1983). Similarly, only 20% of the 139 postmastectomy patients interviewed by Bullough (1981) identified nurses as a significant source of information.

Initial observations in studies exploring the coping strategies of women with breast cancer are showing that patient participation in treatment decision making is helping to speed the rate of emotional recovery by reducing the woman's feelings of helplessness and victimization (Kaplan & Grandstaff, 1979; Craytor, 1979; Wellisch, Jamison, & Pasnau, 1978; Schain, 1978). This is not to imply that all women should participate to the same extent or that more participation leads to a faster recovery for all patients. It is possible that in the face of a life-threatening disease

such as breast cancer some women do not desire control over their health care but rather choose to relinquish responsibility for their care into the hands of the physician. In this case the question is: was the woman given the opportunity to participate so that she could freely choose to give up her responsibility for decision making ?

Therefore, it is important to distinguish between those women who wish to become active participants and those who want someone else to assume the responsibility. Schain ( 1978;1980) reports on ongoing research from the Department of Psychology, Temple University Philadelphia, where a beginning body of knowledge is developing which attempts to "separate out those populations who search out information prior to stressful events and those who choose to block out relevant communication" (Schain, 1978, p. 467). The patient's feelings of worth and sense of control are enhanced when the health care provider shows regard for the patient's desire for involvement in the treatment decision making process.

Early detection of breast cancer and its prompt treatment is primarily the responsibility of the woman. The American Cancer Society estimates that more than 90 % of breast cancers are discovered by women themselves. This is often a chance or accidental discovery since only 24 % of women regularly practice breast self-examination (Cancer Facts, 1979) despite knowledge of the technique (Turnbull, 1978).

When a woman discovers a breast lump and is able to acknowledge its existence she independently begins a process of decision making which will determine how quickly treatment is sought. She may conclude that the growth is a benign lump and does not pose a risk to her health and no treatment is sought. She may think about the possibility of cancer but judge the risk to be only potential and delay seeking treatment hoping that the lump will disappear. Weeks or months may go by before the opinion of a health care provider is obtained. Finally, she may decide that the lump poses an immediate risk and will seek an examination from a physician to either confirm

or dispel her suspicions ( Kaplan & Grandstaff, 1979). This third option is the one followed by many women. In fact, 25 % of physician visits by women are concerned with abnormal findings in the breast ( Townsend, 1980).

At this point in the decision making process, the context within which health care is delivered in Canada often dictates that the woman now relinquish her active decision making role into the hands of a professional. According to the traditional medical model of service the patient is expected to assume a passive dependent role. She is neither responsible for her illness nor responsible for contributing to a cure and thus all future decision making resides in the hands of the health care provider. This is particularly true for a disease such as breast cancer since it is seen as a life-threatening illness and provider controlled decision making is the dominant pattern of control in these situations ( Degner, Beaton, & Glass, 1981). However, there appears to be a growing desire on the part of many women for a reformation of this traditional pattern of diagnosis and treatment to one where the patient can assume, if desired, increasing control throughout the treatment decision making process. A potential shift in this pattern is plausible as new trends in health care emerge in response to the rise of consumers' rights in health care, the women's health movement, and widespread availability of health information to the public.

Today as in the late 1800's, the most prevalent form of initial treatment will be surgery. The traditional one-stage surgical approach has the woman undergoing a general anesthesia for a surgical biopsy and possible mastectomy. Therefore, unless the woman has insisted on a biopsy being performed as a separate procedure she will undergo anesthesia unsure as to whether she will awaken with her breast intact or not. The final decision as to the type and extent of surgery will be made while the woman is unconscious. The lack of personal control inherent in this one-stage procedure is likely to weaken her coping capacity unless the woman has had the opportunity to

consider the options and has deliberately chosen this as the best personal alternative (Scott 1983a).

In the past this one-stage surgical procedure left many Manitoba women with a 50-50 chance of undergoing a simple extended or radical mastectomy as the primary form of intervention. Breast conserving surgery was not the statistical norm in Manitoba. However, as the long-term results of prospective randomized trials are becoming known treatment modalities are shifting and the trend toward breast sparing surgical approaches is evident in several Canadian provinces (Statistic Canada, 1978). Today alternative treatment includes numerous modified surgical approaches, primary and adjuvant radiation, and adjuvant chemotherapy (Donegan, 1984; Osborne et al., 1984; Veronesi et al., 1981; McPherson & Fox, 1977). With earlier detection and less radical surgery breast reconstruction is also becoming available and more acceptable in practice (Schain, 1984; Paschold & Hyman, 1981). Knowledge of these options is providing women with the opportunity to participate more fully in the treatment decision making process.

Several opportunities for the woman to maintain active behavioral involvement in her health care are available after she has sought the services of a physician. She may decide between one-stage or two-stage diagnosis and surgical treatment; agree with the primary form of surgical intervention recommended by the physician or elect to have an alternate form of initial intervention; may accept or decline recommendations for adjuvant treatment; and may consider breast reconstruction, either immediate or delayed, as one of her choices. The patient can respond to each medical recommendation by concurring, by disagreeing, and/or by seeking another medical opinion.

In reality, clinical observations and analysis of verbal and written accounts of women's experiences with the health care system suggest that many women are not afforded these options.

Degner et al. (1981) noted that patients with life-threatening illnesses were more likely to take an active role in treatment decision making if they were initially given the opportunity to participate. If this opportunity did not exist, only the most stubborn or insistent patients were eventually successful in achieving their desired level of participation.

The need for this type of insistent behavior is evidenced in accounts of women with breast cancer who have chosen to document their stories in magazines and books. In general, these women describe the difficulty they had in finding a surgeon who would discuss treatment alternatives or give them the opportunity to participate in treatment decisions (Black, 1973; Kushner, 1977; McCauley, 1979; Shapero & Goodman, 1980; Spletter, 1982; Wallis, 1983).

"I learned that you really have to be informed, to know exactly what you are doing, and you have to convince the doctor in the first five minutes that you know exactly what you're doing, or you're doomed. They take over. You are no longer in control. So I've been very careful to establish, in the first five minutes, who is in control here" (McDonnell, 1984, p. 13).

One response to this type of experience has been the successful lobbying of five state governments in the United States to pass legislation which would ensure that treatment alternatives are adequately presented to all women facing possible breast cancer (Annas, 1980; Wallis, 1983). While this should assist women in finding a surgeon who will refer or discuss alternatives, it is difficult to legislate professional practice in that there is no way of controlling the varying degrees of enthusiasm with which different approaches are presented. Another response has been the development of several intermediary educational services across North America to provide women with information on breast cancer and its treatment alternatives. In part, this has been done to help women communicate more effectively with their health care provider (Patient Services Canadian Cancer Society; Y.W.C.A. breast cancer resource booklets in press; Kushner, 1981, Breast cancer advisory service; Dial-a-cancer tape, 1976).

Therefore, the degree of actual control that a woman has when facing diagnosis and treatment

for breast cancer seems to be less than desired. While there are several recent studies measuring consumer preference for control over health care (Smith, Wallston, Wallston, Forsberg, & King, 1984; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Vertinsky, Thompson, & Uyeno, 1974), there are none describing women's desire for control; particularly in serious illness situations such as diagnosis and treatment for breast cancer.

The primary purpose of this study is to describe the desire for control over health care in Manitoba women with a first time diagnoses of breast cancer. Specifically, do these women desire active behavioral involvement in their health care, and are they seeking information about diagnostic and treatment procedures? This collection of descriptive data will contribute to the current understanding of patient provider control in health care situations. Awareness of desire for control from the perspective of the patient can prove beneficial in facilitating communication and decision making between patients and health care providers. As well, it will assist in the identification of more specific questions for future research.

### Conceptual Framework

This section will begin with a discussion of the general concept of control and the emergence of the conceptually distinct concept desire for control. This will be followed by a discussion of the four models of helping and coping described by Brickman and his colleagues (Brickman, Rabinowitz, Karuza, Coates, Cohn, & Kidder, 1982) which have been incorporated with the four patterns of control over treatment decisions described by Degner & Beaton (in press) to provide the framework from which the concept, "desire for control" will be studied.

#### Desire for Control

In the search for understanding psychosocial well-being, the function of the "control" phenomena has been studied extensively. This is particularly true within the discipline of psychology although findings have been of interest to individuals working in most helping disciplines. The suggestion that patients be afforded the opportunity for increased control over their health care is common in current literature predicated on the belief that having personal control is seen as preferable and as leading to positive effects (Brehm & Brehm, 1981; Lefcourt, 1984). However, it is not universally beneficial for patients to feel increased personal control (Janis & Rodin, 1979) and desire for control may change over time and be dependent on factors such as diagnosis (Strull, Lo & Charles, 1984).

In order to understand the meaning of control it is useful to identify a theoretical distinction between control of outcomes and control of process. Control has been defined as "...the ability to regulate or influence intended outcomes through selective responding (Baron & Rodin 1979, cited in Janis & Rodin, 1979). The crucial component of this definition is the assumption that control holds the individual solely responsible for the outcomes that accrue. In comparison Smith et al., (1984) defined control as "...the ability to regulate or influence behavior or environment in a given situation" (p.416). This definition refers to control of process rather than control of

outcomes. "Although control over process may be motivated by a desire to control outcomes..." (p.416), there is a clear distinction between the two. Control that is contingent on outcome alone leaves patients with a disease such as cancer vulnerable to feelings of failure and guilt should treatment prove unsuccessful and the disease remain out of control. Control that is contingent on the process of treatment decision making allows a patient to retain a relative sense of control even when outcomes are seen as strongly controlled by other forces such as efficacy of existing treatment options. Therefore, the control of process can be seen as a desirable goal in and of itself.

Researchers have become progressively more precise in specifying the many facets of control although these refinements are often easier to differentiate conceptually than empirically (Reid, 1984). There has been substantial experimental research on personal control and its complex relationship to stress (Averill, 1973); on distinguishing between predictability and control (Burger & Arkin, 1980; Greer & Maisel, 1972); on the relationship between reactance theory and control (Brehm & Brehm, 1981; Arakelian, 1984); and on the popular construct locus of control (Lefcourt, 1984). A more recent direction in control research involves the concept desire for control (Smith, Wallston, Wallston, Forsberg & King, 1984).

Perhaps the most influential definition of control is that given by Rotter (1966) in his discussion of locus of control. According to this view, control is defined as an expectancy or belief. Individuals acquire a generalized expectancy about the extent to which reinforcements – the outcomes of their actions – are determined largely by their own efforts – internal control, or by factors in the environment – external control. The extent to which a person believes that he or she is internally or externally controlled has commonly been measured using Rotter's Internal-External Control Scale (Rotter, 1966 cited in Lefcourt, 1984).

Research employing this construct continues to proliferate. Application of the construct locus of control to health situations resulted in the development and validation of the health locus

of control scale and the subsequent multidimensional health locus of control scales (Wallston, Wallston & DeVellis, 1978). Use of these scales in most health-related situations remains problematic. Much of the research uses locus of control as the sole predictor of health behaviors when in actuality it is a mediating variable and a multivariate approach seems essential for prediction in these situations (Arakelian, 1980). Arakelian also noted that the development of disease-specific measures may be necessary, given the distinctive characteristics of many illnesses, and the fact that "...generalized expectancies such as locus of control exert their most profound influence in novel or ambiguous situation" (p. 32). Recent research is making a beginning attempt to develop a cancer specific locus of control scale. To date this effort has met with marginal success but the research is ongoing (Dickson, Dodd, Carrieri & Levenson, 1985).

Only two studies reported in the literature examine the relationship between expectancies for control of one's health and desire for control of health care ( Wallston, Smith, King, Forsberg, Wallston & Nagy, 1983; Krantz, Baum, & Wideman, 1980). Both studies concluded that desire for control as measured by the Information subscale of the Krantz Health Opinion Survey was a different construct than that measured by the Health Locus of Control Scale or the more recent Multidimensional Health Locus of Control scale. "Expectations of control over health outcomes need not necessarily be strongly related to how much one desires control over the health care delivery process" (Wallston, Smith, King, Forsberg, Wallston & Nagy, 1983). Desire for control is a measure of an attitude rather than an expectancy.

Recently, desire for control has become the focus of methodological research (Degner, 1984; Smith et al, 1984). Degner (1984) is currently in the process of developing a simple scale which will enable cancer patients to express their preference for control over treatment decisions. Ultimately such a scale might be used as part of the initial health assessment. The first pilot test of the scale conducted on patients selected from the Manitoba Cancer Treatment and

Research Foundation has been completed. Subsequent testing of the scale in a variety of settings is being planned to eliminate the possibility of setting-specific bias (L. Degner, personal communication, June 26, 1985).

Smith and her colleagues (1984) conducted three studies in which they compared the relative utility of three measures of desire for control: a generalized measure of desirability of control (Burger & Cooper, 1979 cited in Smith et al., 1984), a health-specific measure of preference toward treatment approaches (Krantz et al., 1980), and a measure of desire for control of specific health care situations designed specifically for the study. A known-groups approach was used. People who were anticipating a specific health care encounter, having a baby and dying of a terminal illness, were compared on the basis of those who had and those who had not taken action (or indicated an intention to act). Taking childbirth preparation classes, choosing to die at home and signing a living will were considered control-enhancing actions. The Information subscale of the Krantz Health Opinion Survey was the best discriminator of a choice of a place to die and of the type of preparation for childbirth. The Behavioral Involvement subscale of the Krantz Health Opinion Survey and the situation specific Desire for Control Scale were inconsistent in the discrimination among the groups. None of the measures could adequately distinguish those who had signed a Living Will (or intended to) from those who did not intend to sign one. Finally, the generalized measure did not help to discriminate among groups.

Desire for control over the process of health care is seen as an integral part of psychosocial adjustment. For patients facing life-threatening situations, control over the process of health care may be possible even though control over the outcome may not. Cancer remains an unpredictable disease defying science's attempts to find a cure. A person's psyche can be a powerful ally in effective cancer therapy. However, the nature of the disease is such that a sense of abandonment and guilt can readily occur if the patient has assumed sole responsibility for

control over outcomes and the disease recurs or progresses to a terminal stage. Therefore, control over the process of health care is a potentially helpful perspective, providing cancer patients with the opportunity to maintain or regain a sense of control in spite of frequently unpredictable events throughout the remainder of their lifespan.

### Models of Helping and Coping

Brickman's ( et al., 1982) general theory of helping and coping is based on a review and synthesis of literature found in social and clinical psychology. Four models of helping and coping were derived: the moral model, the enlightenment model, the compensatory model, and the medical model. The assumptions of each model make a distinction between an individual's responsibility for the origin of a problem and that individual's responsibility for finding a solution. Therefore, each model represents a fundamentally different orientation to helping behavior. The critical factor in each of these models is the form that people's behavior takes when they try to either help others or to help themselves.

Generally, people are unaware of the set of assumptions which guide their behavior both in seeking and providing help. However, the assumptions they make have consequences for the helping relationship. For example, the assumptions in most doctor-patient relationships are that the patient is not responsible for either the origin of the problem or its solution. While this makes it easy for patients to accept advice and instruction from a doctor, it also makes it hard for the patient who wishes to assert her own opinion.

#### Moral Model

This model attributes responsibility to the individual for both creating and solving his own problems. Accordingly, the individual is seen as lazy or a failure if an effort is not made to improve the situation. Other people need not feel obliged to help (since each person's troubles are of their own making), and in fact are not seen as capable of helping (since people must find their

own solutions). Help may be given by peers who, within the context of self-help groups, will exhort the individual to change and improve by taking charge of his own fate.

#### Enlightenment Model.

The model in which people are blamed for causing their problems but not believed to be responsible for solving them is called the enlightenment model. Since people are to blame for their problems they see themselves as guilty and sinful. It is their own impulsive behavior which is out of control. In order to improve they must accept a negative image of themselves and submit to an authoritarian agent of help. Under this model helpers possess enormous influential power since the receiver of help believes that their problems are the result of an inability to control undesirable behavior on their part.

