

HIERARCHIAL PROFILES OF INFORMATION  
NEEDS OF WOMEN RECENTLY DIAGNOSED  
WITH BREAST CANCER

BY

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

MASTER OF NURSING

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## DEDICATION

To all the women who took the time  
and risked the emotion of sharing their experiences  
with cancer, in hopes of benefiting the women who will be  
diagnosed with breast cancer in the future.

And

To my parents whose recent diagnosis  
of cancer heightened my commitment to identify  
the priority information needs of the elderly person diagnosed  
with cancer.



## Acknowledgements

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A sincere and heartfelt thank you to my friend and mentor, Joann MacMorran, whose caring and support was evident on an almost daily basis through words of wisdom, cards, articles, books, slides, contact persons, flowers and of course food.

A special acknowledgement of thanks, admiration and congratulations to my long time friend and fellow student, Joan Boyce. Our professional and personal lives have taken us on a journey down many different paths. During this past year we reconnected on the academic path and shared our

frustrations, laughter, successes, and finally the completion of our master's theses. Now, as Joan and her family leave for Vancouver, we again are forced to follow different, more distant paths, but this past year of sharing our research experience will help to keep our special friendship close at heart.

To my classmates, who have become my friends, I extend sincere appreciation for their unique strengths, personalities, and professional knowledge, but more importantly, their understanding of the "lived experience" of nursing research.

And last, but definitely not least, I extend my heartfelt thanks to my parents whose constant love and support made this educational experience so rewarding for me. To those other "special" people in my personal life, I can express my thanks only in a personal acknowledgement. As for "life after thesis" - may I live it according to the advice my grandmother once wrote in my prayer book:

Live without worry,  
Work without hurry, and  
Look forward without fear.

## Abstract

Guided by Derdarian's theoretical framework, this descriptive study used a four part questionnaire to investigate the preferred and actual treatment decision making roles, the preferred and actual sources of information, and the priority information needs of 74 women recently diagnosed with breast cancer. Using unfolding theory for data analysis the majority of participants were found to prefer a collaborative role in treatment decision making. Overall, people sources of information were found to be more important than written sources. The participant's educational level was found to influence their preferred sources of information.

Four hypotheses about these women's profiles of priority information needs were tested. The method of paired comparisons derived from L. L. Thurstone's Law of Comparative Judgement was the major methodological approach. The results of this methodology demonstrated a clear picture of how the participants prioized their information needs from most imporatnt to least imporatnt. Overall, the profiles of information needs for each of the hypothesized patient groups were remarkably similar. Two individual scale value differences involved information about caring for oneself at home. Elderly women 65 to 83 years, ranked this information need more important than women 18 to 64 years. Similarly, women with high school also valued this information more than did the women with greater than high school

education. Based on the study findings, implications for nursing practice and future research are addressed.

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## Problem Statement

### CHAPTER 1

#### STATEMENT OF THE PROBLEM

During 1991 an estimated 14,400 Canadian women faced the diagnosis of breast cancer while an estimated 5,100 women died from the disease (Canadian Cancer Statistics, 1991). Breast cancer is the most common cancer to strike Canadian women, accounting for an estimated 28% of all women's cancers in 1991 (Canadian Cancer Statistics, 1991). The incidence of breast cancer is on the rise.

Advancing age is strongly correlated with increasing breast cancer incidence. The disease is rare among teenagers and uncommon among women under age 30. However, at age 40 the incidence of breast cancer rises sharply and progressively increases through, to, and beyond age 80 (Canadian Cancer Statistics, 1991). At the present rate about 11% of all females in Canada and the United States - approximately one of every nine women - will develop breast cancer, sometime during her life (Morra & Blumberg, 1991).

Of all the cancers, breast cancer is perhaps one of the more personally horrifying for a woman. Although there is currently no demonstrated way to prevent breast cancer, progress in its detection and

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treatment holds promise for reducing this cancer's toll. However, there is continued debate about the best treatment for breast cancer. Levy (1986) described the slow movement from the Halstead radical mastectomy in the early 1970s to the modified radical mastectomy in the late 1970s. The National Surgical Adjuvant Breast Project, a large cooperative research project between Canada and the United States that examined different therapies, found that in most women with breast cancer lumpectomy plus radiation is just as effective at saving lives and preventing recurrence of disease as total mastectomy (Fischer, 1984). According to Margolese (quoted in Jenkins, 1991) mastectomy is only necessary in the 5-10% of women who have diffuse tumors. Dr. R. Clarke - of the Princess Margaret Hospital in Toronto (1992) stated on CBC Radio "local surgical treatment for breast cancer is a regionalization issue". In other words, the surgeon's preference for one type of surgical treatment over another is evident in certain regions of the country.

Statistics from Manitoba indicate that of the 743 women who were diagnosed with breast cancer in 1991, 518 (69.7%) mastectomies were performed compared to 288 (38.8%) lumpectomies (Heather Whittaker, personal communication, Manitoba Cancer Foundation Registry, 1992).

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Regardless of the local treatment chosen or provided by surgeons, breast cancer patients may also be asked to make further decisions about adjuvant therapy (treatment given when no gross evidence of disease remains after surgery) (Cady, Glick, & Hortobagyi, 1990). In Manitoba 48.6% of all women diagnosed with breast cancer were referred to the Manitoba Cancer Treatment and Research Foundation for consultation about further treatment.

Women's journals, television, and other public education efforts have circulated extensive information about available alternatives for the treatment of breast cancer. The feminist and consumer right's movements have also been instrumental in raising women's consciousness regarding their accountability for personal health care. As a result, women expect a voice in any decision making about their preventive health care, but when it comes to treatment of illness, physicians often believe that they are the experts. Margolese (quoted in Jenkins, 1991), professor of surgical oncology at McGill University and director of oncology at Jewish General Hospital, Montreal, warns that some surgeons still insist on a mastectomy even for the woman with a localized tumor. Consequently, the woman with breast cancer may experience pressure to comply with the physician's expert opinion. She may request a second opinion but is often discouraged or directed to someone

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whom the physician knows will agree with the recommended approach. Also, the sense of urgency about the need to make a treatment decision immediately creates enormous stress and discourages women from seeking a second opinion.

The physical and psychological effects of breast cancer can be devastating to female victims. In fact, it has been suggested that a lack of knowledge about breast cancer may in fact be the source of considerable patient anxiety, or may contribute to a "wall of silence," where energy used for repression and denial drains the patient of important energy resources needed for recovery (Messerli, Garamendi, & Romano, 1980). Since the fear and uncertainty associated with cancer produce intense demands for information and assurance, the cancer patient expects special communication with the health care professional (Dyck & Wright, 1985).