#### Compensatory Model.

In this model people are not blamed for their problems, but are still held responsible for solving them. People coping with problems according to the assumptions of the compensatory model see themselves as having to adopt assertive behavior in an attempt to obtain the goods and services to which they are entitled. The responsibility for obtaining help and for determining how successful the help is lies with the recipient. The helper who ascribes to this model desires to mobilize resources on behalf of the deprived person. They see themselves as compensating with resources or opportunities that the recipient of help does not have until the individual can resume this responsibility. A health care professional practicing from the perspective of the compensatory model in effect says, "How can I help you?" rather than "Do as I say."

#### The Medical Model

The model in which people are not held responsible for either their problems or solutions is called the medical model. The practice of modern medicine is the most striking example of these assumptions. People are thought to be victims of disease and therefore are in need of an expert's

help to prescribe the appropriate solution. " Even when the solution is largely one that the person can or must carry out themselves, such as bedrest, the responsibility for prescribing this solution and for judging whether it has been successful rests with the expert " (Brickman et al., 1982, p. 373). This model assumes that the helper's main interest is in controlling the behavior of those receiving help. Therefore, it is unnecessary to request or hear input from the recipient of care, and as a result health care can end up meeting the helper's rather than the recipient's need.

The fundamental concern which these models address is the "likelihood that the assumptions made by a party trying to help someone with a problem will coincide with the assumptions made by the party trying to cope with the problem " (Brickman et al., 1982, p. 370). It is hypothesized that conflict will exist between health care providers and their patients if their models of helping and coping do not coincide. The conflict can be particularly acute when providers, while legitimately concerned with using their expertise to help, ignore the benefits that can be derived from meeting a patient's psychological need to exercise active control over the process of their health care. Perhaps the apparent struggle that women with breast cancer are waging with health care providers is the result of these women desiring health care from the perspective of a compensatory helping model and health care providers ingrained in the use of the medical model.

The two models pertinent to this study are the compensatory and medical model. Both of these models attribute low individual responsibility toward problem causation. For example, even if the woman has contributed to the severity of her cancer, by a delay in seeking treatment, health professionals tend to emphasize low responsibility for problem development. However, the compensatory model attributes high individual responsibility for coming up with solutions, a helping orientation compatible with individuals who have a desire for control.

### Patterns of Control over Treatment Decision Making

For the purposes of this research, these two models of helping and coping have been integrated with the four patterns of control over treatment decisions found in Degner & Beaton's (in press) descriptive theory of life-death decision making. The theory is based on the qualitative analysis of data collected in 14 different clinical settings where treatment decisions were being made for patients with life-threatening illnesses. Four patterns of control: provider-controlled; patient-controlled; family-controlled; and jointly-controlled decision making were identified as central to the descriptive theory. These patterns of control and the strategies and tactics exercised by participants to enhance control over treatment decisions are described below.

#### Provider-controlled decision making

Health care providers most frequently had final control over the design of treatment. In part, this was due to the fact that many patients did not expect to participate. They believed that the serious nature of their illness left them with limited choices or that their choice was between treatment or death. "While some providers of care only used this approach to decision making when the patient and family were unable or unwilling to participate, others practised the approach on a regular basis and viewed it as appropriate" (Degner, 1984, p. 410).

The strategies used to exercise control included presentation of a decision as the "best choice" without discussing alternatives, or presenting a decision and then asking the patient or family if they disagreed. Other tactics included having the patient or family sign a blanket consent form, or seeking consultations from colleagues to convince patients or families that the recommended course of treatment should be followed. Providers justified control of treatment decision making by maintaining that the patient or family did not have the knowledge or background necessary to participate in the decision making process. As well, they wanted to provide emotional protection to the family, particularly if they felt the decision could lead to

negative consequences.

#### Patient-controlled decision making

In this pattern the patient exercised final control over the design of treatment. If participation was desired but denied, several tactics were used by patients to obtain decision making power. These included withholding consent, missing appointments, and writing letters outlining what treatment they were willing to accept. Joining patient education groups was also effective in some cases in helping patients gain control over treatment design.

Patients were more likely to gain control over the treatment design if they were initially given the opportunity to participate. Failing this, only the most stubborn or insistent patients were successful. "Difficulties arose if a patient expected to exercise some control in making decisions about treatment and that expectation was not fulfilled." (Degner et al., 1981 p.137).

#### Family-controlled decision making

"The family had final control over design of treatment. Two effective strategies used by families to gain control were refusal of consent for treatment of the incompetent patient and expression of previously stated wishes of the patient" (Degner, 1984, p.410).

#### Jointly-controlled decision making

"Control over the design of therapy was shared by one or more of the participants in life-death decision making. For example, some providers shared control over treatment decisions with the patient or family members" (Degner, 1984, p.410).

Provider-controlled decision making is the most prevalent pattern in current health care practice. However, for women facing diagnosis and treatment of breast cancer, a potential shift in this pattern to joint or patient controlled decision making is plausible in light of the rise of consumers' rights, the women's health movement, and widespread availability of health information to the public.

The compensatory and medical model in combination with Degner & Beaton's four patterns of control will be used to frame the general research question for this study: Do Manitoba women with a first time diagnoses of breast cancer desire control over their health care?

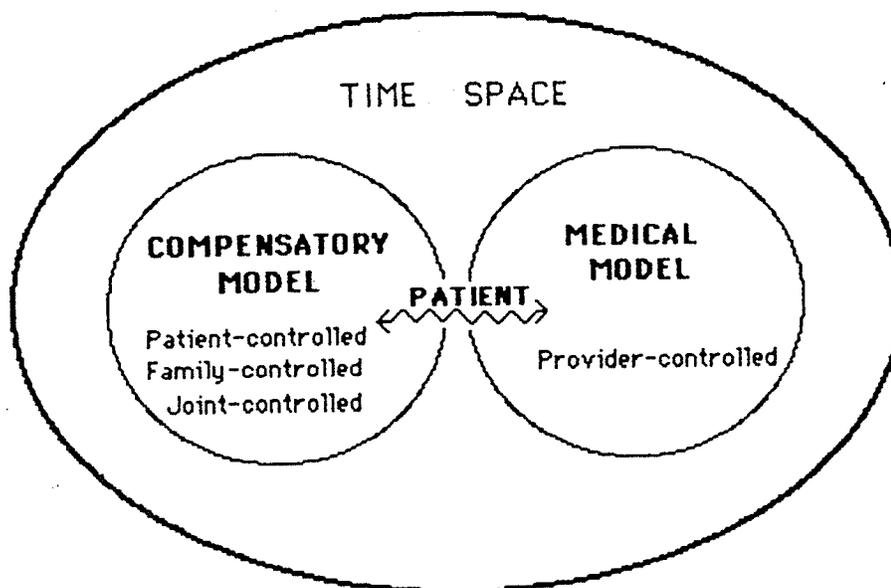


Figure 1.  
Conceptual Framework of Patient Desire for Control

#### Summary

Desire for control can be seen as a potentially beneficial behavior that allows for direct influence over the process of health care in a situation where control of outcomes remains relatively unknown. The compensatory and medical models are used to provide a general theoretical understanding of the conflict occurring between patient and health care provider as a result of the apparent shift in responsibility for treatment decision making that breast cancer patients are seeking. If in fact the majority of these women desire control over their health care, their demands for more autonomy necessitates the revision of the traditional concept of helping (the medical model) to a concept which incorporates active patient participation (the

compensatory model). It is extremely likely that women facing a breast cancer experience will show a high variation in their desire for control, both as a group, and as individuals at varying points in the treatment process. Degner & Beaton's four patterns of control contribute the theoretical understanding of variations in patient participation in life-threatening situations. A compensatory orientation to health care can incorporate joint-controlled, patient-controlled and family-controlled decision making.

## CHAPTER 2

### Review of the Literature

Two primary sources of information were considered while conducting a review of the literature for this study: (a) academic and scientific literature; and (b) the anecdotes of women who have chosen to discuss their experience with breast cancer through the popular medium of short stories, autobiographies, and journal articles. The impressions of these women was considered just as meaningful, rational and valid as the empirical findings of scientific research. They contributed a women-identified perspective to a unique female health issue.

The review of the literature discusses factors that have contributed to the general trend, desire for control over health care. Relevant research which has contributed to our current understanding of patient desire for control in breast cancer management will be incorporated throughout.

#### Factors Contributing To Desire For Control Over Health Care

A review of knowledge from widely dispersed writings in nursing, sociology, psychology, medicine and women's studies suggests that dominant forces shaping and supporting women's desire for control over their health care include: the women's health movement, the consumer rights movement, and increasing exposure and access to health-related information. For women facing diagnosis and treatment of breast cancer, the continuing controversy over medical treatment becomes another important consideration.

### The women's health movement

Over the past decade the women's health movement has grown to become an identifiable nationwide force. Issues regarding the quality of care, sex biases in the health system, and equitable access to health care have been raised. These issues appeared in feminist health literature, as well as in medical and social scientific literature (Ruzek, 1979). They are issues of concern for both men and women. It is therefore reasonable to ask: why the emergence of a women's health movement? Feminist literature in particular, suggests that sexism within the health care system is the major contributing factor (Sandelowski, 1981; Marieskind, 1980; Ruzek, 1979; Sherwin, 1979; Ehrenrich & English, 1977). Sexism affects the way women are treated by health care professionals and the quality of care they receive. It places women in a position where it is difficult to question or exercise any degree of control.

Physicians, like many men in American society, treat women as children—persons to be sheltered and protected from unpleasant facts and relieved of responsibility for decision making, ostensibly for their own good. Thus, when women seek medical care, physicians often fail or openly refuse to give women enough information to discuss procedures or make decisions in a reasoned, competent manner (Ruzek, 1979, p. 33).

Early rhetorical allegations of medical sexism in the feminist press have subsequently been supported by nearly identical claims, written in more neutral language and backed by statistical measures of significance, in academic literature (Ruzek, 1979).

In response to this sexist and monopolistic control over health care practice, self-help groups, clinics, and resource centers emerged to specifically address the health needs and social concerns of women. The concept of self-help assumes that individuals desire active participation in health care and that they wish to eliminate the patient role and replace it with a participant role. This role shift is facilitated through the sharing of experience and collective information seeking (Naisbett, 1984). Many patients will need to be taught how to achieve collaborative

status with their health care providers. Questioning is valued as an appropriate method for establishing control. However, how much does the individual woman really want to know about herself? How comfortable is she with being in control? As Vachon (1981) points out, learning to become assertive and living with assertiveness isn't always easy. This is particularly true for women, who have been socialized to accept the decisions made by others in authority. Many women will require a major reorientation process if they wish to adopt the participant role integral to the concept of self-help (Sandelowski, 1981).

Lipson (1980) suggested that participation in self-help groups appeared to increase consumer effectiveness and improve the members sense of self-esteem. Using an ethnographic approach, Lipson conducted a descriptive exploratory study of four chapters of the La Leche League and three Cesarean support groups. The study focused on how these groups functioned to socialize their members into increased consumer activism in health care and self-care responsibility. Both groups encouraged cooperation with health care professionals, but advocated that members be active and informed consumers. Socialization activities observed in meetings included exchange of information, assertiveness training and the encouragement of self-care and self-responsibility.

Some women's self-help groups are designed specifically to provide emotional support. Mastectomy support groups operated by the Young Women's Christian Association and the Manitoba Division of the Canadian Cancer Society are examples of self-help programs intended to augment traditional health care with a much needed empathetic service. The emotional support and education they provide is one way of alleviating a woman's sense of helplessness and powerlessness when facing treatment and recovery from breast cancer. In addition, the widespread acceptance of and demand for services from these groups functions to sensitize health care professionals to the needs women have when they encounter a breast cancer experience.

Health activists' belief in self-help logically led to the development of women's health

clinics. In Winnipeg, the Women's Health Clinic was established in 1982 to offer an alternative health care delivery system for women within the structure of traditional medicine. Its goal is to address physical and emotional needs from a women's perspective, to promote health maintenance and disease prevention, and emphasize responsibility and informed choice in health care. It is committed to offering quality health services, education, and supportive counselling, with concern for human dignity and respect for individual rights (Women's Health Clinic, 1983). Clinics such as these are a resource for women. Their educational outreach activities help to raise women's consciousness about individual responsibility for health; they can teach women how to inquire of their doctors about the options they will have if they develop breast cancer.

In the past, many women's health issues were overlooked, disregarded as trivial, or deemed uninteresting for research (Sandelowski, 1981; Marieskind, 1980; Ruzek, 1979). In nursing, a profession dominated by women, there remains a predominance of research on women directed towards her function as wife and mother rather than research that is intended to gather knowledge about women's experiences per se. Dunbar and her colleagues (1981) conducted a review of four nursing journals, American Journal of Nursing, Journal of Psychiatric Nursing and Mental Health Services, JOGN Nursing, and Nursing Research from January 1970 through December 1979 to provide data on nursing's attention to women's health. They found that of a total of 371 clinical nursing research reports, 13.4% related to the maternal role, 5.6% to women's health, and 80% to other clinical studies. "Nursing research has paid little attention to health care needs determined by sex" (Dunbar, Patterson, Burton, & Stuckert, 1981, p. 9). What is needed is more research about women that focuses on their experience as female. The study revealed no statistically significant increase in the numbers of women's health research reports throughout the decade. However, the number of cases may be too small (N=20) to be conclusive. These investigators encouraged the nursing profession to take the lead in critically investigating

women's health and establishing a sound theoretical basis for practice.

Feminist scholars are attempting to build a field of knowledge about women and health that will eventually offer a unique contribution to science that is complementary to current information about diseases and deviations from normalcy (McCrea, 1982; Smith, 1979; Ehrenrich & English, 1977). The advent of feminist perspectives has the potential to integrate male-biased and fragmented conceptual approaches within the health care system. Women need to be encouraged to make their own contributions to research; research that focuses on their experience as female (Dunbar et al., 1981; Vachon, 1981; Smith, 1979).

The rush to validate and verify feminist perspectives actually indicates widespread adoption of a new paradigm, which assumes male-female relations to be a crucial dimension in understanding and improving the social and behavioral sciences, medical science, and clinical practice (Ruzek, 1979, p. 66)

Nurses have a responsibility to make health care responsive to women's needs; to make a concerted effort to examine new or different ways of addressing some of the unmet and emerging needs of women. This leads us to ponder some fundamental questions: Should not people be active participants in decision making concerning their health? Should not the patient be regarded primarily as a thinking, responsible person? Do the silent majority of women desire to be passive, docile, and compliant health-care recipients? Do women facing a breast cancer experience, desire greater opportunity to exercise varying degrees of control over the treatment decision making process?

#### Consumer Rights Movement

Changes in Canadian society over the past thirty to forty years have profoundly affected twentieth-century decision making in matters of health care. The basic institutions through which people manage their daily lives have been altered. Urbanization, bureaucratization, specialization, a transfer of functions to government and changing values have brought about

major shifts in the characteristics of community and family institutions (Storch, 1983). These changes left individuals with feelings of alienation and loss of control (Naisbett, 1984). Within this social context, the consumer rights movement evolved.

In the early seventies, as a part of this total concern for individual rights, the rights of patients received increased attention from Canadian hospitals as well as the medical and nursing professions (Storch, 1983). From this interest and concern emerged "Consumer Rights in Health Care"; a document published by the Consumers' Association of Canada. This charter states that the consumer has: 1) the right to be informed; 2) the right to be respected; 3) the right to participate in decision-making affecting his or her health; 4) the right to equal access to health care (Canadian Consumer, 1974). Problems that patients were experiencing with the health care system had now been translated into demands for patients' rights.

Women facing treatment for breast cancer find that exercising the right to be informed and to participate in treatment decision making can prove to be a difficult process. Physicians, nurses, medical care consultants, feminists, and former breast cancer patients all write of unfortunate women whose breast surgery was performed, albeit medically in their best interest, in opposition to their judgement or preference, or without their full comprehension (Edsall, 1982a; Bullough, 1981; Schain, 1980; Marieskind, 1980; Kushner, 1977; Crile, 1973). In Breast Cancer: A Personal History and an Investigative Report (1977), R. Kushner documents the struggle she encountered when she insisted on being informed and on participating in her treatment. She called eighteen surgeons before she found one who was willing to perform a biopsy separately. To maintain her feeling of control she *had the surgeon sign* a form saying he would not do more than a biopsy at the initial surgery. She is not alone.