However, controversy exists around the whole issue of information sharing. Although controversy and problems involving disclosure of information are not unique to cancer patients, they somehow seem more dramatic than those associated with other illnesses. In part, this may be because of the assumption that the impact of hearing about cancer will be devastating to people (Goldberg, 1984). More recently, much attention has

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been focused on the need for health professionals to communicate with and provide information to patients so that patients may participate in informed decision-making about health care (Degner & Russell, 1988).

Numerous factors influence female decision making capabilities and subsequent health behaviours. Historically, women been dependent and allowed others to make decisions and exercise control. A woman's ability to make an informed decision can be inhibited if physicians and other health professionals provide inadequate information about important aspects of her disease and treatment (Semprevivo, 1985). When health professionals fall victim to common social attitudes and beliefs about women, they are restricting opportunities for female patients' growth, problem-solving, adaptation and self-actualization (Wilson, 1979).

Physical loss or illness affect different people differently. Breasts are among the most important body parts for maintaining an integrated sense of self and such losses are not easily forgotten because the individual carries with her a constant reminder of the loss (Schmale, 1979). Goldberg and Tull (1983) found that the loss of body integrity or of a body part causes a grief situation often characterized by typical signs of severe psychological distress. As suggested by Sutherland and colleagues (1989) patients may actively

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seek information to satisfy an aspect of psychological autonomy that does not necessarily include participation in decision-making.

Although a high incidence of breast cancer is found in the elderly population, little research has addressed this issue. One study that discussed the development of a cancer control program for senior citizens (Rimer, Jones, Wilson, Bennet, & Engstrom, 1983), found that many of the 334 respondents held negative attitudes toward physicians and also held many myths regarding cancer treatment. With the expected increase in the elderly population over the next 15-20 years, the incidence of breast cancer in these women will be of major concern. Investigation of this population is required because they may have different information needs than younger women.

Leather and Roberts (1985) explored the relation of attitudes and motivation to social class, especially in relation to breast screening attendance. They found older, working class women had emotional fears associated with the developing expectation of ill health as well as with a lack of factual information about breast disease. The older woman who is experiencing other losses may be particularly vulnerable to the fear of losing a breast.

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According to Williams, Edwards, and Hane (1987), the frequency of Breast Self Examination (BSE) in older women is only 5%. Other studies have shown that the physician is least likely to examine the breast of a female who is elderly, poorly educated, of lower socioeconomic status, or black (Ludwick, 1988; Rudolph & McDermott, 1987). This same population of women, when diagnosed with breast cancer, would appear to be at high risk of receiving inadequate amounts of information about their disease.

In fact, despite patient requests and a shift to more open communication, studies still cite communication problems with the amount and kind of information patients are given (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Jones et al., 1982; Rimer, Jones, Wilson, Bennet, and Engstrom, 1983; Rimer, Keintz, & Glassman, 1985; and Taylor, 1988). It appears that although physicians and other health professionals believe they are informing patients, their patients continue to regard the flow of information as inadequate. Green (1984) noted that, in the broader context of patient education, cancer has lagged behind other diseases in the attention that health educators and other behavioural scientists have devoted to the subject. Even within the area of cancer education, patient education has been overshadowed by prevention and public education about cancer.

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Of particular significance are two recent studies that investigated the needs of cancer patients in Manitoba. The Manitoba needs study of cancer patients and their families stressed the importance of reviewing health professionals' role in relation to the large number of unresolved patient needs. Vachon, Lancee, Conway, and Adair (1990) identified the following as priority areas for further study: women; financial concerns; patients age-under 55, and over 75; and the Reach to Recovery Program (Breast Cancer Support Group) as priority areas for further study. Neufeld (1986) found in her study of women with a first time diagnosis of breast cancer that the overwhelming majority of respondents wanted information, although this may not be evident from their usual questioning behaviour.

Patient care consists of many different components, and nurses must help meet the verbal and nonverbal cues that patients give concerning their individual information needs. The issue of information sharing in health care is of significance for the nursing profession because of the integral role that nurses can play as part of the health care team that provides individualized patient care. As nurses in their varied practice settings have gained responsibility for providing patient information, it is crucial that nurses know how patients view their own information needs.



## Problem Statement

### Purpose Of The Study

Cassileth, Zupkis, Sutton-Smith and March (1980) found that most cancer patients, especially those who were young, white and well-educated, wanted maximum amounts of information. One of the difficulties these and other investigators face in pursuing this issue is a measurement problem; because patients invariably want maximal information, current measures produce "ceiling effects" that usually impede subsequent analyses.

In one carefully crafted study, informational needs of recently diagnosed cancer patients (n= 60) were assessed and categorized in relation to disease, personal, family, and social concerns and these needs were subsequently ranked in order of importance (Derdiarian, 1986). Derdiarian (1987b) suggested that in future research, informational needs should be investigated using measurements of hierarchy of needs concurrently with the measurement of informational needs.

The purpose of this study was to a) determine from the breast cancer literature patients' most frequent requests for information and b) pilot test a method for eliciting hierarchial profiles of these information needs from women newly diagnosed with breast cancer. Prior knowledge and

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understanding of womens' informational needs, at a time of emotional stress and fast paced decision making, may assist physicians/nurses in meeting these patients specified needs more effectively.

Profiles may also provide an empirical basis for the development of written, audiovisual, and computer aided patient education materials to address the identified priority information needs.

Chapter II

LITERATURE REVIEW

The review of the literature was the process by which the current knowledge about information needs of women recently diagnosed with breast cancer was examined, analyzed, and synthesized. A variety of sources were used to investigate this particular phenomenon, including 1) computer searches, 2) manual searches, 3) the annotated bibliography: *Communication Between Cancer Patients and Health Care Professionals*, 4) tracking of citations, and 5) presentations at the 1990 Terry Fox Workshop (Degner, Jerry, & Till, 1991).

Basic communication and information giving issues involved in interactions between cancer patients and health care professionals were explored. Perceptions of information needs were examined within this framework from patient's, nurse's and physician's perspectives. Strategies for improving communication/ information sharing were also reviewed, including consideration of patient's information processing ability. Secondly, the role that information plays in assisting women to participate in treatment decision making and in promoting psychological adjustment was examined. The influence of particular coping responses

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on the prognosis of cancer patients was explored. Thirdly, the effect of treatment options on women's specific information needs, psychiatric morbidity and sexual dysfunction was addressed. Finally, there is an examination of the information needs of women considering reconstructive surgery.

### Communication/Information Sharing

Reactions to the diagnosis of cancer include fear, shock, numbness, grief, denial, and loss of control, which are believed to occur in response to a threat that is perceived as serious (Schain, 1990). For a woman diagnosed with breast cancer, the toughest part of the process may be in finding out there is a lump, and that it is cancerous. Suddenly, the woman is seeing any or all of the following: family physician, surgeon, radiologist, oncologist, and plastic surgeon.

Communication is especially important in serious illnesses, like cancer that are often surrounded by myths and misconceptions. Forty years ago, Bacon, Renneker, and Cutler (1952) suggested that the physician try to steer a middle course between "terrifying obscuratism and equally terrifying unabsorbable information." In addition they

## Literature Review

recommended the physician use language that would dispel ignorance without dispelling hope. Today, Dr. M. Stefanek, assistant professor at the St. Johns Hopkins Oncology Centre (quoted in Laurence, 1991, p. 141), stated "doctors need to appreciate what a scary time it is and that women have a sense of being in limbo." This plea for sensitivity illustrates the continued dilemmas associated with information disclosure.

### Physician's Perspective

The literature is replete with studies that concern the overall issue of communication and information sharing between the physician and cancer patient. Northouse and Northouse (1987) examined over 200 clinical papers and research studies published between 1966-1986 that focus on communication dimensions of the cancer experience. They found the primary communication issues for health professionals were on imparting information, communicating hope, and sharing control. After a similar review, Tuckett and Williams (1984) found that more attention has been paid to examining the way information is given than to the information itself.

Disclosure is always selective and, therefore, dependent on the

provider. Even well intentioned advocates of complete disclosure must make decisions about what to select from a relatively unlimited pool of possible information. What, when, how, and who should inform cancer patients about their diagnosis are issues of great controversy. Hardy, Green, Jordan and Hardy (1980) explored these issues with 185 practising physicians (aged 28-80 years) from Tennessee. Ninety-eight percent of physicians reported that they always or usually inform patients that they have cancer. The most common influencing factors for informing patients of their diagnosis were stage of illness, followed by the physician's age, the required treatment, the wishes of family members, and the histopathology; however, no single factor was predominant.

In a study of 336 patient encounters (10 patients had cancer or other potentially fatal illness), internists from Massachusetts and California underestimated their patients' desire for information in 65% of the encounters (Waitzkin, 1984). The doctor characteristics found to be related to the transmission of information were social class background, income, and perception of patients' desire for information. Doctors who came from an upper- or upper-middle-class background tended to spend more time informing their patients, and gave more explanations than

doctors from a lower-middle class or lower-class background. Doctors who earned less money tended to spend more time informing their patients. Information giving takes time, and doctors overestimated the time they spent giving information by about a factor of nine. Doctors on average spent a little more than a minute out of a 20 minute encounter giving information.

In a study aimed at assessing whether and how patients (n=1262) with breast cancer are informed about their diagnosis and treatment, a large group of physicians participating in a quality of care evaluation program were asked to report what they told patients about diagnosis and treatment (GIVO, 1986). The physicians and patients involved in this study were from 62 hospitals in Italy. Seventy-one percent of the patients were older than 50 years of age, and 67% had less than six years of education. It was determined that 48% of patients received thorough information on diagnosis and 14% detailed information about surgery. Physicians, however, considered this communication thorough for 69% of patients. Among patient-related characteristics, age, education and stage of disease were independent predictors of quality of information.

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Taylor (1988) studied the event of telling the patient for the first time that she has cancer from the physician's perspective. This Canadian study showed that all 17 surgeons adopted a routinizing pattern of disclosing information which varied according to whether the physicians' usual approach to patients was one of researcher or therapist. In only 10% of 118 disclosures did the physicians provide a realistic and specific prognosis using terms the patient could understand. This report suggested that although it is becoming generally accepted that cancer patients have the right to be adequately informed, many physicians may not be convinced that it is always in the patients' best interest to be given full details of her case.

Siminoff, Fetting, and Abeloff (1989), after observing 100 women with breast cancer who were receiving information about adjuvant chemotherapy concluded: "something is prohibiting comprehension of treatment risks and benefits other than physicians not telling all" (p.1197). Although physicians tended to present risks and benefits in general terms, patients who received numeric information still overestimated the benefits of treatment by 20% or more. This finding was similar to that of a Canadian study that found one-third of cancer



patients (n=100) being treated palliatively thought they were receiving curative treatment (Mckillop, Stewart, Ginsburg, & Stewart, 1988).

A more recent study from Canada attempted to establish the types and relative importance of items of information required by patients with ovarian cancer by asking surrogate patients to respond to an imaginary scenario (Hayter, Stewart, Chammas, Arya, & Mackillop, 1991). From a list of 57 items, the top ranked questions were "life and death issues" such as the possibility of cure or remission and the chance of death if the disease were left untreated. Four questions concerned quality of life issues such as whether the disease would affect the patient's ability to carry on normal employment or whether the treatment would affect the ability to care for oneself. The least important questions were those concerning epidemiology and etiology of the disease and the cost and convenience of treatment. Of the various population characteristics identified, only age appeared to have an impact on the ranking of certain questions. A preliminary survey of 20 patients with a variety of malignant diseases found there was a surprisingly high correlation between the views of these ovarian cancer surrogates and those of this small group of cancer patients (Hayter et al., 1991).

The above studies are pertinent in view of Canada's changing cultural mosaic and the identified influence of cultural factors on the patient/oncologist disclosure of a diagnosis of cancer (Holland, Marchini, & Tross 1987).

#### Nurses's Perspective

In order to provide cancer patients with pertinent information, nurses and physicians need to know how patients view their own learning needs. A study by Lauer, Murphy, and Powers (1982) conducted in Chicago found that significant differences existed between 33 nurses' and 27 patients' perceptions of learning needs of cancer patients. Patients included were those with any type of cancer who were receiving or who had received chemotherapy and/or radiation therapy. The nurses rated availability of financial assistance, caring for self at home and work, and discussing concerns with family and friends as most important. The patients, in contrast rated knowing their diagnoses, their plans of care, caring for themselves at home and work, and what they would experience during diagnostic procedures as most important. These authors suggested that teaching cancer patients information which

they have identified as important and relevant should enhance learning and health-related decision making.

The complexity of the nurse-patient communication process is further illustrated in a study of cancer patients (n=48) by Thorne (1988). She suggested these patients often misinterpret the intentions of health care professionals in such basic communications as information-giving and the expression of caring. Patients were more likely to perceive the health professional's (physician and nurse) effort to provide social support as helpful rather than not helpful, and to perceive the relay of advice and information as not helpful. Instances of not helpful communication were attributed to lack of concern and intentional disregard by the health professional. While nurses' and physicians' communication were equally likely to be reported as unhelpful, differences in the context and content of communications by the two professional groups were identified. Physicians communicated about the disease, and treatment, while nurses tended to communicate about treatment and the illness experience. Physicians most often gave information, while nurses often gave advice.