"My one objection to having cancer really is that the person you have to deal with is a surgeon. I was not sure that I would find one who wasn't going to take my breast. I didn't want that to happen. I had to go from A to H in the Yellow Pages of the phone book before I found a surgeon who would talk to me about something other than

mastectomy" (Edsall, 1982a, p. 70).

Another example comes from a woman in Massachusetts. When she was confronted by a surgeon who would not discuss alternatives, or refer her to a surgeon who would, she researched breast cancer in a medical school library and then located a surgeon who discussed alternatives. Eventually she had a lumpectomy, a less radical procedure than a mastectomy. In an attempt to ensure that no other woman in Massachusetts would suffer similarly she turned to the state legislature. A disclosure requirement stating that all physicians must "fully advise each patient suffering from a form of breast cancer, of all alternatives available for treatment in addition to mastectomies" was signed into law May 23, 1979 (Annas, 1980). Since then four additional states, California, Minnesota, Hawaii, and Wisconsin have passed similar laws (Wallis, 1983). Although legislation may appear to be an extreme measure, perhaps nothing less will suffice.

It is considered no accident that Massachusetts was the first state to require doctors to inform breast cancer patients about alternative treatments available. Massachusetts is home of the Boston Women's Health Book Collective; a center committed to advocacy on women's health issues. Reduction of the physical and emotional trauma of breast cancer treatment is an issue of high priority. "The need for women to have adequate information about medical decisions affecting their treatment--and a voice in those decisions--has been a major goal of the organization..." (Consumer Reports, 1981, p. 25).

There are, of course, patients who do not want information and who do not want to make treatment decisions. Some patients may want the doctor or nurse to make decisions for them, since they perceive this to be the health care professional's role; because the information about breast cancer is ambiguous; or because conflicting types of treatment exist. Forcing unwanted information on a patient is as paternalistic an act as failing to disclose the full details (Storch, 1983). Women need to be given the opportunity to freely choose between options, including the option to relinquish responsibility for decision making.

For patients undergoing treatment for possible or actual breast cancer, a crucial aspect of the nurses role is to provide informational and emotional support. Scott (1983b) studied anxiety, critical thinking and information processing during and after breast biopsy in 85 women aged 18-60 years. Participants were tested after hospital admission but before diagnostic results were known. Six to eight weeks later, when an acute crisis is considered ended, women whose results were benign were tested again. Findings revealed extremely high anxiety levels overall. Women falling in the highest anxiety category were also found to have positively correlated critical thinking ability scores. This means that above a certain anxiety level, patients had increasing difficulty in the reasoning process and in decision making. Since this preoperative stage represents a time when demands on cognitive functioning are high, these women are in need of extra support to help them consider and weigh treatment options.

"I'm sure that without my husband I would have had a mastectomy. Now I'm very much in control of my own health and my breast cancer; I read everthing, and I ask questions. But it has not always been that way. For the first week...when you are confronting the alternatives - my initial reaction was: Cut it off. ...Without him [the husband], I would have picked up, say, in about eight days - and said, 'OK, Molly, get your act together; this is your life. Do something'. But that could have been too late. I was so devastated - an emotional wreck - because I felt doomed, thinking: You've got cancer; you're going to die." (Edsall, 1982a p. 81-82)

Respecting the patient's right to be informed and to participate in her health care reinforces the assumptions of the compensatory model. The health care provider helps the patient to help herself; and in so doing preserves the qualities of autonomy and individuality for the patient as well as acknowledging the skill and expertise of the health care provider.

#### Exposure and access to health-related information

An examination of common sources of lay health information suggest that women's expectations and definitions of what constitutes quality health care have changed over the past two decades. It proposes that women no longer desire to give control of their "health destinies" into the hands of a professional (Sandelowski, 1981). Rather, women are seeking a participatory role in

their health care; they are searching for information about their bodies and their health. The overwhelming acceptance and success of publications such as Our Bodies Ourselves, (Boston Women's Health Collective, 1976 revised ed. ) is an indication of the desire for such knowledge.

In the early 1970's these changing attitudes and values regarding women's health issues became evident in popular women's magazines. McCall's, Vogue, Redbook, Women's Day, and Family Circle are examples of conventional women's magazines that published health material which advised women to "remember that they, not doctors, 'own' their bodies, to 'shop around' for a doctor, [and] to be assertive about their rights" (Ruzek, 1979, p. 218). These articles challenged orthodox medicine and the belief that medical authority is sacred.

Numerous articles also presented personal stories, fictional accounts, and educational information on breast cancer. Examples of articles include: "Breast Cancer: Odds, Options, Arguments" Vogue, (Weber, 1983); "Easing Women's Constant Fear" Time, (Wallis, 1983); "New and Better Breast Cancer Treatments" Women's Day, (Switzer, 1976); and "Don't Sit Home and Cry" McCall's (Black, 1973). These articles vary in quality and perspective; some demonstrating positive ways in which women can interact with health care professionals; others offering a genuine attempt at consumer education. They attempt to reduce the fear associated with the disease and advise women about the choices and responsibilities they have. Unfortunately, cancer is also the topic of sensationalistic journalism. Distorted or highly subjective reporting, designed to sell magazines, can result in "...heightened anxiety, a distrust of health care providers, and panicky attempts to find solutions" (Schain, 1980 p. 1037).

The St. Vital library, a small local branch in a south Winnipeg suburb, has holdings of fourteen books specifically on breast cancer. The authors are predominantly women who have had a personal experience with breast cancer. To varying degrees each book stresses a woman's responsibility for educating herself about breast cancer so that she can participate in the treatment

decision making process. For example:

"Because of new techniques available, women must accept the responsibility of knowing about breast cancer treatment, so that, if the circumstance arises, they will be able to discuss the alternative treatments suggested by their doctor" (Shapiro & Goodman, 1980, p. 142).

"Any decision you do not make or participate in will be made for you - unless you demonstrate the ability to cope, reason, and choose among possibilities" (McCauley, 1979, p.156).

Common themes include: the "facts" about breast cancer, its diagnosis and treatment; the women's right to "know" and "choose" between treatment alternatives; selecting a doctor; and how to get a second opinion.

The themes of choice and loss of control are also evident in current fictional books, such as, Bodily Harm (Atwood, 1981) and Tree (Meitzger, 1981) where the protagonist was faced with the diagnosis of, or rehabilitation from breast cancer.

I was ready to give myself over like the other one out of ten. Without protest, without rattling the bars. Without asking questions, without asking why.... Why are surgery, chemotherapy, and radiation the only treatments? Why do we cure by assault? Who are the culprits? (Meitzger, 1981, p. 156)

Radio, television and films also frequent the topic of breast cancer. This broadcasting varies from short radio interviews (C.B.C. Information Radio, April 25, 1985) to four hour television dramas, portraying a woman's struggles with breast cancer (C.B.C. The Other Kingdom, January, 1985). As well, just four weeks after the results of the National Surgical Adjuvant Breast Project were published in the New England Journal of Medicine, (March 14, 1985) The Journal, a nightly C.B.C. news program, presented an informative discussion on treatment alternatives for breast cancer (April 17, 1985). Women have also had the opportunity to watch lead female characters in popular prime time evening television encounter possible diagnosis and/or treatment for the disease (Cagney & Lacey, Hotel, St. Elsewhere).

It is difficult to measure the impact that personal accounts found in magazines, books and the

broadcast media have. However, they do represent models of decision making for women who may wish to take a more active role in their treatment plan. They may help women to anticipate the type of questions they would like to ask as well as illustrate that patients can have a say in their treatment decision making process if they make the effort.

It cannot be inferred that mass media coverage of the topic means that all women have been exposed to current treatment options for the disease; that they have access to information sources; or that given access they would use them. Lenz (1984) identified empirical evidence that the active search for health-related information is a widespread activity for patients with cancer. She also noted that "despite desire and effort to acquire health-related information, clients often perceive that they are unsuccessful in obtaining the information they need, particularly from health professionals who may hold erroneous views of what and how much clients want to know" (Lenz, 1984, pp. 59-60). Several sociodemographic variables that appear to influence information seeking behavior were also identified. Younger adults have been found to be more active seekers of information than older persons. As well, persons with a higher socioeconomic status seek information more extensively.

Several of these conclusions, which drew heavily from consumer literature, are supported by current descriptive studies of information seeking behavior for breast cancer patients. In a telephone survey of 50 women treated with primary radiation for stage I or II breast carcinoma, Greiner & Weiler (1983) found that women who sought information were from middle- to upper-class socioeconomic groups as defined by the Hollingshead Index of Social Position. For 29 of the 50 women in this study, lay literature, family and friends *not* associated with health care, a women's health advocate, and television formed two-thirds of their information sources. Family and friends associated with health care and medical literature accounted for the other third. Similarly, Bullough (1981) interviewed 139 white, middle-class post mastectomy patients to

find out patients' perception of the teaching and support they received from nurses during their illness. Only 20% of the women indicated that nurses were a significant source of information and 37% found doctors as a source of information. There are some limitations inherent in both of these studies. Both are retrospective studies and persons are likely to forget or under-report information seeking behavior. Greiner & Weiler (1983) did not indicate the time that has elapsed between diagnosis, treatment, and data collection for the study; while Bullough (1981) identified the median length of time since diagnosis as 18 months. The lapse of several months and the high anxiety state which accompanies a diagnosis of cancer may make it difficult for subjects to accurately recall thoughts, motives and goals of information seeking behavior.

It is apparent that there is a variety of information available for the woman interested in learning more about breast cancer. The quality, accuracy and readability of the information can vary widely. Younger women from middle-upperclass socioeconomic strata are the primary seekers of information; nurses and doctors are not widely utilized as sources of information.

The idea that patients actively seek and acquire health-related information to guide decisions is compatible with the compensatory model of helping and coping which emphasizes the clients ability and right to make purposeful and independent health decisions. It also advocates active patient participation in health care. Greiner & Weiler suggest that "health care workers can influence the quality of information by contributing articles to the lay press, responding to published material, and participating in consumer groups " (Greiner & Weiler, 1983, p. 1570).

#### Medical Controversy Over Treatment

Theories of what causes breast cancer and what is the best treatment are the subject of heated controversy. The standard treatment for breast cancer was set in the 1890's when Dr. W.S. Halsted reported his technique of removing the breast, lymph nodes and pectoral muscle for large primary tumors of the breast. This technique proved to be a major advance in decreasing the

incidence of local recurrence (Paschold & Hyman, 1981).

Since 1955, less mutilating treatment modalities for breast cancer, have emerged. Although the incidence of breast cancer has been rising, the treatment has become less radical, and survival curves have remained constant (McPherson & Fox, 1977). A summary of randomized trials from 1964-1974 in the treatment of stage I or II breast cancer found that there were no significant advantages in terms of "cure" rate or length of survival between radical mastectomy with radiotherapy and the more moderate procedures, tylectomy (lumpectomy) with radiotherapy (McPherson & Fox, 1977). More recent evidence to prove that breast sparing techniques are meeting with the same results as the more radical procedures include the report of a ten-year study conducted by Dr. Umberto Veronesi (1981), a noted Italian oncologist, and recent results from two multicenter studies by the National Surgical Adjuvant Breast Project (Mueller, 1985). The encouraging conclusions about breast sparing surgery from these studies must be kept in context. These were primarily women with Stage I or II disease and in one of the studies the life-table estimates were for only five years. However, the present evidence is highly encouraging that more conservative operations eradicate the primary lesion with an acceptable cosmetic result, minimal rate of local recurrence, and maximal benefit to the quality of remaining life (Mueller, 1985). Major gains in survival may only come from better systemic therapy.

There is also an escalation of interest and acceptance of a number of breast repairing and reconstructive surgical techniques (Schain, Wellisch, Pashau & Landsverk, 1985; Scabin, 1984; Teimourian & Adam, 1982). Discussion of this issue is an important consideration before and after the issue of primary intervention has been settled between doctor and patient. "Today, women have the option of immediate (intraoperative) repair, early reconstruction (from a few days after the mastectomy to many months later), and delayed reconstruction, which is any time from one year after cancer surgery" (Schain, 1984, p. 249). In a study of psychological factors

in women undergoing immediate versus delayed breast reconstruction, Schain and her colleagues (Schain et al., 1985) found that the wish to be rid of the external breast prosthesis was one main motivation for breast reconstruction in 100% of the patients in the sample who had worn a prosthesis. They concluded that "...an external breast prosthesis is never incorporated into a woman's body image..."(p. 45). They suggested that "...once an internal prosthesis is implanted, the woman may feel more physically intact and less focused on the mastectomy site as the location of a treated malignancy" (p.45). Findings such as these suggest that reconstructive breast surgery is more than just an issue of cosmetic result; it is also an issue of body integrity.

Many women are still not aware of the possibility of having reconstructive surgery. A public opinion survey conducted by the National Cancer Institute in 1980 revealed that "less than 25 % of the national probability sample cited breast reconstruction as a procedure for restoring normal appearance after mastectomy" (Schain, 1984, p. 238). To assist in informing women about the risks and benefits of breast reconstruction, The American Cancer Society has recently adopted an educational slide program that discusses the medical/technical and psychological aspects of the procedure. It clearly illustrates reasons women express for electing to have *or not to have* reconstruction following their mastectomy.

Controversy also surrounds the issue of choice between a one-stage ( biopsy and mastectomy at the same time) or two-stage surgical approach (Scanlon, 1984; Scott, 1983a; Schain, 1978). Although more women are presented with the latter option, observations during clinical practice suggest that some Manitoba women still unknowingly sign a one-stage surgical approach consent form. Similiar observations are reported in current medical literature.

"I have witnessed many occasions where consent to one-step surgery was obtained in an almost offhand manner, with little regard to the patient's fears and anxieties. As a result, I can sympathize with any women who wants a two-step procedure so that she can be as certain as possible an operation of such magnitude - especially with regard to psychological overtones - is really necessary." (Edsall, 1982a, p. 72).

Advocates of the one-stage procedure argue that exposing a woman to a second surgical incision and general anesthesia is a needless risk incurring more physiological and psychological trauma and the inevitable (mastectomy) is only postponed (Scanlon, 1984; Scott, 1983a). On the other hand it is argued that the two-stage procedure provides women with the opportunity to exercise personal control; is easier on the woman whose lesion is benign (Scanlon, 1984); and if the lesion is malignant the time period between biopsy and further surgery allows for the expression of anticipatory grief and provides the woman with the time to consider treatment alternatives (Scanlon, 1984; Scott, 1983a; Schain, 1978). It is argued that women do better, as measured by rate of recovery from surgery (Taylor and Levin, 1977 cited in Janis & Rodin, 1979) and are less likely to be depressed (Schain, 1978) when they have had a two-stage surgical procedure. This controversy is becoming less important as the trend toward aspiration or core needle biopsy is becoming more common (Scanlon, 1984; McCann, 1984).

To date, no single treatment has demonstrated superiority over all others, and as a result many aspects of treatment are still embroiled in controversy. Until clinical trials settle the issue, patients with newly diagnosed breast cancer may continue to experience difficulty in obtaining objective up-to-date facts about the risks and benefits of alternative types of treatment. "Old habits" and "past experience" are hard to change. Surgeons trained in one method - radical or modified radical mastectomy as the treatment of choice - may be reluctant to change to more conservative surgery until conclusive long term evidence emerges.

Many health care providers encourage women to become actively involved in the treatment decision making process; maintaining that as long as there is no scientific evidence to prove one treatment better than the others, the patient should have the opportunity, if desired, to choose the treatment alternative since she is the one who has to live with the consequences. Breast cancer is not a medical emergency and there is time to investigate alternatives. A sense of helplessness,

magnified by the universal belief that cancer is equivalent to death, to being a victim, to suffering, and to mutilating and disfiguring treatment can be reduced through participation in the treatment decision making process (Kaplan & Grandstaff, 1979; Craytor, 1979; Wellisch et al., 1978).