These findings show similarities to those of Frank-Stromborg and

Wright (1984). They found that ambulatory cancer patients who discussed concerns with their nurses felt that nurses helped them, not by providing information, but by providing emotional support. Most patients stated their attitudes towards health care professionals had not changed since they received their diagnosis. However, 52% of those who did state their attitudes had changed reported they had increased respect for their physicians, compared to the 91% of patients who reported increased respect for their nurses. According to the authors, the results suggested that a) the health care experience of cancer patients leads them to a greater respect for nurses, and b) nurses do not effectively utilize opportunities for patient education in ambulatory care settings.

The findings on the different context and content of communications from nurses and doctors raise some interesting points. Given the role identities of the two professions, nurses predictably might be represented more strongly in the category of supportive communication. Thorne (1988) suggested that since information-giving is basic to nursing practice, patients may not perceive the information from nurses the same way they perceive information from doctors. Brown's (1986) study of patients' perceptions of caring demonstrated another

central aspect of caring: caring is always understood in a context. In other words, when the situation calls for technical proficiency, then technical proficiency (swift, accurate actions) is experienced as caring. When the patient situation does not require technical actions, expressive actions such as recognition of the patient's uniqueness are identified as caring.

The same act done in a caring and noncaring way may have quite different consequences. A caring relationship sets up the conditions of trust that enable the one cared for to accept the help offered and to feel cared for. According to Benner and Wrubel (1989), even patient teaching has different effects in a caring context than a noncaring one. Teaching patients has always been an important part of nursing; it is a role that has been a challenge and a source of satisfaction. According to Morra and Grant (1991), patient education has been an integral component of oncology nursing since the earliest days of the specialty.

Scientifically based knowledge of caring is limited, and nurses cannot be certain that their behaviour consistently creates in patients a sense of "feeling cared for." Nurses, when asked to identify the important aspects of caring, have consistently ranked the affective aspects, such

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as listening, touching and talking, as the most important ones (Larson, 1984). In contrast the hospitalized patients in Brown's (1986) study saw care demonstrated by the nurse's accessibility and professional competency.

The above findings and observed realities in clinical practice would lead one to conclude strongly that nurses have a major role to play in patient education of the oncology patient. The focus of the majority of the research on information giving was on the physician's role. Their historical position as gatekeepers of medical information and research does not make these findings totally surprising. However, nurses in their varied oncology practice settings have obviously gained responsibility for patient education, and must, therefore, work towards meeting the associated challenges.

### Patient's Perspective

The importance of understanding the patient's desire for information is evidenced in a study by Waitzkin (1984), who found that the transmission of information from doctor to patient was in part related to doctors' perceptions of patients' desire for information. The following

studies examine patients' desire for information.

In a study of 256 cancer patients, Cassileth, Zupkis, Sutton-Smith, and March (1980) found that young, white, and well-educated patients desire detailed information from the health care provider, while older, black, and poorly educated patients avoid detailed information. More than 50% of the patients said they needed verification that the disease was cancer and information about the possible side effects of treatments, the outcomes to expect from treatments, the likelihood of cure, the extensiveness of the disease, the effects of treatment on the body, and their day to day or week to week progress. Similarly, Jones et al., (1982) found that more educated cancer patients and their relatives were more likely to prefer information in writing, but in general, patients wanted more information than they had been given.

In contrast, Waitzkin (1984) found no difference between poorly educated, lower-class and better-educated, upper-class patients in their self-rating of desire for information. However, during doctor-patient encounters, lower-class patients asked fewer questions so doctors assumed they had little desire for information. Women asked more questions of doctors and engaged in more verbal behaviours within the

encounters.

A study that considered the needs of breast cancer patients (n=50) and husbands indicated that emotional support, information, attitude and religion were the factors that helped them cope with the illness (Northouse, 1989). Although a number of the women identified nurses and physicians as providing information and support, they also talked about being in an emotional upheaval during this time, yet having to make important decisions with little professional help. Similarly, another US study of 58 mastectomy patients indicated that 86.2% of the patients felt that at the time prior to the mastectomy questions were unanswered by the surgeon (Messerli, Garamendi, & Romano 1980). These patients most frequently sought out more information from an additional source. They placed greater importance on discussion, counselling, and professional services of mental health workers than did surgeons.

Cawley, Kostic, and Cappello (1990) conducted a retrospective exploratory descriptive study with 160 women (age 28-84 years) in the United States to assess the physical and psychosocial needs of these women who chose breast conserving surgery with primary radiation.



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Seventy-five percent of the women believed they had received all the information they wanted about lumpectomy before having their surgery. The physician was the primary information provider; 23% reported receiving information from nurses, and several commented on their seeking information independently from the American Cancer Society, library, pamphlets, and friends. Of the 26% of patients who were not satisfied with preoperative information, recurrent themes included omission of information regarding lymph node removal and its effects and the need for radiation therapy postoperatively. However, 85% of the sample reported receiving information regarding the side effects of radiation prior to starting treatment. Only six women were visited by someone who had the same surgery, and they reported that the visit was helpful. Many reported feeling isolated by the lack of contact from people with similar experiences.

In one important study, informational needs of 60 (age 18-70 years) recently diagnosed (1-18 days) cancer patients were assessed and categorized in relation to four major categories (Disease, Personal, Family, and Social) with their respective five subcategories (Derdiarian, 1987b). These needs were subsequently ranked in order of importance.

Comparisons of informational needs and their importance values indicated the following minor descriptive differences by gender, age, and stage of cancer. Women required more information about prognosis, psychological well-being, and siblings; and they attached more importance to information about parents. The young adults (age 18-35 years) and the adults (age 36-55 years) tended to need more information than the older adults (age 56-70 years) about spouses and parents. These groups also differed in relation to job/career relationships, with young adults and adults tending to need more information about this subcategory than the older adults. Patients with local and regional disease tended to need more information about spouse than those with disseminated disease. Multivariate analysis of these data was not possible because of the small sample sizes of the subgroups. Derdarian (1987b) suggested that in future research, informational needs should be investigated using measurements of hierarchy of needs concurrently with the measurement of informational needs.

Strategies To Improve Communication/Information Sharing

Of course, the responsibility for a harmonious relationship does not fall entirely on the physician/nurse, the patient must also participate. Interventions have been aimed at expanding patient involvement in care by teaching patients to be more proactive in their interactions with physicians. The following two studies assess the practicality of recording the bad news consultation with cancer patients and their surgeons. In an Australian study Reynolds, Samson-Fischer, Poole, Harker, and Byrne (1981) found there was no difference in the amount of information that was recalled by a group of patients who received a tape-recording of the consultation compared with the group who did not receive a tape-recording (n=67).

In contrast, Hogbin and Fallowfield (1989) in Britain found that all 39 patients found the audiotape helpful, although only 15 thought it contained forgotten information. The most frequently forgotten points were concerning the radiotherapy treatment and the way in which tamoxifen worked.

Roter (1977) found that most patients make few attempts to gain information from doctors, although they can be trained to increase

information-seeking attempts. However, active participation may also have its drawbacks. For example, more anger and anxiety (Roter, 1977) and tension (Tuckett, 1985) were expressed in doctor-patient consultations that followed an intervention in which patients were helped to write down the questions they wished to raise with their doctor. However, Robinson and Whitfield (1985) found that patients who were advised prior to their consultation about ways of checking their understanding of their doctor's suggestions for treatment, more frequently produced questions and comments about those suggestions during their consultation, and also gave more accurate accounts of these subsequently.

Robinson and Whitfield (1987a, 1987b, 1988) conducted a series of studies which make a distinction between participation as a result of patient's predetermined questions, and participation arising from patient's questions or comments that occur as a result of new information given by the doctor during the consultation were conducted by Robinson and Whitfield (1987a, 1987b, 1988). The incidence of increased patient participation was positively related to the incidence of doctors' questions to patients about proposed treatment (1987a).

Comparing trainees and experienced doctors, twice as many patients of the trainees than those of the experienced doctors produced questions and comments that followed from something already said by the doctor (1987b). Patients who made errors or omissions in their accounts of instructions and advice offered were more likely than those who gave accurate accounts to have produced spontaneous comments or queries during their consultation (1988). The findings suggested that patients find it difficult to switch from presenting their views to receiving new information, and that those who choose to concentrate on the former perform relatively poorly at the latter. Therefore, we need to take into account the information processing demands place on the patient who attempts to present, to receive and to integrate ideas within a short space of time. Although these studies were not conducted with cancer patients, this advice may be particularly significant for the woman who is being presented information about an emotional, life-threatening illness such as breast cancer.

Information Processing

The importance of information processing ability is illustrated in two studies (n=100), the first of which found that patients with greater understanding and retention of the information they received are indeed more satisfied with their physicians (Bertakis, 1977). It was also shown that patients are more satisfied with their physicians when they are given more information concerning their illness. According to Siminoff (1988), lack of patient comprehension is positively associated with severity of illness and with increased age. The author suggested that increased specificity of information may result in better patient recall and comprehension.

The relationship between reasoning ability and anxiety was illustrated as early as (1951) by Bier when he found loss of intellectual flexibility and disorientation of visual- motor coordination occurred when subjects were faced with threat. He concluded that in real-life circumstances, anxiety increases when threat places a strain on normal coping strategies. More recently, Scott (1983) conducted a study of 85 women (age 18-60 years) who were interviewed and tested for anxiety, critical thinking ability and information processing capacity following

hospitalization, but prior to breast biopsy and knowledge of diagnostic results. Findings revealed exceptionally high anxiety levels overall. However, in the highest anxiety group in the sample, a significant negative correlation was found between anxiety level and critical thinking ability. The results suggest that a moderate level of anxiety is necessary for optimal performance, but at the point where anxiety increases above norms for general medical-surgical patients, the ability to reason declines precipitously. The author questioned whether age may be an influencing factor.

### Age

The question that age may constitute a factor in the anxiety level and critical thinking ability of women facing a diagnosis of cancer is of significance considering the wide age span of women affected. The increased incidence of breast cancer in the elderly female makes investigation of this group of women particularly important.

Despite the high incidence of breast cancer found in the elderly female population, little research has addressed this issue. Illness at any age produces anxiety but older people are particularly vulnerable. In a

health care system geared to curing rather than caring, a sick elderly person may have less social value than a sick young person. Newgarten (1984) contended that most older people are aware of this fact, accept it, and either speak up for themselves or live with unexpressed rage and become demanding in hostile ways. For the older adult, cancer is often seen as an acceleration of the aging process that results in more rapid disengagement from work and social activities and need for increased dependency on others (Newgarten, 1984).

Elderly women diagnosed with breast cancer become dependent on health care professionals for provision of pertinent comprehensible verbal and written communication about their disease. Prosody is a general term that includes the intonation pattern (pitch contour) of speech, word stress, pauses that sometimes occur at the ends of major syntactic elements of sentences, and the lengthening of final vowels in words immediately prior to clause boundaries (Wingfield, Lahar & Stine (1989). The following studies address the role that prosody in verbal communication and narrative type in written communication may play in aiding the information processing ability and memory performance of the elderly female diagnosed with breast cancer.



Elderly adults are frequently spoken to by younger adults with an exaggerated intonation not dissimilar to the "motherese" typically used when speaking to small children with limited linguistic ability. Cohen and Faulkner (1986) have called this pattern "elderspeak," and they have raised the question of whether it reflects only a patronizing attitude on the part of the speaker, or whether exaggerated intonation and stress may also serve to facilitate communication. Although elderly subjects may show age-sensitive decrements in rapid speech processing and recall, Wingfield et al., (1989) found these age differences in recall performance were diminished by the presence of normal prosody.

Although older adults typically show poorer memory performance than young adults when words are the to-be-remembered items, the findings for prose are less conclusive (Tun, 1989). Many but not all studies of memory for prose have shown age deficits, which are often attributed to a reduction in attentional, or processing resources with increased age (Tun, 1989). In a study by Tun (1989), a dual-task procedure was used to examine the effects of text genre (type) on prose processing, comprehension, and recall in 20 young (age 18-33 years) and 20 old (age 65-80 years) adults. Both groups recalled more of

narratives than of expository passages, although old subjects recalled less than young. It appears that the narrative genre facilitated most measures of performance and partially compensated for some limitations in the older group. These findings underscore the importance of considering the structure of text materials used in health education of the public, and most particularly the older adult.

The findings of these studies can assist health professionals as they strive to engage more effectively in verbal, written, and audiovisual communication with the female patient newly diagnosed with breast cancer.

### Treatment Decision Making

Treatment is the phase that has received the most attention from program developers and researchers alike. During treatment, patients require information about the specific treatment modality or modalities, such as chemotherapy, radiation therapy, and surgery (Rimer, Keintz, & Glassman, 1985). Requisite to treatment is the patient's informed consent to be treated.

Recent research indicates there is a choice of surgical and

adjuvant treatment available to many patients with early stage breast cancer. Such results may lead to one of two approaches in management; surgeons and oncologists can continue to make decisions on behalf of their patients, or patients can become more involved in the decisions made about their treatment. The expectation that the cancer patient should be told his/her diagnosis has been accompanied by a consumer movement to include patients in treatment decision making. Controversy exists about the appropriate role for patients in medical decision making. A wide variety of opinions exist, ranging from the view that patients should assume at least some responsibility for selecting their own treatments to the position that it is unwise to encourage such participation because patients do not have the specialized knowledge required to make treatment decisions.

According to Lenz (1984), the information seeking behaviours of clients are important antecedents of health-related decisions and behaviour. There is evidence that despite desire and effort to acquire health-related information, clients often perceive 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 (Messerli et al., 1980; Rimer et al., 1985).