### Conclusion

It is evident from this review of the literature that a significant wave of social change is prompting health care professionals to take a new look at the role of women both as providers and recipients of health care services. It appears that more women facing the experience of breast cancer desire control over the process of their health care. Breasts are unique female organs; their "disposition" should not be out of the woman's hands. It is important for nurses to identify and value a female perspective of health and to ensure that the patient is seen as an equal partner on the treatment decision making team. More women facing a breast cancer experience appear to be seeking a participatory role in treatment decision making as well as in decisions which influence the quality of their survival. This right has not always been easy to exercise although the consumer rights movement has contributed to bringing this issue to the fore. Increasing access and exposure to health-related information, places women in an era where the power of knowledge is beginning to be shared between provider and consumer of health care. Mass media coverage of the topic of breast cancer means that more women are exposed to current treatment options for the disease. It is also evident that in general younger cancer patients actively search for information and that nurses and doctors are not widely used as sources of information. The continued medical controversy regarding the management of the patient with breast cancer suggests that women need to be educated about the fact that they have options and provided with the opportunity to make choices. Finally, the assaultive nature of the disease and its treatment can quickly erode any sense of control which a woman may have had.

These forces have coalesced to provide the impetus and support for women with breast cancer to question their health care. They appear influential in assisting women to gain control over the process of their individual health care. For nurses, this apparent demand for increased control in health care coincides with a demand for increased knowledge about nursing. A new perspective of women's health presents challenges to nurses to question and test their rationales for practice.

## CHAPTER 3

### Methodology

The study design was descriptive. This design was selected to provide empirical data for a phenomenon, desire for control, which had been observed in clinical situations and anecdotal reports in the literature. The Krantz Health Opinion Survey and Desire for Control Scale were used to collect quantitative data. The main objective was to describe desire for control over the process of health care in Manitoba women with a first time diagnoses of breast cancer. Two questions were asked: Are the majority of these women seeking information about diagnostic and treatment procedures? Do the majority of these women desire active behavioral involvement in their health care? A secondary objective was to report reliability levels as well as convergent validity for the KHOS and DCON scales when used in adult populations experiencing a serious illness situation. This chapter describes the methods used for data collection.

### Hypotheses

The review of literature generated two hypotheses related to the general research question.

These were:

1. Younger woman will desire greater control over health care than older women.
2. Women with early stage breast cancer will desire greater control over health care than women with more advanced stages of the disease.

The literature suggested that age was the variable most predictive of desire for control over treatment decisions, with younger patients desiring greater control (Smith et al., 1984; Lenz, 1984; Wilkinson & Wilson, 1983; Haug & Lavin, 1981; Cassileth, 1980). Severity of illness also appeared to be related. In a year long panel-study of 1210 adults (56% women), Seeman and Seeman (1983) found a pattern of significant association between a high sense of control and superior health ratings. A sense of control was associated with the practice of preventative health behaviors such as breast self-examination and a hopeful attitude regarding early medical

treatment for cancer. This suggests that desire for control is an attitude congruent with the immediate treatment seeking behavior of women with early stage breast carcinoma. Theoretically, women with early stage breast cancer have more treatment options providing greater opportunity for participation in the treatment decision making process. As well, absence of distant metastatic disease would suggest that these women will feel in better health and thus may be more desirous of assuming control.

### Definition of Terms

Desire for Control - a preference for behaviors that either allow for direct influence on the process of health care, or provide relevant information about the health situation, or both as measured by the Krantz Health Opinion Survey and Desire for Control Scale.

Younger women - women aged 54 years and under

Older women - women aged 55 years and over

Early Stage - Nodes Negative

Advanced Stage - Nodes Positive

### Setting

Subjects were obtained from a wide variety of settings including surgeons offices in Winnipeg and rural Manitoba, two community hospital outpatient oncology departments, and The Manitoba Cancer Treatment and Research Foundation clinics located in Winnipeg's two teaching hospitals. Several settings were chosen to increase the probability of obtaining a large sample size and to ensure representativeness of treatment alternatives. Variability of hospital type was included since women who seek treatment from large teaching hospitals may differ in their desire for control from those who go to smaller community hospitals. Finally, rural settings were included to access the 20% of Manitoba women undergoing mastectomy surgery outside of greater Winnipeg (M.H.S.C. 1984).

### Sample

The study's descriptive data is based on a 10% non-probability convenience sample. Quota sampling had originally been selected to ensure that age and extent of disease variables of the sample would be proportional to that found in the target population. A slow accrual rate of subjects necessitated the use of a convenience sample. Few women refused to participate. Those who did, did so primarily because of current involvement in another survey type research project. There were 47 questionnaires returned by the end of May 1986. Of these, four were unusable because of missing data.

The final sample consisted of 43 subjects who met the following criteria: (1) women with a first time diagnosis of breast cancer, (2) within one year from initial diagnosis, (3) who were able to read and understand English and (4) whose psychological and physiological adjustment to the disease was sufficient to permit completion of the questionnaire. Only women with a first time diagnosis of breast cancer were included since past experience with the illness situation may influence desire for control. Initially, a time frame of seven weeks to six months from diagnosis was selected to allow for initial resolution of the acute crisis (Scott, 1983b; Infante, 1982) while at the same time minimizing retrospective self-report bias resulting from faulty recall (Lenz, 1984). This time frame was expanded to within one year of diagnosis following four months of data collection in which only 17 subjects had been accrued for the study. Sufficient psychological adjustment was indicated when at least two of the following three factors were present: a) verbalized a realistic perception of her experience with breast cancer, b) utilized situational supports (i.e. family, friends, neighbors, community resources), and c) initiated use of successful coping resources (i.e. makes an attempt to express feelings, draws on own past experience as well as that of others, makes plans or sets goals) (Aguilera, 1978). Sufficient physiological adjustment was indicated when treatment side effects were within manageable limits

(i.e. the patient was comfortable and had the energy and ability to concentrate on a 15 - 20 minute task). The criteria related to psychological and physiological adjustment were included to protect women experiencing major adjustment difficulties from being exposed to a situation they may perceive as causing additional stress.

### Instruments

#### The Krantz Health Opinion Survey (KHOS)

The Krantz Health Opinion Survey (Krantz, Baum, & Wideman, 1980), was administered to provide descriptive data regarding women's attitudes toward assuming an active and informed versus a relatively inactive and trusting role in the health care process. It is a health-related scale measuring desire for control in general health care situations. It contains two subscales. The KHOS-I is a 7 item subscale which measures the respondents usual information-seeking and choice making behavior. The KHOS-B is a 9 item subscale concerned with attitudes towards self-care. It was possible to score between 1 and 4 points for each item depending on whether the respondent circled strongly agree, agree, disagree, or strongly disagree. Points for each item were summed resulting in a total score (KHOS) which could range between 16 and 64, a behavioral involvement subscale score (KHOS-B) which could range between 18 and 36, and an information subscale score (KHOS-I) which could range between 14 and 28. Scoring was reversed for negatively worded items so that higher scores represented a greater inclination toward self-care and informed treatment. The two subscales were only moderately correlated and can be combined into a total score. The KHOS was chosen for use in this study because previous research supported the KHOS-I as the best discriminator between groups known to take control enhancing actions versus groups which did not.

Previous research had established the predictive, construct and discriminant validity, of the KHOS scale. The scale successfully discriminated between a criterion group of high self-care

subjects, users of clinic facilities and a general student population. The KHOS and its subscales also demonstrated relative independence of other scales (health locus of control, repression-sensitization, social desirability, and hypochondriasis). The Kuder-Richarson formula 20 (KR 20) reliability when scored on a binary agree-disagree format is 0.74 for the KHOS-B subscale and 0.76 for the KHOS-I subscale in a population of 200 college students. The overall KR 20 reliability is 0.77.

Krantz and his colleagues described their scale as needing further testing and refinement. Originally the value of the KHOS was demonstrated for predicting behaviors relating to routine medical care for relatively short-term minor illness. It has subsequently been used in three studies with adult populations (N=400) anticipating a specific health care encounter; having a baby, or dying of a terminal illness. In these studies a 6 point Likert-type agree-disagree continuum was used to score the responses and acceptable level of internal consistency (KHOS-B alpha = 0.80 & KHOS-I alpha = 0.78) were achieved (Smith, Wallston, & Wallston, 1984). Smith et al., (1984) found the KHOS-I subscale to be the best discriminator among groups known to differ in their choice of control-enhancing actions. The KHOS-B subscale also emerged as a significant discriminant variable in two of the three studies although it yielded findings opposite to those predicted. Further work is warranted to determine the utility of this scale for measuring desire for control of health care in adult populations experiencing more serious illness. (See Appendix C PART I: for a copy of the KHOS)

#### Desire for Control Scale (DCON)

The Desire for Control scale (Smith, Wallston, Wallston, Forseberg & King, 1984) was the only scale found in the literature designed to measure desire for control of the process of health care delivery as opposed to control of outcomes. The instrument was developed with the intent of improving measurement of desire for control by increasing specificity. It was constructed so that

a standard set of items could be administered to participants asking them to respond with reference to what they desire as a patient in a particular specified health care setting or situation (e.g. as a patient in this clinic; in your experience with breast cancer). It was chosen to provide descriptive data regarding women's desire for information and control in their experience with breast cancer.

The DCON scale consisted of 14 items with 8 items reflecting desire to influence the process of health care and 6 items reflecting desire for information. (See Appendix C: PART II for a copy of the DCON scale). It was possible to score between 1 and 4 points for each item depending on whether the respondent circled strongly agree, agree, disagree, or strongly disagree. Points for each item were summed resulting in a score ranging between 14 and 56. Scoring was reversed for negatively worded items so that higher scores represented a greater desire for control; an inclination toward informed health care over which they had some influence. The scale had been tested in three studies and in each case achieved an acceptable level of internal consistency,  $\alpha = 0.80, 0.87, \text{ and } 0.86$ .

Previous research evaluated the DCON scales ability to discriminate among persons who desire varying degrees of control of their health care (Smith et al., 1984). DCON was found to be a significant discriminant variable in the childbirth study but not in the two studies related to control-enhancing actions that a person with a terminal illness could take. The researchers suggested that the familiarity of the childbirth situation may account for the efficacy of specific measurement. However, it is also possible that variation in the situational context between the studies accounts for the different findings. In the two terminal illness situation studies, subjects were asked to speculate on the control-enhancing actions they would choose if they were facing imminent death while the subjects in the childbirth study were all pregnant women receiving prenatal health care services.

### Demographic Variables

A short demographic questionnaire was included to enable a comparison of the sample population with the target population and to observe possible relationships between these variables and the scale scores. Data pertaining to education, income and employment were requested from the subject and nurses or physicians in each setting were asked to complete a short patient information sheet which provided data on age, length of time since diagnosis, extent of disease and type of treatment (see Appendix C: Part III). These variables were included as possible correlates of desire for control as suggested from the review of the literature.

### Pre-Test

A preliminary test of the questionnaire package was conducted by the investigator. Three women with a past experience of breast cancer were asked to complete the questionnaire. The purpose was to allow the researcher to: (1) pretest the amount of time it took to complete; (2) assess the readability of the instructions and questionnaire items; and (3) examine the feasibility of self-administration of the questionnaire. Completion time was between 15 and 20 minutes and each respondent was able to follow the instructions. Two women questioned their understanding of item six on the KHOS and all three questioned the redundancy of some items; for example "I usually don't ask the doctor or nurse many questions about what they are doing during a medical exam" (item 1 KHOS) and "I usually ask the doctor and nurse lots of questions about the procedures during a medical exam" (item 8 KHOS). On the basis of the pre-test it was decided to include the following general instruction, feel free to write any comments that make your answers more complete, and to include a general comments section at the end of the scales. Comments were included on 27 of the 47 questionnaires. Physicians and nurses responsible for handing out the questionnaire were alerted to the possible concern over redundancy of items.

### Procedure

In each setting nurses and/or physicians were designated to: (1) identify subjects who met the selection criteria; (2) obtain written consent from all interested participants; (3) distribute the questionnaire to all consenting participants; (4) complete the patient information sheet on all subjects who consented to participate; and (5) take receipt of all completed questionnaires which were returned in a sealed envelope. Active practicing registered nurses were designated in each hospital oncology outpatient setting. Office nurses in conjunction with the physician were responsible for questionnaire distribution in physicians offices. These were medical and nursing personnel who had an established therapeutic relationship with the patient and access to the patient's chart. This permitted them to readily assess when a patient met the selection criteria and to complete the patient information sheet. There was no need for the investigator to have access to the patient's chart.

The investigator met in person with all Winnipeg nurses and physicians who consented to participate in the data collection phase and by letter and/or telephone with the rural physicians. Specific instructions were discussed regarding the procedure to be followed. Written instructions and blank questionnaires were left with a designated nurse/physician in each setting (see Appendix A).

Women attending a regularly scheduled appointment at a hospital outpatient oncology department or surgeons office, who met the selection criteria, were approached on an individual basis by their nurse or physician and told that a nursing study was currently being conducted with Manitoba women newly diagnosed with breast cancer. They were informed that they were a potential subject for the study and asked if they were interested in reading a written description of what participation in the study would involve. Those women who were interested were given a copy of the consent form to read (see Appendix B). This contained a written description of the

study, an explanation of the information required, assurance that the information provided was confidential and that participation was voluntary. Those indicating an interest in participating were asked to sign a consent form. Subjects who consented were given the questionnaire which contained: (1) a general instruction sheet, (2) the Krantz Health Opinion Survey, (2) the Desire for Control Scale, (3) the demographic sheet, (4) an envelope, and (5) an address sheet to complete if interested in the study results. The consenting participants were instructed to read the general instruction sheet and to proceed with the questionnaire. The patient's nurse or physician then completed the corresponding patient information sheet. Completed questionnaires were returned to the nurse or physician in a sealed envelope to maintain confidentiality of the data. The majority of the questionnaires were completed while the patient was waiting for their appointment. Several women requested to complete the questionnaire at home and either returned it at their next appointment or returned it to the hospital or office by mail. Completed questionnaires were picked up by the investigator on follow-up visits made to each setting. Questionnaires from two rural settings were mailed to the investigator.

#### Protection of the Rights of Subjects

A study proposal was submitted to each participating agency and approval for access to their patients and participation from nurses was obtained before the study commenced. Each agency was informed of the general purpose and aims of the study. A written letter of approval was obtained from each setting prior to commencing data collection (Appendix D). In each instance setting approval included receiving the approval of the attending physician.

To ensure that a free and informed consent was obtained all subjects were individually approached and asked if they were interested in participating in a nursing research study. Interested women were given a letter presenting a description of the study; written assurance that participation in the study was voluntary and that they may choose to withdraw at any time;

and written assurance that all data collected was anonymous and confidential. All data collected were numerically coded so that no names would be associated with any of the data. Written consent was obtained prior to the collection of any data, including completion of the patient information sheet by the nurse or physician. Only the investigator and her advisors had access to the raw data. The study reports group information and no single individual is identifiable.

The study was approved by the ethical review committees of the School of Nursing and Faculty of Medicine University of Manitoba (see Appendix E ). Patients and staff who would like information concerning the final results will be sent a summary at the conclusion of the study.

#### Data Analysis

All data were coded and the Statistical Package for the Social Sciences (SPSSx) was used to calculate results. Internal consistency, a parameter of reliability, were estimated for the KHOS and DCON scales using Chronbach's alpha. Scale scores and demographic data were analysed using descriptive statistics. The shape of the KHOS and DCON distributions were presented graphically. Since the data were ordinal, the median was reported as the measure of central tendency and the range, interquartile range, and standard deviation were all reported as descriptors of variability. High, medium, and low parameters of control were identified by dividing the scales into thirds; a method similar to that suggested by Krantz ( 1980) and Wallston and Wallston ( 1984). Interrelationships between variables were examined using non-parametric correlational techniques. Non-parametric statistics were used because the data measured was ordinal, the sample was small, and it could not be assumed that the variables were normally distributed.

### Summary

This chapter has outlined the methods used in conducting a descriptive study to explore the phenomenon of desire for control over health care in women experiencing a first encounter with breast cancer. Desire for control was operationalized as scores on the Krantz Health Opinion Survey and Desire for Control scale which captured four separate dimensions: past information-seeking behavior, attitudes toward self-care, desire for information, and desire to influence the process of health care. Higher scale scores represented a greater desire for control. Of particular interest were the potential influence of age and extent of disease on scale scores. The data were analysed using basic descriptive statistics.