Recent research has identified at least five distinct roles of participation in decision making, based upon the patient's personal representation of the decision problem and desire for participation in treatment decision making (Degner & Russell, 1988; Pierce, 1988; Schain, 1990). These decision making styles range from assuming an active role in treatment decision through a collaborative role, to a passive role in which the physician assumes responsibility for treatment decisions. The following research studies determine patients' preferences about participation in treatment decision making.

Cassileth et al., (1980), found that older and less educated cancer patients preferred to have treatment decisions made by the physician while younger and more educated cancer patients preferred to participate in formulating treatment decisions. For those who wanted detailed information, about one-quarter wanted the physician to make the actual decision about treatment.

In a study of 439 interactions between adult cancer patients and oncologists, Blanchard, Labrecque, Ruckdeschel, and Blanchard (1988) found that those who desired an active role in decision making were

young, female, not married, and had a prognosis of less than three months or greater than one year.

A study conducted by Degner and Russell (1988) included 33 breast cancer patients, out of 60 cancer patients, who also confirmed that they wanted to be included in treatment decision making, and they were reluctant to allow family members to make these decisions. These patients preferred to share control with their physicians rather than with family members. In contrast, Ward, Heidrich, and Wolberg (1989), found that for the 22 breast cancer patients in their study, 11 wanted the decision to be fully their own, while the other 11 wanted to share the decision with either the physician, spouse or family members.

Neufeld (1986) found in her study of Manitoban women with a first time diagnosis of breast cancer that an overwhelming majority of respondents wanted information, although this may not be evident from their usual questioning behaviour. Clients may not ask questions because they believe physicians and nurses will tell them everything they need to know. Lenz (1984) described how individuals may decide that active information search is not necessary if needed information can be acquired passively.

Another more recent study conducted by Degner and Sloan (1992) involved 436 newly diagnosed cancer patients and 482 members of the general public. Findings revealed that preferences seemed to be influenced by situational factors. Only 12% of patients wanted an active role, whereas 64% of the public thought they wanted an active role if they developed cancer. Only 10% of cancer patients wanted their families to dominate decision making if they were too ill to participate, whereas 40% of the public wanted their families to assume a dominant role. The most important predictor of role preference was age with older people wanting less control in decision making. The researchers concluded that most people newly diagnosed with cancer want their physicians to make decisions on their behalf, and that individual assessment of patient preferences is the most appropriate clinical approach.

Hack (1991) used the model of treatment decision making roles developed by Degner and Russell (1988) to examine the relationship between 35 breast cancer patients' preferences for involvement in making treatment decisions and their preferences for information about diagnosis, treatment, treatment side effects, and prognosis. Results

showed that patient preference for involvement in treatment decision making was significantly related to patient information preferences with respect to a) degree of diagnostic detail desired, b) preference for receipt of a taped versus a written copy of the diagnosis, c) preference for the type of verbal label attached to the illness by the physician, d) preference for number of treatment alternatives proposed, and e) degree of detail desired regarding treatment procedures. Patients believed it was not necessarily better to play an active or passive role, and that not all patients should be given the same kind and amount of information regarding their illness.

The older woman may be less well informed about her medical condition or treatment options and may choose to remain so (Leathar & Roberts, 1985; Schain, 1990), expecting the physician to make the decisions about treatment (Schain, 1990). It is unclear if older cancer patients and their families or health care professionals make the decisions about aggressive treatment. Given and Given (1989) suggested that the decisions for cancer treatment in the elderly may be based not on disease status but on availability of family resource persons to implement or push for more aggressive treatment. Beisecker

(1987) concurred that older patients were more likely than younger ones to bring a companion with them to the interaction with the physician and that it was the companion rather than the patient who made more consumerist statements to the physician.

The assumption that the older woman is considered less capable of participating in major health care decisions and that a paternalistic approach is employed more often with women of this age group is addressed in a study by Cawley et al. (1990). Comments from the 60- and 70-year -old population included: "The doctor yelled at me for insisting on a lumpectomy"; "The surgeon just assumed he would do a mastectomy"; "My doctor minimized the lesion." Also in this population of women, only 61% felt well informed (Cawley et al., 1990, p. 92). However, the assumption that elderly women do not mind losing a breast was not supported in a study by Fallowfield, Hall, Maguire, and Baum (1990), who found 13 of 21 women over 60 who were able to choose their treatment opted for lumpectomy.

According to Valanis and Rumpler (1985), a physician who ignores the patient's value system and prohibits her involvement in decision making furthers her dependency role rather than promoting



self-responsibility during treatment and convalescence. What many women want, rather than the ultimate decision on surgical treatment, is more adequate information as to why one treatment is recommended over another (Sutherland, Llewellyn-Thomas, Lockwood, Tritchler & Till, 1989). However, one potential difficulty with giving patients responsibility for the treatment decision could be that they then assume responsibility for the outcome of the treatment (Fallowfield et al., 1990).

Physicians and patients may or may not differ in their preferred position of sharing information and responsibility for making decisions. The amount of patient participation deemed acceptable in any given physician-patient interaction should be determined early in the relationship so that each person is clear on how to proceed and who holds what rights and what responsibilities.

### Psychological Adjustment

Compared to breast cancer no other single organ-site malignancy has been so often discussed with regard to the psychological consequences of its diagnosis and treatment (Schain, 1990). Schain (1990) believed this was attributable in part to the high incidence of this

disease in the population and to the fact that the female breast is imbued with special nurturant and sexual connotations. Soon if not immediately after hearing the diagnosis, the patient is asked to make choices about treatment, but in fact she has few emotional resources to do so at the moment. Most studies have found information disclosure to have a salutary effect on psychological adjustment.

A now classic study by Egbert (1964) launched several decades of research investigating the effect of psychological preparation, through the provision of information and support, to patients undergoing medical procedures. This early study showed quite dramatic benefits in decreased anxiety, reduced use of pain medication, and shorter hospital stay. In contrast, Bloom, Ross and Burnell (1978) suggested that certain information should be withheld from patients because it could disrupt mechanisms of denial and generate loss of hope and depression.

Early social scientists dichotomized the responses of patients seeking information into two types: monitors and blunterns. Miller and Mangan (1983) have shown the effect of information and coping style in response to colposcopy, a diagnostic procedure for gynaecological cancer. The authors found that patients were less distressed when

preparatory information was consistent with their coping styles. So called "blunters" (information avoiders) were less distressed with low information and, generally speaking, "monitors" (information seekers) were less aroused with higher levels of information.

A study of the information-seeking behaviours of 58 breast cancer patients who were receiving chemotherapy found no significant relationship between information-seeking and the adaptational outcome measures of mood states and level of functioning (Hopkins, 1986). However, information preferences were negatively correlated with subject's age and severity of disease. Subjects most frequently reported receiving verbal information about their disease and treatment from their oncologist, television programs, and the oncology nurse. Reading materials distributed in the oncologists office, newspapers, and magazines were the sources of written information most often reported.

Rainey (1985) found that a preparatory patient education program for 60 cancer patients undergoing radiotherapy significantly increased treatment-related knowledge and decreased emotional distress regardless of coping style. Another study that assessed 51 newly diagnosed breast cancer patients' coping strategies after mastectomy

noted that a breast cancer patient who is more openly aware of her situation and expressive of her emotions and fears, exhibits better adjustment than a patient who practices denial (Orr, 1986). Yet another study, investigating the coping styles of 35 breast cancer patients undergoing chemotherapy, reported that the majority of patients named the acquisition of treatment-related information as invaluable to the development of a coping strategy (Myerowitz, Watkins, & Sparks, 1983).

Sutherland et al., (1989) found that 63% of the 55 cancer patients who wanted detailed information about their disease thought that the physician should take the primary responsibility in decision making. They concluded that patients may desire information, not only to enable them to participate in treatment decision making, but also to maintain psychological autonomy.

The effect of satisfaction with information is addressed by Fallowfield et al. (1989) who assessed the psychological outcome in 269 women with early stage breast cancer in Great Britain, who underwent either mastectomy or breast conservation surgery. Of the 176 women who thought they had been well informed, 46 (26%) were assessed as anxious or depressed; but of those women who thought that they had

been poorly informed 32 out of 70 (46%) were anxious or depressed, or both. Comparison of these results with preoperative Spielberger state/trait anxiety inventory scores suggested that women in whom anxiety is a characteristic trait are more likely to perceive the information as inadequate and be clinically anxious or depressed, or both, at 12 months.

The emotional responses to a recent cancer diagnosis were explored in a study with hospitalized adults (n=133) from different age groups (Edlund & Sneed 1989). The youngest age group (< 50 years) experienced the most distress in learning of their diagnosis, while the oldest group (> 70 years) experienced significantly less psychological distress than all other age groups. However, the oldest age group was significantly less positive than the youngest group in their attitudes toward cancer. This negative attitude toward cancer is further illustrated in a study that discussed the development of a cancer control program for senior citizens (Rimer, Jones, Wilson, Bennet, & Engstrom, 1983). Many of the 334 respondents held negative attitudes toward physicians and believed many myths regarding cancer treatment. More than 75% of the elderly respondents believed that physicians create undue worry in

the minds of senior citizens by failing to provide enough illness-related information.

In contrast, Beisecker and Beisecker (1990), who investigated 106 rehabilitation medicine patients, found that higher ages and longer interactions were associated with a greater number of information seeking communication behaviours when interacting with their doctors. The increased length of time in the interaction provided older patients more time in which to initiate these behaviours. This finding may not be so surprising considering older patients have more chronic problems and more frustrations regarding their health.

Another study explored older women's attitudes towards breast disease, self examination and screening and found many areas of factual uncertainty and emotional reactions associated with the possibility of ill health (Leathar & Roberts, 1985). This is not surprising, considering all the literature and patient education pamphlets for Breast Self Examination (BSE) and breast cancer treatment are targeted at younger women. According to Williams, Edwards, and Hane (1987), the frequency of BSE in older women is only five percent. Other research has shown that the physician is least likely to examine the breast of a

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female who is elderly, poorly educated, of lower socioeconomic status, or black (Ludwick, 1988; Rudolph & McDermott, 1987). Physicians may not initiate breast examination with the elderly, because they are focusing on chronic ailments or other matters. In these cases the task of requesting an examination falls to the women themselves.

However, the elderly woman may be less likely than women of other ages to request a breast examination. Consistent with traditional elderly female health education practices, this population of women is at risk of receiving inadequate information in the event of receiving a diagnosis of breast cancer. With the expected increase in the elderly population over the next 15-20 years, the incidence of breast cancer in these women will be of major concern. The older woman who is experiencing other losses may be particularly vulnerable to the fear of losing a breast.

Identification of these high risk women before seeing a surgeon could facilitate appropriate interventions, such as: a companion to accompany them during the consultation (Fallowfield & Baum, 1989); an audio tape recording of the interview (Hogbin & Fallowfield, 1989); and discussing the information with a properly trained oncology counsellor or

breast nurse specialist (Fallowfield, 1988).

### Outcomes

According to some clinicians, the particular coping responses adopted by cancer patients may influence prognosis. In one study, 35 women with metastatic breast cancer received a battery of base line psychological tests, and the results were correlated with length of survival (Derogatis, Martin, Abeloff, & Melisaratos, 1979). It was noted that the long term survivors were more symptomatic overall, with particular elevations on measures of anxiety and alienation, and substantially higher levels of dysphoric mood (eg. depression, guilt) than the short-term survivors. Treating oncologists perceived the long-term survivors to show significantly poorer adjustment to their illness than the short-term survivors.

Greer, Pettingale and Morris (1979) conducted a prospective, multidisciplinary, five year study of 69 early stage breast cancer patients. Patients' psychological responses to the diagnosis of cancer were assessed three months postoperatively. These responses were related to outcome five years after operation. Recurrence-free survival was



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significantly more common among patients who had initially reacted to cancer by denial or who had a fighting spirit than among patients who had responded with stoic acceptance or feelings of helplessness and hopelessness. A subsequent five year follow-up of these same patients found a higher mortality rate than the first five years; however, a favourable outcome was still commoner among those whose responses were categorized as demonstrating a fighting spirit and denial (Greer, Pettingale, Morris, & Haybittle, 1985).

In contrast, Spiegel, Kraemer, Bloom, and Gottheil (1989) noted that a battery of extensive psychological assessments before intervention did not significantly predict survival. However, this 10 year prospective study did show the effect of psychosocial intervention on time of survival of 86 patients with metastatic breast cancer. The one year intervention consisted of weekly supportive group therapy with self-hypnosis for pain. Survival from time of randomization and onset of intervention was a mean 36.6 months in the intervention group compared with 18.9 months in the control group.

In summary, patients typically report that they desire as much information as possible from their doctor. However, the reasons patients

want information from doctors and what they expect to do with the information are less well understood. The above research studies do suggest that adequate information is crucial in assisting patients to participate in treatment decision making and/or maintain psychological autonomy.