## CHAPTER 4

### Results

The results are presented in a sequence which should facilitate the understanding of their impact on the research question. First, the setting and sample are described including a comparison of sample characteristics with the target population. Next, the reliability and convergent validity of the instruments in this sample are reported. Finally, the scale scores are described, along with a comparison of scores between the two scales.

#### Setting and Sample

Data were collected in 12 different settings between November 1985 and May 1986. The length of the data collection period varied from setting to setting lasting between three and five consecutive months dependent on the length of time required to negotiate access to the setting. Seventeen Winnipeg surgeons were contacted; three agreed to participate, three indicated that all of their breast cancer patients were seen for followup at one of the oncology departments already participating in the study, three declined on the basis of small numbers of patients who met the study criteria, six sent no reply, and two refused. This process resulted in two subjects (4.7%) for the study. Thirteen rural physicians who work in collaboration with the Manitoba Cancer Treatment and Research Foundation outreach program were contacted; five agreed to participate, two refused and six sent no reply. Three subjects, two from Dauphin and one from Thompson participated in the study comprising 6.9% of the sample. Three community hospitals were contacted; two agreed to participate and one refused. Fifty three point five percent (53.5%; n=23) of the sample was collected from a community hospital setting. Finally, data were collected from the MCTRF's chemotherapy and radiotherapy clinics located in Winnipeg's two major teaching hospitals resulting in 34.9% (n=15) of the sample (see Table 1).

TABLE 1

FREQUENCY OF RESPONDENTS BY TYPE OF SETTING

Type	Frequency	No. of Subjects	Percent
Rural surgeons offices	5	3	6.9
Winnipeg surgeons offices	3	2	4.7
Community Hospital	2	23	53.5
Teaching Hospital	2	15	34.9
TOTAL	12	43	100.0

The majority of subjects were under the age of 55 years (65.1%, n=28) with no representation in the 75 years of age and over category; 72.1% (n= 31) were within 6 months from initial diagnosis. Almost three quarters had a positive node status (72.1%, n=31) with only one subject having no nodal dissection. The most common type of treatment was surgery with adjuvant chemotherapy (55.8%, n=24), although all six treatment combinations were represented. The sample was well educated, 72.2% (n= 31) having completed highschool including 32.6% (n= 14) with some or a completed university education. Most women lived in a household with an annual income over \$25,000 (53.7%, n= 22), including 29.3% (n=12) with incomes of \$40,000 and over. Two subjects refused to answer this question, commenting that it was irrelevant. Only four subjects (9.3%) had no history of employment outside of the home; 39.5% (n=17) had worked for 11 or more years. Table 2 illustrates these sample characteristics.

TABLE 2

SAMPLE CHARACTERISTICS

Demographic Variables	Frequency	Cumulative Frequency	Percent	Cumulative Percent
<b>AGE:</b>				
44 years and under	14	14	32.6	32.6
45 - 54 years	14	28	32.6	65.1
55 - 64 years	8	36	18.6	83.7
65 - 74 years	7	43	16.3	100.0
75 years and over	0	43	0	100.0
<b>EXTENT OF DISEASE</b>				
No Nodal Dissection	1	N/A	2.3	N/A
Nodes Negative	11		25.6	
Nodes Positive	31		72.1	
<b>TOTAL</b>	<b>43</b>		<b>100.0</b>	
<b>TREATMENT:</b>				
Surgery	6	N/A	14.0	N/A
Chemotherapy	1		2.3	
Radiotherapy	3		7.0	
Surgery/Chemo	24		55.8	
Surgery/Rad	4		9.3	
Surgery/Chemo/Rad	5		11.6	
<b>TOTAL</b>	<b>43</b>		<b>100.0</b>	
<b>TIME SINCE DIAGNOSIS:</b>				
3 months or less	12	12	27.9	27.9
4 - 6 months	19	31	44.2	72.1
7 - 9 months	3	34	7.0	79.1
10 - 12 months	9	43	20.9	100.0

TABLE 2 Continued

SAMPLE CHARACTERISTICS

Demographic Variables	Frequency	Cumulative Frequency	Percent	Cumulative Percent
EDUCATION:				
Less than grade 9	3	3	7.0	7.0
Some highschool	9	12	20.9	27.9
Highschool graduate	11	23	25.6	53.5
Diploma/certificate	6	29	14.0	67.4
Some university	7	36	16.3	83.7
University graduate	7	43	16.3	100.0
ANNUAL HOUSEHOLD INCOME:				
\$ 5,000 - \$ 9,999	2	2	4.9	4.9
\$10,000 - \$14,999	8	10	19.5	24.4
\$15,000 - \$19,999	3	13	7.3	31.7
\$20,000 - \$24,999	6	19	14.6	46.3
\$25,000 - \$29,999	4	23	9.8	56.1
\$30,000 - \$39,999	6	29	14.6	70.7
\$40,000 and over	12	41	29.3	100.0
Missing Data	2	43	**	**
YEARS OF EMPLOYMENT OUTSIDE OF HOME:				
None	4	4	9.3	9.3
1 - 5	7	11	16.3	25.6
6 - 10	15	26	34.9	60.5
11 or more	17	43	39.5	100.0

\*\* this column reported as valid percent due to missing data

The sample varied significantly from the target population with respect to age and extent of disease (Records and Registry MCTRF, 1985; Annual Report MCTRF, 1984; Statistics Canada, 1980). Sixty five point one percent (65.1%) of respondents were women 54 years and under opposed to 31.1% in the target population; there were no respondents in the 75 years and over age

group although this makes up 18.9% of the target group. An inverse proportion occurred with the variable extent of disease; 27.9 % of the sample had a negative node status opposed to 73% in the target population. When these two main variables were combined younger women with a positive node status were over represented, 44.2% (n=19) in the study opposed to 9.0% in Manitoba. Concomitantly older women with a negative node status were under represented, 9.3% (n=4) in the study opposed to 50.0% in Manitoba. The sample was better educated than the average female population of Winnipeg. Thirty two point six percent (32.6%) had attended university including 16.3% with a completed university degree. In the metropolitan area of Winnipeg only 8.8% of women have some university education or a completed university degree.

#### Demographic Data and Scale Scores

Spearman rank correlation coefficients were computed to examine the correlation of both scales with the following demographic data: age, extent of disease, time since diagnosis, education, income and years of employment outside of the home. The hypothesis that younger women would desire greater control was rejected. There was no significant correlation between age and the desire for control measures (see Table 3). There was some support for the hypothesis that women with early stage breast cancer desire greater control than women with more advanced stages of the disease. A significant negative relationship was found between extent of disease and the KHOS ( $R_s = -.3999$ ,  $p < .01$ ) and between extent of disease and KHOS-I ( $R_s = -.4009$ ,  $p < .01$ ). The remaining demographic data did not correlate significantly with DCON, KHOS or its subscales with the exception of education which showed a significant positive correlation with the KHOS-B subscale ( $R_s = .3304$ ,  $p < .05$ ).

TABLE 3

SPEARMAN RANK CORRELATION COEFFICIENTS OF DESIRE FOR CONTROL MEASURES WITH EXTENT OF DISEASE AND AGE

VARIABLE		VARIABLE	SPEARMAN $R_s$	SIGNIFICANCE	PROBABILITY
KHOS	WITH	EXTENT OF DISEASE	-.3999	.008	P< .01
KHOS-I	WITH	EXTENT OF DISEASE	-.4009	.008	P< .01
KHOS-B	WITH	EXTENT OF DISEASE	-.2369	.126	NS
DCON	WITH	EXTENT OF DISEASE	-.2248	.147	NS
<hr/>					
KHOS	WITH	AGE	-.1827	.241	NS
KHOS-I	WITH	AGE	-.1112	.478	NS
KHOS-B	WITH	AGE	-.2461	.112	NS
DCON	WITH	AGE	-.1474	.346	NS

Reliability of Measures

The most widely used method of estimating an instrument's reliability is to assess its internal consistency (Polit and Hungler, 1983). Cronbach's alpha is one of the most useful index's of reliability available. The normal range of values for Cronbach's alpha is between 0.0 and + 1.00 with higher values reflecting a higher degree of internal consistency. Reliability coefficients for the desire for control measures are reported in Table 4. These represent acceptable levels of internal consistency for group-level comparisons (Polit and Hungler, 1983) and are similar to values obtained when the scales were administered to adult populations in non-serious illness situations (Smith, Wallston, & Wallston, 1984; Krantz, Baum, & Wideman, 1980).

TABLE 4

ALPHA RELIABILITIES FOR DESIRE FOR CONTROL MEASURES

MEASURE	CRONBACH'S ALPHA
KHOS	0.79
KHOS-B	0.78
KHOS-I	0.71
DCON	0.86

Convergent Validity

An examination of relationships based on theoretical predictions is one means of providing support for the validity of an instrument. For example, if the KHOS and DCON scale both measure desire for control, albeit at differing levels of specificity, then scale scores should show a positive correlation (see Table 5). The magnitude of the significant correlation between the KHOS and DCON ( $R_s = .4332$ ,  $p < .01$ ) and KHOS-I and DCON ( $R_s = .4955$ ,  $p = .001$ ) is reasonably substantial to provide support for convergent validity between the KHOS-I subscale and DCON. The findings did not show a significant correlation between the KHOS-B subscale and the other desire for control measures.

TABLE 5

SPEARMAN RANK CORRELATION COEFFICIENTS AMONG DESIRE FOR CONTROL MEASURE

MEASURE	SPEARMAN'S $R_s$	SIGNIFICANCE	PROBABILITY
KHOS with DCON	.4332	.004	$p < .01$
KHOS-I with DCON	.4955	.001	$p \leq .001$
KHOS-B with DCON	.1747	.263	NS
KHOS-I with KHOS-B	.2140	.168	NS

### The Krantz Health Opinion Survey

Item frequencies for the KHOS are reported in Table 6. Composite KHOS scale scores ranged between 24 and 50, with an interquartile range between 33 and 38, median of 36.0, and a standard deviation of 5.60. When the scale was divided into thirds as a criterion measure for high, medium and low desire for control, 6.9% scored within the "high" range, 69.8% within the "medium" range, and 23.3% within the "low" range (see Table 7). The KHOS frequency distribution is illustrated in figure 2.

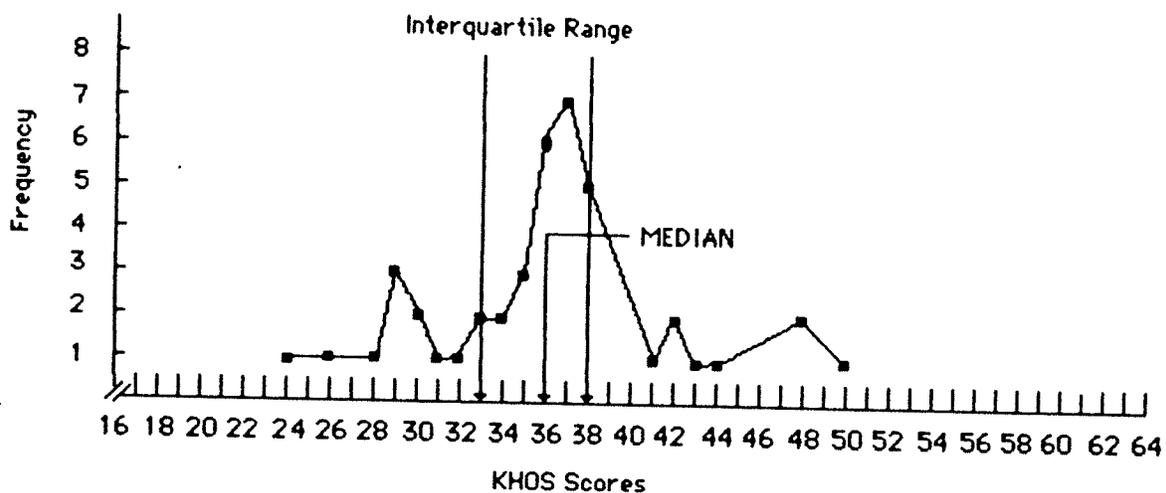


Figure 2

Frequency Distribution for the Krantz Health Opinion Survey.

TABLE 6

## ITEMS AND FREQUENCIES FOR THE KRANTZ HEALTH OPINION SURVEY

Item	Frequency n=43			
	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
Information subscale				
(1) I usually don't ask the doctor or nurse many questions about what they're doing during a medical exam. *	2	24	12	5
(3) I'd rather have doctors and nurses make the decisions about what's best than for them to give me alot of choices.*	2	21	16	4
(4) Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health.	5	22	15	1
(8) I usually ask the doctor and nurse lots of questions about the procedures during a medical exam.	3	16	23	1
(10) It is better to trust a doctor or nurse in charge of a medical procedure than to question what they are doing.*	4	12	26	1
(15) I usually wait for the doctor or nurse to tell me the results of a medical exam rather than asking them immediately.*	3	19	19	2
(16) I'd rather be given many choices about what's best for my health than to have the doctor make the decisions for me.	3	19	17	4

Note: Numbers in parentheses indicate the sequence of items on the scale.

\* Negatively worded item - agreement indicative of a lower desire for control

TABLE 6 Continued

ITEMS AND FREQUENCIES FOR THE KRANTZ HEALTH OPINION SURVEY

Item	Frequency n=43			
	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
Behavioral Involvement subscale				
(2) Except for serious illness, it's generally better to take care of your <u>own</u> health than to seek professional help.	2	7	23	11
(5) It is better to rely on the judgements of doctors (who are the experts) than to rely on "common sense" in taking care of your own body.*	8	18	15	2
(6) Clinics and hospitals are good places to go for help since <u>it's best for medical experts to take responsibility</u> for health care.*	10	26	5	2
(7) Learning how to cure some of your own illness without contacting a physician is a good idea.	1	10	26	6
(9) It's almost always better to seek professional help than to try to treat yourself.*	14	25	4	0
(11) Learning how to cure some of your illness without contacting a physician may create more harm than good.*	10	26	7	0
(12) Recovery is usually quicker under the care of a doctor or a nurse than when patients take care of <u>themselves</u> .*	11	25	6	1
(13) If it costs the same, I'd rather have a doctor or nurse give me treatments than do the same treatments myself.*	9	23	10	1
(14) It is better to rely less on physicians and more on your own common sense when it comes to caring for your body.	0	17	21	5

Note: Numbers in parentheses indicate the sequence of items on the scale.

\* Negatively worded item - agreement indicative of a lower desire for control

TABLE 7

PERCENTAGE OF SCALE SCORE RANKED HIGH MEDIUM OR LOW

SCALE NAME		SCALE RANKS		
		LOW	MEDIUM	HIGH
KHOS	range	16-32	33-47	48-64
	percent	23.3%	69.8%	6.9%
KHOS-I	range	7-14	15-20	21-28
	percent	14.0%	67.4%	18.6%
KHOS-B	range	9-18	19-26	29-41
	percent	46.5%	53.5%	0%
DCON	range	14-28	29-41	42-56
	percent	0%	55.8%	44.2%

The Krantz Health Opinion Survey Information Subscale

The KHOS-I items measured questioning and choicemaking behavior in general health care. Five items measured the respondents' description of past information-seeking behavior and two items related to a preference for choice. Summated scores for the KHOS-I subscale ranged between 10 and 26, with an interquartile range between 16 and 19, median of 18, and a standard deviation of 3.03. Eighteen point six percent (18.6%) scored within the "high" range, 67.4% within the "medium" range, and 14% within the "low" range (see Table 7). The KHOS-I frequency distribution is illustrated in figure 3.

Item frequencies were reported in Table 6. Sixty three percent (63%) felt it was better to question a doctor or nurse than to simply trust what they were doing (item 10). Forty-two percent (42%) usually ask questions of the doctor or nurse about a procedure (items 1 & 8) and 56% usually ask questions about their health after a medical examination (items 4 & 15). Forty-nine percent (49%) would rather be given choices than to have the doctor or nurse make

the decision about what's best for their health (items 3 & 16); with 8% strongly agreeing and 7% strongly disagreeing.

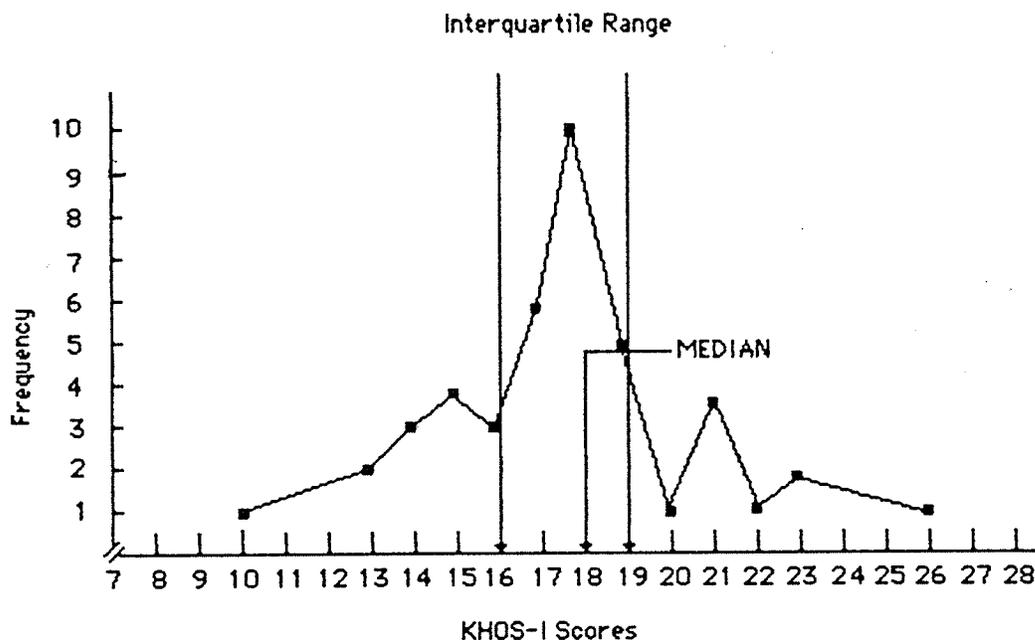


Figure 3

Frequency Distribution for the Krantz Health Opinion Survey Information Subscale

#### The Krantz Health Opinion Survey Behavioral Involvement Subscale

The KHOS-B subscale measured the subjects propensity toward self-care in general health care situations. Summated subscale scores ranged between 9 and 26, with an interquartile range between 16 and 20, median of 19, and a standard deviation of 3.84. There were no respondents within the "high" range, 53.5% within the "medium" range, and 46.5% within the "low" range (see Table 7). The frequency distribution is illustrated in figure 4.

Item frequencies for the KHOS-B were reported in Table 6. They provide little support for the prevailing assumption that many women are adopting a philosophy of self-care. Only 23% felt it was better to use "common sense" or learn how to cure or treat some of their own illnesses

than to rely on professional help for health care; with 2% strongly agreeing and 23% strongly disagreeing with this attitude.

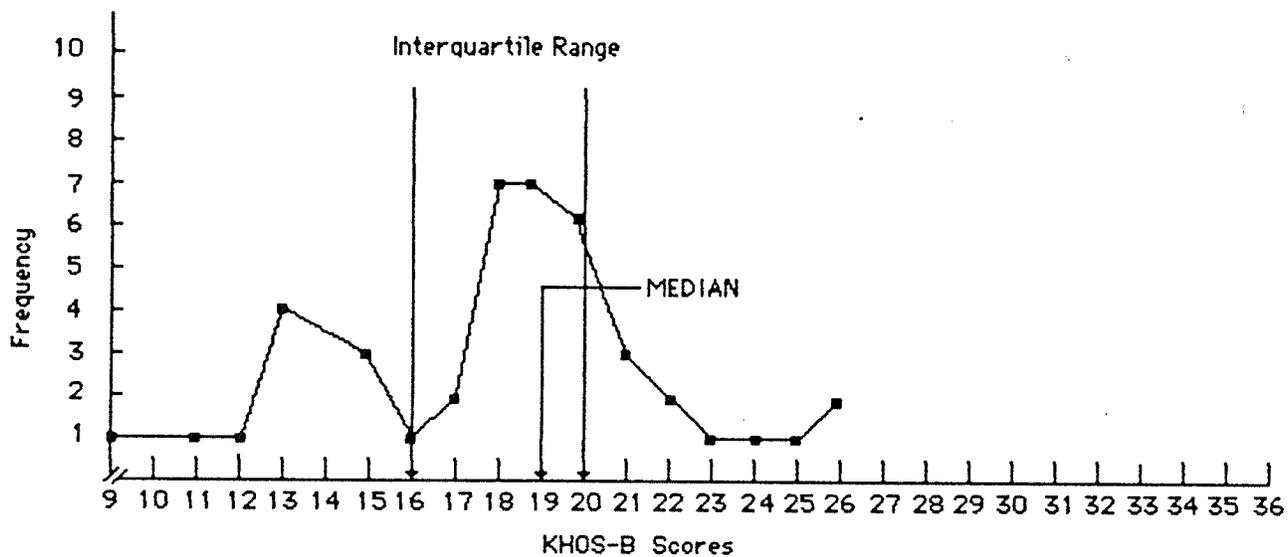


Figure 4

Frequency Distribution for the Krantz Health Opinion Survey.

Behavioral Involvement Subscale

### Desire for Control Scale

DCON scores ranged between 36 and 55, with an interquartile range between 39 and 47, median score of 41, and standard deviation of 5.24. The frequency distribution was multimodal and skewed to the right (see Figure 5). When the scale was divided into thirds as a criterion measure for high, medium and low desire for control, 44.2% scored within the "high" range, 55.8% within the "medium" range, and 0% within the "low" range (see Table 7).

Item frequencies are reported in Table 8. One hundred percent (100%) circled agree or strongly agree for four of the six items reflecting a desire for information. All respondents wanted to know in advance which qualified health professional would take care of her (47% strongly agreed; 53% agreed), which procedures would be used (49% strongly agreed; 51% agreed), what the procedures would feel like (37% strongly agreed; 63% agreed), and what the procedures would do to her (44% strongly agreed; 56% agreed). On the remaining two items which were negatively worded, 93% disagreed or strongly disagreed with not being told in advance what would be done to her, and 81% disagreed or strongly disagreed with being told only what the doctors and nurses thought she needed to know about her care.

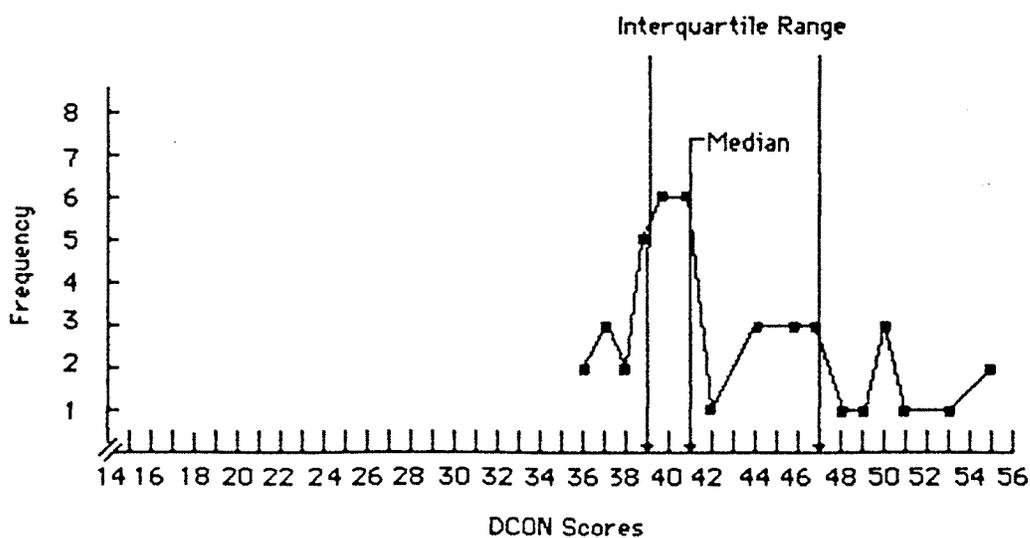


Figure 5

Frequency Distribution for the Desire for Control Scale

TABLE 8

## ITEMS AND FREQUENCIES FOR THE DESIRE FOR CONTROL SCALE

Item	Frequency n=43			
	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
INFORMATION ITEMS				
(2) I do not want to know in advance what will be done to me.*	0	3	17	23
(3) I want to know which qualified health professionals will take care of me.	20	23	0	0
(5) I want to know in advance which procedures will be used.	21	22	0	0
(8) I want to know in advance what the procedures will feel like.	16	27	0	0
(11) I want to know what the procedures will do to me.	19	24	0	0
(12) I want to be told only what the doctors and nurses think I need to know about my care.*	1	7	18	17
CONTROL ITEMS				
(1) I want to have a say in what will be done to me.	15	27	1	0
(4) I want the doctors and nurses to decide what is best for me.*	5	26	9	3
(6) I want to influence the kind of care I get.	6	31	6	0
(7) I want the doctors and nurses to decide what procedures I should have.*	4	28	9	2
(9) I do not want to choose which qualified health professional takes care of me.*	1	9	21	12
(10) I want to be able to interrupt a procedure once it has started.	4	22	16	1
(13) I want to have a say in what procedures I will get.	11	27	5	0
(14) I want to have doctors and nurses do things for me even if I could do them for myself.*	2	3	27	11

Note: Numbers in parentheses indicate the sequence of items on the scale.

\* Negatively worded item - agreement indicative of lower desire for control

A high desire for control was also evident in items questioning the respondents wish to "have a say" or "influence" her care (see items 1, 6 and 13 Table 8). Ninety one percent (91%) agreed with these items including 25% who strongly agreed. No respondents strongly disagreed. In contrast, the majority (73%) wanted doctors and nurses to decide "what is best" or "what procedures I should have" (see items 4 and 7 Table 8). A desire for control was also suggested by responses to several other items. This included 77% wanting to choose which qualified health professional provided care (item 9), 88% wanting to do things for themselves even if a doctor or nurse could do it for them (item 14), and 60% wanting to have enough control to be able to interrupt a procedure once it had started (item 10).

#### Comparison of KHOS and DCON scale scores

There was a significant difference in a woman's desire for control between general health care situations (KHOS) and the specific situation of breast cancer (DCON). A Wilcoxon matched-pairs signed-rank test confirmed that KHOS scores were significantly lower than DCON scores ( $z = -5.2586$ ,  $p = .0000$ ). There were only four cases where the DCON score ranked lower than the KHOS score. To illustrate the magnitude of difference, DCON scores were weighted-multiplied by 1.14 - and a comparison of range and median scores made (see Table 9).

TABLE 9

#### COMPARISON OF DESCRIPTIVE STATISTICS BETWEEN KHOS AND DCON\* SCALE SCORES

SCALE	RANGE	MEDIAN	INTERQUARTILE RANGE
KHOS	24 - 50	36	33 - 38
DCON*	41 - 62	46	44 - 53

\*Note: This represents a weighted DCON score

### Summary

The overall results indicated that when facing treatment for breast cancer the majority of women in this study had a high desire for control although this may not be evident from their usual questioning behavior. They wanted information as well as the opportunity to "have a say" and to "influence" the process of their health care. At the same time they desired to leave the final decision of "best" treatment up to the health professional. Self-care scores were generally very low. There was no significant correlation between desire for control measures and age. There was some support for an association between desire for control and extent of disease; women with early stage breast cancer had significantly higher scale scores than women with more advanced stages of the disease.

## CHAPTER 5

### DISCUSSION

In this final chapter study results are discussed in light of methodological contributions and study limitations. The descriptive data reported in this study represent a preliminary analysis. Data collection is ongoing in several settings in an attempt to obtain a larger more representative sample. The chapter concludes with a discussion of the implications of the descriptive data for nurses and future nursing research.

#### Methodological Contributions

The desire for control measures used in this study had previously been tested for reliability and validity on college students and adult populations in non-serious illness situations. This study also provided support for the reliability of the KHOS and DCON scales. Acceptable levels of internal consistency, the most useful and widely used method of estimating an instruments reliability, were achieved. These values were similar to those obtained in previous research (Krantz et al., 1980; Smith et al., 1984).

The question of instrument validity was also addressed. Desire for control is a psychologically-oriented concept making it difficult to provide solid evidence supporting the validity of the scales. Support for content and construct validity was established from a review of research which reported on the scales development (Krantz et al., 1980; Smith et al., 1984). This study provided additional support for convergent validity, a form of construct validity, between the two scales. Significant correlations were found between the KHOS and DCON and KHOS-I and DCON scales. The magnitude of the correlation was the highest between the DCON and KHOS-I scales which was similar to the findings of Smith and her colleagues (1984). The KHOS-B subscale did not correlate significantly with any of the other desire for control measures.

This is contrary to previous research in which both KHOS subscales revealed significant correlation with each other as well as with DCON (Smith et al., 1984). The difference in the populations under study may account for this. Perhaps the serious nature of the illness situation with which the women in this study were coping influenced their attitude toward self-care. It may be difficult to recall attitudes toward self-care in general health care while attempting to cope with treatment for cancer. The respondents were all undergoing their first series of treatments for the disease which may have fostered a greater feeling of dependence on health professionals for help. One respondent commented "I found many of these questions difficult to answer. I don't believe in running to a doctor with every ache and pain but I do recognize the importance of early treatment of a serious problem." Others commented that their answers really "depended on the circumstances." Finally, one woman wrote "I'm only on my second cycle so my answers could change, as far as self-help goes, as time goes on but I doubt it, as I'm pretty chicken." It is also possible that in general the Canadian public does not wish to accept much individual responsibility for health with the expectation that the health care system will take care of them. Perhaps the Canadian system of health insurance has reduced the public's need to think of self-care as a responsibility that accompanies the right to universal access to health care.

#### Limitations

The results must be discussed in light of study limitations. The sample size was small and atypical of the target population. Younger women with node positive disease were over represented, and older women with node negative disease were under represented. The small number of respondents may have been a function of the settings in which data was collected. Nurses and physicians from all settings reported low accrual rates because few patients met the selection criteria. As a result, the selection criteria was expanded from a maximum time of six months since diagnosis to within one year of diagnosis to allow more women to participate. The

small sample size was also a function of the relatively limited numbers of women with node negative disease obtaining adjuvant treatment from out patient oncology departments. Failure to access this segment of the target population, which comprises almost three quarters of all newly diagnosed cases each year, severely limited the sample size. Very few women refused to participate. Demographic data or reason for refusal was not collected so it is unknown if those who refused to participate differ significantly from those who volunteered. Finally, data was not collected on how many women were excluded from participation because they did not meet the criteria for psychological adjustment to the treatment process. This criteria was included to obtain approval from the nursing ethical review committee. It is left to speculation as to how many women were excluded because they did not meet this criteria and what role, if any, desire for control plays when a woman fails to make a sufficient psychological adjustment to the disease and treatment process.

Considering these limitations the results of this study cannot be generalized to a larger population. It must be left to a future research to overcome the difficulties in access to data. At best the sample may be seen as representing the opinions of women with a first time diagnosis of breast cancer receiving treatment from hospital oncology out patient departments. Therefore, study results may prove to be the most useful to nurses practicing in hospital oncology out patient settings.

#### Discussion of the Research Question

Is desire for control the voice of a vocal minority or a phenomenon representing the majority of women facing breast cancer? Specifically, are these women seeking information about diagnostic and treatment procedures? Do they desire active behavioral involvement in their health care?

The data unequivocally supports the respondents desire for information about breast cancer diagnostic and treatment procedures. DCON scores all fell within the "high" and "medium" scale range. DCON items measuring the desire for information received the strongest agreement ratings of all scale items. Respondents wanted to know in advance which qualified health professional would take care of her, which procedures would be used, what the procedures would feel like, and what the procedures would do to her. As suggested in the literature, the women in this study wanted honest and complete answers and were not satisfied with being told only what doctors and nurses think patients need to know about their care. These findings parallel those found in the literature which support the woman's need for knowledge regarding diagnosis, tests, treatment, and lifestyle changes when coping with breast cancer (Reynolds, Sachs, Davis, & Hall, 1981; Morris, Greer, & White, 1977).

A comparison of responses from the KHOS-I subscale with the responses on the DCON scale suggests that a patient's usual questioning behavior is not necessarily indicative of their desire for information. On the four KHOS-I items dealing with descriptions of past information seeking behavior 42% usually ask questions of the doctor or nurse about a procedure and 56% usually ask about their health after a medical examination. The majority of the respondents (67.4%) scored in the "medium" range of the KHOS-I subscale. A woman may "want" to know what the procedure will do to her but "usually" does not ask the health professional many questions about what they are doing. One woman wrote:

It takes time for people to learn the language of medicine. By the time I figured out what was said and its implications there was nobody there to ask questions of.... As for feeling one has any control or say, forget it. It only causes trouble.

Does this suggest that provider controlled decision making may be occurring by default? What factors contribute to the discrepancy between desire for control and an apparent inability to exercise this preference? Lenz (1984) found that despite effort and desire to acquire

information patients often felt unsuccessful in obtaining the information they needed from health professionals. Similarly, Degner and Beaton's (in press) research suggested that health professionals' attempts to communicate treatment plans were often unintelligible to patients and families. Considering these findings, it is not surprising that half of the women in this sample do not usually ask questions of their health professional. It has also been suggested that lay literature and family and friends not associated with health care are primary sources of information for the breast cancer patients (Geiner and Weiler, 1983). In another study only 20% of the 139 postmastectomy patients interviewed identified nurses as a significant source of information (Bullough, 1981). Why are nurses underutilized or not seen as important sources of information? What nursing interventions would be supportive to women seeking information about breast cancer treatment procedures? These become questions of the utmost importance considering the high desire for information found in this study.

The findings related to the question of active behavioral involvement in health care are more tenuous. From a conceptual point of view the DCON item responses and KHOS-I scores suggest that a pattern of joint control possibly based on the assumptions of the compensatory model of helping and coping represent the attitudes of the majority of the sample. In general health care situations, 49% would rather be given choices than have a health professional make the decision about what's best for their health. In contrast, in the respondents' experience with breast cancer the majority (73%) were not prepared to assume responsibility for deciding "what is best" or "what procedures I should have" but most definitely wanted to "have a say" or to "influence" the care received (91% including 25% who strongly agree). Areas in which a substantial proportion of the respondents desired to have control included being able to choose which qualified health professional provided care (77%), remaining independent & doing things for themselves even if a doctor or nurse was available to do it for them (88%), and having enough control to be able to

interrupt a procedure once it has started (60%). This suggests that although they rely on a health professionals expertise to provide the best treatment, they also desire to be heard and to be able to contribute to the decision making process.

The items on the KHOS-B subscale did not correlate significantly with the other desire for control measures. Scores on the KHOS-B subscale were lower than for any of the other desire for control measures. No respondents scored within the "high" range of the KHOS-B, 53.5% scored within the "medium" range, and 46.5% scored within the the "low" range. Less than one quarter (23%) of the sample felt it was better to use "common sense" or to learn how to "cure" or "treat some of your own illness" than to rely on professional help for health care. Considering situational factors such as a relatively recent diagnosis of cancer, no past personal experience with the disease, and being in an active phase of treatment, it is not surprising that the respondents would score low on a self-care scale. It is possible that the KHOS-B subscale is not an appropriate measure of desire for control in populations currently experiencing a serious or life-threatening illness. Smith et al., (1984) found results from the KHOS-B subscale to be ambiguous. It did not assist in discriminating between women who had taken or were intending to take childbirth preparation classes from those who had not. In two studies, groups choosing to die in a hospice facility scored significantly higher on the KHOS-B than groups choosing to die at home. These were findings opposite to the direction predicted. The question that remains is: are the study findings indicative of patients limited view regarding responsibility for health or a function of the timing when attitudes toward self-care are measured?

The demographic variables played an insignificant role in the study findings. There was no support for the hypothesis that younger women desire greater control than older women. This is contrary to previous research which had shown significant negative correlations between age and desire for control (Smith et al., 1984; Haug & Lavin, 1981; Cassileth, 1980). As well, younger

adults had been found to be more active seekers of information than older persons (Lenz, 1984; Wilkinson & Wilson, 1983). The small sample size, including a limited number of respondents in the over 55 years of age category ( $n=15$ ) with no women in the 75 years of age and over group (although this made up 18.9% of the target group) may be responsible for the absence of association between age and desire for control scores. Length of time since diagnosis, income and years of employment outside of the home did not correlate with DCON or KHOS and its subscales. The KHOS-B subscale showed a positive significant correlation with education.

Desire for control may be strongly affected by the situational factor of the nature of the illness. There were significantly higher scores on the situation-specific DCON scale than on the general KHOS scale. In only four cases did KHOS scores rank lower than DCON scores. When facing diagnosis and treatment for breast cancer the majority of the sample had a much stronger desire for control than in general health care situations. Desire for control also appeared to be associated with the extent of the disease. As predicted a significant negative association was found between the extent of disease and KHOS-I subscale scores. Women with early stage breast cancer had a significantly higher desire for information than women with node positive disease. It is left to a future study to see how strong a correlation this is when the sample reflects a true proportion of node negative cases. Also, if the practice of regular breast self-examination is viewed as a control enhancing action, what proportion of node negative cases were receiving early treatment as a result of their own health care practices?

#### Implications for Nursing

This study offers some useful data for nurses. The majority of the respondents wanted information although this may not always be evident from an assessment of their past information-seeking behavior. If the acquisition of knowledge is vital for the woman who wishes to participate in the process of her health care then nurses have a responsibility to see that the

patient receives the desired information. Nurses will need to adopt a more active approach in educating the public on the role of the nurse and the services nurses have to offer. Many women may not even know which questions to ask especially during a first encounter with breast cancer. Nurses involved with community health clinics and service groups such as Cansurmount and Mastectomy support groups are in an excellent position to help women identify the questions they want to ask in order to communicate more effectively with health professionals. As Degner and Beaton (in press) suggest, consumer groups could formulate a series of general questions to guide lay people during their initial interactions with health professionals. Simple questions such as "What are the results of my biopsy?" "Does this mean it's cancer?" "What are my treatment options?" "Are there other options that you have not told me about?" would help the patient to obtain the information they desire. Unless patients become more assertive in their information seeking behavior they will only be told what the health professional thinks the patient needs to know. An incomplete information base may be a major factor contributing to the discrepancy between a patient's desire for control and their usual pattern of behavior when interacting with health professionals.

A pattern of jointly-controlled decision making was suggested by the respondents high desire for information and desire to "have a say" and to "influence" the process of their health care, while at the same time leaving the final decision as to the best treatment up to the health professional.

Comments from several respondents illustrated this position:

I would like the doctor to make the decision but would like to know the choices.

I do want the doctors opinion on all the choices but the decision should be mine.

All doctors are not the same - sometimes I think they don't know their patient very well, taking the attitude that the less they know the better, well this may work for some but not for others. I like all the questions and answers to be laid out on the table and then to face what is ahead.

I want the doctors and nurses to decide what is best for me but I want to have the

choice to decide if I feel very strongly for or against.

Too many choices would most likely result in the wrong choice. The doctor should narrow it down to 2 or 3 at most and then decide each with me.

When patient and health professional arrive at a mutual pattern of helping and coping the needless expenditure of energy in trying to obtain control, overcome communication barriers and establish ones self as a credible partner in the health care process can be avoided. Mutuality in treatment decision making can only occur when patient and health professional become informed of their rights and responsibilities within the health care system.

Nurses can facilitate patient participation by representing the views of patients to other members of the health team and by educating the public regarding their rights and responsibilities before they require health care. Nurses are in the position to encourage women to discuss their concerns, to observe for information-seeking behavior, to identify the type and amount of information desired, and to provide support for a patients attempts to participate in treatment decision making. If patients are to have a significant impact on the process of their health care they must be seen by all health professionals as having valuable information to contribute to the treatment plan.

#### Recommendation for future Research

The results of this study suggest several areas for continued research in nursing. Although a wide variety of settings were used to recruit subjects, the resulting sample was not representative of women with a first time diagnosis of breast cancer. The limited numbers of respondents over age 55 years or with node negative disease leaves one to question: Would a larger more representative sample yield comparable results? How strong is the association between extent of disease and desire for control? What improvements can be made in the study design?

This study found that women with a first time diagnosis of breast cancer had a high desire for information regarding diagnostic and treatment procedures although this may not be evident

from their usual questioning behavior. Is there a significant difference between a woman's usual pattern of questioning behavior and her desire for control? What do women perceive as the impediments to questioning behavior? What specific nursing interventions are most helpful to women in encouraging and supporting them to obtain the desired information and behavioral involvement? If women do not usually ask questions of the health professional, what is their information source and what role, if any, does nursing have in ensuring that this information is accurate?

Only women with a first time diagnosis of breast cancer were included to control for the effect of past experience with the disease. Therefore it remains to be seen what influence past experience with the disease has on desire for control. Are there differences in desire for control between women with recurrent cancer of the breast and first time diagnosis? Are variables such as past experience with the illness, relationships with family or friends who have had experience with the disease, and the presence of support from significant others more important to a woman's desire for control than variables such as age, education and socioeconomic status?

The study suggested that there is some support for a joint pattern of control in specific health care encounters such as treatment for breast cancer. The assumptions of the conceptual framework need to be examined more closely including further methodological study of the desire for control measures and their usefulness with different populations.

### Summary

Clinical observations and a review of written accounts of women's experiences with the health care system suggested that the degree of actual control that a woman had when facing diagnosis and treatment for breast cancer was less than desired. This was not to imply that all women desire control over the process of their health care or that more control is necessarily better. Previous research had indicated that the general public and patients with cancer and

chronic medical conditions wished to take some responsibility for medical decision making (Strull, et al., 1984; Haug & Lavin 1981; Cassileth et al., 1980; Vertinsky et al, 1974). It suggested that some groups of patients may desire joint-control over health care as opposed to the more traditional provider controlled decision making process based on the assumptions of a medical model of helping and coping. These patients wished to share the responsibility for treatment decision making by taking an active role in the health professional/patient relationship. In this study, the overwhelming majority of respondents wanted information although this may not be evident from their usual questioning behavior. In general health care situations, approximately half of the sample preferred to be given choices about what was best for their health rather than have the doctor make the decision for them. Slightly less than one quarter of the sample felt it was better to use "common sense" or to learn how to "cure" or "treat" some of their own illnesses than to rely on professional help for health care. When facing treatment for breast cancer the vast majority desired to "have a say" and to "influence" the process of their health care while at the same time delegating final authority regarding "what is best" or "what procedures I should have" to the health professional. The descriptive data in this study suggest that from the patient perspective, and depending on the nature of the illness, a pattern of jointly-controlled decision making is the model of choice. Desire for control is not the voice of a vocal minority but a phenomenon representing the majority of women **in this sample.**

## Appendix A

**INSTRUCTIONS FOR SUBJECT SELECTION AND QUESTIONNAIRE DISTRIBUTION****1. IDENTIFY POSSIBLE PARTICIPANTS.**

Selection Criteria include: a) women with a first time diagnosis of breast cancer  
 b) from seven weeks to six months from diagnosis  
 c) able to read and write English  
 d) psychological and physiological adjustment to disease sufficient to permit completion of the questionnaire.

Sufficient psychological adjustment is indicated when at least two of the following three factors are present: 1) verbalizes a realistic perception of her experience with breast cancer, 2) uses situational supports (i.e. family, friends, community resources) and 3) initiates use of successful coping mechanisms (i.e. makes an attempt to express feelings, draws on own past experience as well as that of others, makes plans or sets goals).

Sufficient physiological adjustment is indicated when treatment side effects are within manageable limits (i.e. the patient is comfortable and has the energy and ability to concentrate on a 15 - 20 minute task).

**2. APPROACH A POSSIBLE PARTICIPANT**

State that a nursing study is currently being conducted with Manitoba women recently diagnosed with breast cancer. Inform them that they are a potential participant in the study and ask them if they are interested in reading a written description of what participation in the study would involve. IN ORDER NOT TO BIAS RESPONSES IT IS VERY IMPORTANT THAT YOU DO NOT USE THE WORDS DESIRE FOR CONTROL OR INFORMATION WHEN APPROACHING A POSSIBLE PARTICIPANT. IT IS BEST NOT TO ATTEMPT TO DESCRIBE THE STUDY. THE WRITTEN DESCRIPTION IS SUFFICIENT.

**3. GIVE ALL INTERESTED WOMEN A COPY OF THE CONSENT FORM - STUDY DESCRIPTION TO READ.**

**4. OBTAIN WRITTEN CONSENT FROM THOSE WILLING TO PARTICIPATE.**

**5. REMOVE THE PATIENT INFORMATION SHEET FROM THE TOP OF THE QUESTIONNAIRE PACKAGE. HAND OUT QUESTIONNAIRE PACKAGE TO ALL CONSENTING PARTICIPANTS AND INSTRUCT THEM TO READ THE GENERAL INSTRUCTION SHEET AND THEN TO PROCEED.**

**6. COMPLETE THE PATIENT INFORMATION SHEET.**

It is **very important** that the code #'s on the patient information sheet and questionnaire package match.

**7. ONLY ACCEPT A COMPLETED QUESTIONNAIRE BACK WHEN IT HAS BEEN SEALED IN THE ENVELOPE PROVIDED.**

**8. PLACE THE SEALED ENVELOPE AND PATIENT INFORMATION SHEET IN THE FOLDER PROVIDED.**

**THANK YOU FOR YOUR COOPERATION AND PARTICIPATION.**

## Appendix B

## CONSENT FORM-STUDY DESCRIPTION

You are invited to take part in a study of 125 Manitoba women diagnosed with cancer of the breast. From this study we hope to learn more about women's opinions of different kinds of health care specifically during an experience of breast cancer. We would like to learn about this from the woman's point of view as few studies have done this. You are being invited to participate in this study since you have recently experienced a diagnosis of breast cancer.

The study is conducted by Kaaren Neufeld, R.N., Master's student at the School of Nursing, University of Manitoba, under the direction of Professor Lesley Degner and advisors Professor Lynn Scruby and Dr. David Bowman.

If you decide to participate in this study we would like you to answer a short two part check-list type questionnaire and then answer a few brief general questions about yourself. This will take approximately 20 minutes for you to complete. We think you will find the questionnaire easy to do as well as interesting. The opportunity to answer the questionnaire may be helpful to you in clarifying some of the feelings and concerns you might have about your treatment. The time you take to fill out the questionnaire will not interfere in any way with your care at the clinic and will not unduly inconvenience you. We will also be asking a nurse or your doctor to complete a few brief questions about your diagnosis and treatment.

The information you provide will be strictly confidential, because no identification will be associated with the information you provide. Only the investigator and her advisors will have access to the completed questionnaires. The written report of this study will report only group information and no single individual will be referred to or will be identifiable.

Your decision whether or not to participate in this study will not affect your care by clinic staff or your physician. If you do decide to take part in this study you are, of course, free to discontinue participation at any time.

If you have any questions please ask. If you have any questions later you may contact the investigator, Kaaren Neufeld, at the School of Nursing, University of Manitoba, 474-9080 and she will be happy to answer them.

**YOU WILL BE GIVEN THIS PORTION OF THE CONSENT FORM TO KEEP.**

Appendix B  
WRITTEN CONSENT

You are making a decision whether or not to participate. Your signature indicates that you have read the information above and have decided to participate in this study. You are free to withdraw at any time after signing this form should you choose to discontinue participation in this study.

---

Date

---

Signature

---

Date

---

Signature of Witness

## Appendix C

code # \_\_\_\_\_

## TO BE COMPLETED BY THE PATIENT'S NURSE OR PHYSICIAN

## PATIENT INFORMATION SHEET

1. AGE: Check one response.

44 & under    45-54    55-64    65-74    75 & over

2. EXTENT OF DISEASE: Check one response.

No Nodal Dissection    Nodes Negative    Nodes Positive

3. TYPE OF TREATMENT : Check all responses that apply

surgery    chemotherapy    radiotherapy

4. LENGTH OF TIME SINCE DIAGNOSIS: Check one response.

7-12 weeks    13-18 weeks    19-24 weeks

## Appendix C

## GENERAL INSTRUCTIONS

1. There are three parts to the questionnaire. Please follow the instructions given at the beginning of each part.

Part I has 16 questions

Part II has 14 questions

Part III has 3 questions

2. Answer all questions on the questionnaire itself.
3. Answer in pencil in case you wish to change your response.
4. All questions can be answered by circling or checking one of the answers.
5. Feel free to write in any comments that make your answers more complete.
6. This is NOT a test, so there are no right or wrong answers.
7. When you have completed the questionnaire please seal it in the envelope provided BEFORE handing it back to your nurse or doctor.
8. If you are interested in receiving a summary of the results of the study please complete the final page of the questionnaire package. Return this page along with , BUT NOT INCLUDED IN, the sealed envelope which contains your completed questionnaire.
9. You will notice a code\* in the top right hand corner of each page. This is done so that the questionnaire pages can be matched should they become separated as well as identify the hospital or clinic where you are obtaining your treatment.

**PLEASE PROCEED WITH PART I OF THE QUESTIONNAIRE**

## Appendix C

PART I: (Krantz Health Opinion Survey)

code# \_\_\_\_\_

INSTRUCTIONS: The following questions ask for your opinions about different kinds of health care. For each statement below, decide whether you strongly agree, agree, disagree or strongly disagree and circle the answer which best fits your opinion. Each person is different, so there are no "right" or "wrong" answers. Please try to circle an answer for each question, and don't leave any blank. Please respond to all items below choosing the one answer that comes closest to what you believe.

Your answers are confidential and will be used for research purposes only. Thank you for your assistance.

For each question, circle  
only one answer that comes  
CLOSEST to what you believe:

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. I usually don't ask the doctor or nurse many questions about what they're doing during a medical exam.	SA	A	D	SD
2. Except for serious illness, it's generally better to take care of your <u>own</u> health than to seek professional help.	SA	A	D	SD
3. I'd rather have doctors and nurses make the decisions about what's best than for them to give me alot of choices.	SA	A	D	SD
4. Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health.	SA	A	D	SD
5. It is better to rely on the judgements of doctors (who are the experts) than to rely on "common sense" in taking care of your own body.	SA	A	D	SD
6. Clinics and hospitals are good places to go for help since <u>it's best for medical experts to take responsibility</u> for health care.	SA	A	D	SD
7. Learning how to cure some of your own illness without contacting a physician is a good idea.	SA	A	D	SD

PART I continued:

code# \_\_\_\_\_

For each question, circle  
only one answer that comes  
CLOSEST to what you believe:

	Strongly Agree	Agree	Disagree	Strongly Disagree
8. I usually ask the doctor and nurse lots of questions about the procedures during a medical exam.	SA	A	D	SD
9. It's almost always better to seek professional help than to try to treat yourself.	SA	A	D	SD
10. It is better to trust a doctor or nurse in charge of a medical procedure than to question what they are doing.	SA	A	D	SD
11. Learning how to cure some of your illness without contacting a physician may create more harm than good.	SA	A	D	SD
12. Recovery is usually quicker under the care of a doctor or a nurse than when patients take care of <u>themselves</u> .	SA	A	D	SD
13. If it costs the same, I'd rather have a doctor or nurse give me treatments than do the same treatments myself.	SA	A	D	SD
14. It is better to rely less on physicians and more on your own common sense when it comes to caring for your body.	SA	A	D	SD
15. I usually wait for the doctor or nurse to tell me the results of a medical exam rather than asking them immediately.	SA	A	D	SD
16. I'd rather be given many choices about what's best for my health than to have the doctor make the decisions for me.	SA	A	D	SD

## Appendix C

PART II: (Smith Desire for Control Scale)

code# \_\_\_\_\_

INSTRUCTIONS: The items below all deal with what you want to happen in your experience with breast cancer.

For each item below, circle the response which indicates what you actually want. There are no right or wrong answers. If you really want whatever is mentioned in the item to happen, circle SA (Strongly Agree); if you want it to happen but don't feel that strongly about it, circle A (Agree). Similarly, if you do not want what is mentioned in the item to happen, circle either D (Disagree) or SD (Strongly Disagree) depending on how strongly you feel about it.

Please respond to all items below. Remember, they are all in reference to what you want to happen in your experience with breast cancer.

---

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. I want to have a say in what will be done to me.	SA	A	D	SD
2. I do not want to know in advance what will be done to me.	SA	A	D	SD
3. I want to know which qualified health professionals will take care of me.	SA	A	D	SD
4. I want the doctors and nurses to decide what is best for me.	SA	A	D	SD
5. I want to know in advance which procedures will be used.	SA	A	D	SD
6. I want to influence the kind of care I get.	SA	A	D	SD
7. I want the doctors and nurses to decide what procedures I should have.	SA	A	D	SD
8. I want to know in advance what the procedures will feel like.	SA	A	D	SD
9. I do not want to choose which qualified health professional takes care of me.	SA	A	D	SD



## Appendix C

## PART III: (Demographic Data)

code# \_\_\_\_\_

## INSTRUCTIONS:

Please answer the following questions as truthfully as possible. The information gained from these questions will be used to determine relationships between personal characteristics and information from the other questionnaires.

1. EDUCATION: Check highest year of education completed.
 

<input type="checkbox"/> less than grade nine	<input type="checkbox"/> trades certificate or diploma
<input type="checkbox"/> some high school	<input type="checkbox"/> some university or college
<input type="checkbox"/> high school graduate	<input type="checkbox"/> university or college graduate
  
2. INCOME: Check the one response that comes the CLOSEST to the approximate annual income of your family.
 

<input type="checkbox"/> under \$5,000	<input type="checkbox"/> \$20,000 to \$24,999
<input type="checkbox"/> \$5,000 to \$9,999	<input type="checkbox"/> \$25,000 to \$29,999
<input type="checkbox"/> \$10,000 to \$14,999	<input type="checkbox"/> \$30,000 to \$39,999
<input type="checkbox"/> \$15,000 to \$19,999	<input type="checkbox"/> \$40,000 and over
  
3. EMPLOYMENT: Are you now, or have you ever been employed outside of the home?
 

<input type="checkbox"/> YES	<input type="checkbox"/> NO
------------------------------	-----------------------------

If yes approximately how long?

<input type="checkbox"/> 5 years or less	<input type="checkbox"/> 6 to 10 years	<input type="checkbox"/> 11 years or more
--	--	---

DETACH THE LAST PAGE AND FILL IN IF INTERESTED IN RECEIVING A SUMMARY OF THE STUDY RESULTS. Return along with, BUT NOT INCLUDED IN, the sealed envelope which contains your completed questionnaire.

SEAL THE COMPLETED QUESTIONNAIRE IN THE ENVELOPE PROVIDED.

THANK YOU FOR YOUR PARTICIPATION.

APPENDIX D  
LETTERS OF APPROVAL



**Manitoba Cancer Treatment and Research Foundation**

100 Olivia Street • Winnipeg, Canada R3E 0V9

*January 8th, 1986.*

*Ms. K. Neufeld,  
70 Thunder Bay,  
Winnipeg, Manitoba.  
R2M 4S2*

*Dear Ms. Neufeld:*

*You may now proceed. Please make suitable arrangements for handling of  
Doctor Israels' questionnaire.*

*At H. S. C. please communicate with Nancy Johnson and/or Doctor Bowman;  
at St. Boniface with Doctor Weirnerman or his "designate."*

*Sincerely,*

*MARTIN LEVITT, M.D.,  
Director,  
Clinical Investigation.*

*ML/tlr*

*CC: N. Johnson, R.N.  
D. Bowman, M.D.  
B. Weirnerman, M.D.*

HEALTH SCIENCES CENTRE

DATE: December 12, 1985

FROM: Pharmacy and Therapeutics Committee

TO: Ms. Kaaren Neufeld

SUBJECT: Clinical Trial

NO: E 85:136

TITLE: Desire for Control over Health Care in Manitoba  
Women Newly Diagnosed with Cancer of the Breast.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

The above study has been reviewed by the Clinical Trials Subcommittee and approved for Health Sciences Centre adult areas.

COMMENTS: \_\_\_\_\_

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\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



Hôpital Général — St. Boniface — General Hospital  
409 Taché Avenue,  
WINNIPEG, MANITOBA R2H 2A6 (204) 233-8563

86 01 30

MEMORANDUM:

TO : V. Mann  
Director of Ambulatory Care Nursing Programs

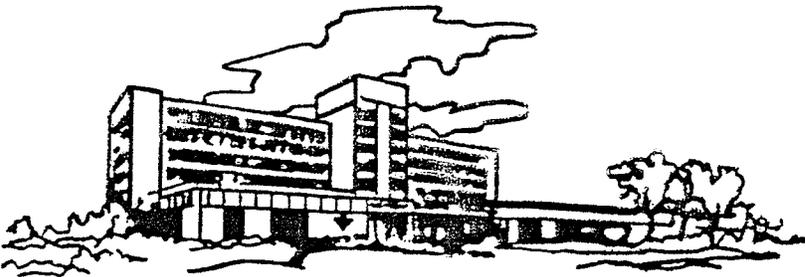
FROM : J. Dick  
Vice-President, Nursing -

SUBJECT : REQUEST FOR ONCOLOGY PARTICIPATION IN DATA COLLECTION  
FOR A NURSING RESEARCH STUDY

I have reviewed your memorandum of January 29, 1986 regarding the above request.

It would appear that Ms. Neufeld has acquired all the necessary approvals. We have no formal process for reviewing these requests, other than the Vice-President being made aware of same and okaying them. If you have no objections and if this is okay with Drs. Schipper and Weirnerman, you may advise Ms. Neufeld that she may begin her research study.

JD/jrh



# VICTORIA GENERAL HOSPITAL

340 Pembina Highway, Winnipeg, Manitoba R3T 2E8 (204) 269-3570

September 17, 1985

Karen Neufeld  
70 Thunder Bay  
WINNIPEG, Manitoba  
R2M 4S2

Dear Karen:

I have received medical approval for your research project.  
Could you please make an appointment to discuss further details.

Thank you.

Yours truly,

 Bonnie Lynn Wright  
Reg.N., B.A., B.Sc.N., M.Sc.N.,  
Assistant Executive Director-Nursing

BLW,AED-N/gsb  
Att.

WILLIAM BOOTH . . . . . FOUNDER  
 JARL WAHLSTRÖM . . . . . GENERAL  
 ARTHUR R. FITCHER . . . . . TERRITORIAL COMMANDER



THE SALVATION ARMY

## GRACE GENERAL HOSPITAL

300 BOOTH DRIVE

— WINNIPEG, MANITOBA R3J 3M7 —

TELEPHONE (204) 837-8311

October 15th, 1985

Ms. Kaaren Neufeld  
 70 Thunder Bay  
 Winnipeg Manitoba  
 R2M 4S2

Dear Ms. Neufeld:

I am pleased to inform you that your request for participation of the Grace General Hospital Patient Proposal through the Chemotherapy Department has been approved by Nursing Administration, the Administrative Committee and the Medical Executive.

We would be interested in having a copy of the results of your research Desire for Control Over Health Care in Manitoba Women Newly Diagnosed with Cancer of the Breast.

Please feel free to contact Mrs. Lorraine Bruce, Senior Nurse in Chemotherapy at 837-0246.

Please be in touch if I can be of assistance.

Sincerely,

(Miss) E. M. Nugent  
 Director of Nursing Services

/leb

copy / Mrs. L. Bruce

# DAUPHIN MEDICAL GROUP

PHYSICIANS AND SURGEONS

622 - 3RD ST. S.W.      DAUPHIN, MANITOBA      TELEPHONE 638-6445  
R7N 1R5

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*DEPARTMENT OF SURGERY*

A.M. LYSACK, B.A., M.D., F.R.C.S. (C)  
D.K. McIVER, B.Sc., B.Sc. (MED.), M.D., C.C.F.P., F.R.C.S. (C)

---

D.J. McDILL — ADMINISTRATION

*FAMILY PRACTICE*

V.R. BREEN, M.D., C.C.F.P.  
G.J. BRETECHER, B.Sc., M.D.  
W.H. COLBORNE, B.Sc., M.D.  
R.F. DECKER, M.D., B.Sc. (MED.), C.C.F.P.  
J.P. POTOSKI, B.Sc., M.D.  
E.S. SIGURDSON, B.A., M.D., C.C.F.P.  
L.E. SOMMER, M.D.  
L.J. STEPHEN, B.Sc., M.D., C.C.F.P., F.C.F.P.  
W.G. WARRIAN, B.Sc., (MED.), M.D., C.C.F.P.  
W.C. WILKIE, M.D.  
B.E. WILSON, M.D.

October 31, 1985

Ms. Kaaren R. Neufeld  
70 Thunder Bay  
Winnipeg, Manitoba  
R2M 4S2

Dear Ms. Neufeld:

Thank you for your letter of October 17th, regarding your research proposal. I would be willing to help out in what fashion I can.

I would trust that the long term goal of this article is to enhance patient care and good working relations with all members of the health team. I am concerned about the implications of the framework as indicated on page three of the proposal. All too often, these days, issues regarding patient care are superficially lumped into medical model versus some other model. This makes broad statements and implications regarding patient care from physicians which frequently is incorrect and does not reflect their concern for patient knowledge control, supplemented by family involvement and good rapport with patients.

Yours sincerely,

Eric Sigurdson, M.D.

ES/kw

c.c. Dr. David Bowman

# REPLY FORM

## DESIRE FOR CONTROL OVER HEALTH CARE IN MANITOBA WOMEN WITH A FIRST TIME DIAGNOSIS OF BREAST CANCER

Please check the appropriate box, sign and return to:

Ms. Kaaren R. Neufeld  
70 Thunder Bay  
Winnipeg, Manitoba  
R2M 4S2

YES, I am willing to assist in data collection. I anticipate that over the next four months I will see 6 (fill in the *approximate* number) women with a first time diagnosis of breast cancer who are between seven weeks and six months from initial diagnosis.

NO, I do not wish to have my patients participate in this study.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Please print name

APPENDIX E  
ETHICAL APPROVAL

UNIVERSITY OF MANITOBA  
FACULTY COMMITTEE ON THE USE OF HUMAN SUBJECTS IN RESEARCH

NAME: MS. KAAREN NEUFELD

OUR REFERENCE: E85:136

DATE: 7 October 1985.

YOUR PROJECT ENTITLED:

Desire for Control over Health Care in Manitoba Women Newly Diagnosed with Cancer of the Breast.

HAS BEEN APPROVED BY THE COMMITTEE AT THEIR MEETING OF: September 30, 1985

COMMITTEE PROVISOS OR LIMITATIONS:

You will be asked at intervals for a status report. Any significant changes of the protocol should be reported to the Chairman for the Committee's consideration, in advance of implementation of such changes.

If you are applying for funds for this project, please advise the Committee Secretary whether or not you need a statement of local review committee for the granting agency.

\*\*This approval is for the ethics of human use only. For the logistics of performing the study approval should be sought from the relevant institution if required.

Sincerely yours,

✓  
J.P. Maclean, M.D.,  
Chairman,  
Faculty Committee on the Use of Human  
Subjects in Research.

JPM/lrm

TELEPHONE ENQUIRIES  
786-4375 - Laurie



THE UNIVERSITY OF MANITOBA

SCHOOL OF NURSING

Room 246 Bison Building  
Winnipeg, Manitoba  
Canada R3T 2N2

October 9, 1985

Ms. Kaaren Neufeld  
Graduate Student  
School of Nursing  
University of Manitoba  
WINNIPEG, Manitoba  
R3T 2N2

Dear Ms. Neufeld:

Your proposal entitled "Desire for Control over Health Care in Manitoba: Women Newly Diagnosed with Cancer of the Breast" has been approved by the Ethical Review Committee with the alterations you submitted.

The Committee joins with me in wishing you success with your project.

Sincerely

Karen Chalmers, R.N., M.Sc.(N)  
Assistant Professor  
Chairperson, Ethical Review Committee

KC/se

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