### Mastectomy/Lumpectomy/Reconstructive Surgery

#### Mastectomy/Lumpectomy

The issue of being informed and involved in choosing treatment alternatives is well illustrated in a study by Ward et al., (1989). They determined factors women considered important when deciding between modified radical mastectomy (MRM) and breast conservation (BC), and the sources of information they used. Two factors, concerns about radiotherapy and body integrity, emerged as significantly different for women choosing BC over MRM. Many said they were concerned about the efficacy, side effects and inconvenience of radiotherapy. For all participants, the three most important factors were fear of cancer recurrence, desire to avoid a second surgery in the future, and the physician's preference. Fallowfield et al. (1990) concurred that "fear of

cancer and of its possible recurrence seems to be a compelling factor in determining a woman's preference for treatment" (p. 579). The women in Ward et al.'s (1989) study rated "people" sources of information as more important than written or visual materials, suggesting physicians, nurses, families and friends are important in supporting women through the decision-making process.

Most of the psychosocial consequences of breast cancer have been attributed to the impact of the mastectomy. It was hoped that breast conserving surgery (i.e., lumpectomy) would reduce psychiatric morbidity and sexual dysfunction. Larsy et al., (1987) investigated the psychological and social adjustment of 123 women in Montreal, Canada, following either total or partial mastectomy. Total mastectomy patients showed higher levels of depression and less satisfaction with body image. Partial mastectomy patients did not display any measurable increase in fear of recurrence. However, patients undergoing radiation showed a surprising increase in depressive symptoms.

In contrast, Fallowfield et al. (1990) concluded that none of the 13 studies that have compared and adequately assessed the psychological impact of mastectomy with that of lumpectomy show any advantage to

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women who underwent breast conservation surgery. They noted that the small numbers of patients studied meant that differences in psychiatric morbidity between treatment groups would have had to be very large to attain significance. These same researchers assessed the psychological outcome of different treatment policies in 269 women with early stage breast cancer in Great Britain who underwent either mastectomy or breast conservation surgery depending on the surgeon's opinion or the patient's choice. After assessments at two weeks, three months, and 12 months, they concluded that there is still no evidence that women who undergo breast conservation surgery have less psychiatric morbidity after treatment than those who undergo mastectomy.

More recently, Schover (1991) summarized the findings on differences between treatment groups (mastectomy versus lumpectomy) in body image, marital satisfaction, psychological adjustment, fears of recurrence of cancer, frequency of sexual activity with a partner, and prevalence of sexual dysfunction. The most striking aspect of this comparison is the narrow impact of breast conservation on quality of life. The one consistent finding is that women whose breasts are conserved have more positive feelings about their bodies, particularly their

appearance in the nude, than do women after mastectomy. In other important areas, however, including general psychological distress, psychiatric disorders, marital happiness, frequency of sex, and sexual dissatisfaction, no significant differences are seen between groups. According to this author, we need more information on how chemotherapy and hormonal therapy affect women's sex lives.

With a single self report item on the Rotterdam symptom checklist, Fallowfield et al. (1990) assessed loss of sexual interest of the 269 women who underwent either mastectomy or lumpectomy. There was no significant difference between the two groups, with over one-quarter of all women reporting sexual dysfunction. Although patients usually do not initiate the subject of sex, health professionals should include sexual consequences as part of the information they provide to the patient, giving the patient the opportunity to discuss concerns and have questions answered (Smith, 1989).

Of possible significance is the effect of choice on psychological outcome. Some surgeons might feel that offering a choice of surgery reflects indecisiveness and that this might have deleterious effects on patients' well-being. There is little published data which indicates

psychological outcomes following choice of treatment (Morris & Royle, 1988).

In the study by Fallowfield et al. (1990), a significant effect ( $p=0.06$ ) of surgeon type on the incidence of depression was observed, with patients treated by surgeons who offered a choice showing less depression than those treated by other surgeons. However, there were no significant differences in the incidence of depression between those women who had a real choice and those given no choice at any of the three assessments. These findings would suggest that the surgeon type and the manner in which decisions on treatment are made may be equally as important as the element of choice.

Other factors affecting choice were as follows: women who chose mastectomy had firmer convictions about the benefits of mastectomy in terms of removing all of the cancer and most women gave fear of cancer as their worst thought rather than fear of loss of a breast, irrespective of the eventual surgical treatment. The findings also allude to the possible influence of socioeconomic status on the treatment chosen/provided. An equal percentage of women in both higher and lower socioeconomic groups underwent mastectomy. However, of 115 women who underwent

breast conservation, 77 belonged to the higher socioeconomic groups (Fallowfield et al. 1990).

In another study from Great Britain, 30 patients with early breast cancer and their husbands were studied prospectively to assess whether being offered a choice of simple mastectomy or wide excision plus radiotherapy influenced levels of anxiety and depression pre-and post-operatively (Morris & Royle, 1988). Significantly more patients not offered a choice of surgery were clinically anxious ( $p < 0.01$ ) and depressed ( $p < 0.05$ ) compared with the patients offered a choice. Similarly, more husbands of the patients not offered a choice were clinically anxious ( $p < 0.05$ ) and depressed ( $p < 0.05$ ) compared with the husbands of the patients offered a choice of surgery. At six months, differences between the two groups were not statistically significant, although the trend remained the same. Considering the effect of type of surgery, levels of anxiety and depression were lower in those patients who chose mastectomy, compared with those mastectomy patients not given a choice. These authors concluded that offering a choice of surgery is not a simple matter and recommended the choice should only be offered after counselling and in conjunction with discussion of breast

reconstruction. Inclusion of written information outlining the two types of surgical procedures was also recommended.

A third study using data from two American prospective studies examined the psychological sequelae of breast conserving surgery versus mastectomy (Levy, Herberman, Lee, Lippman, & d'Angelo, 1989). The two samples, although not initiated for this purpose, offered an opportunity prospectively to examine baseline (approximately five days postsurgery) and three month follow up data. The women in the first sample (n=93) were randomized to treatment while those in the second sample (n=98) exercised some choice in their treatment decision. When "choice" played a major role, the patients who had breast conserving surgery (ie. excisional biopsy) were psychologically worse off, at least at three month follow-up. According to the researchers this distress did not appear to be attributable to disability status, subsequent adjuvant treatment, or extent of the early stage disease. Coincident with overall higher levels of emotional distress in patients opting for breast conserving surgery was a decrease in emotional support from significant others in the patients' environment.

In comparison, the randomized trial sample showed that patients'



emotional distress sequelae increased over time, irrespective of treatment modality (Levy et al., 1989). Surgical group differences appeared to be more subtle, with depression increasing over the follow-up period for those assigned to excisional biopsy. In the lay-person's view, excisional biopsy may still be an experimental treatment, and the patient lives everyday with the subjective experience of possibly harbouring malignancy in the spared breast. Having to make a treatment choice within such a risky context of perceived unknowns can be threat-producing. Rodin, Rennert, and Solomon (1980) suggested that perhaps choice and control are only positively motivating for an individual when he or she has enough information to evaluate the alternatives effectively.

These studies suggest that the woman who has a lumpectomy versus a mastectomy may be better off cosmetically, but the verdict is not yet in on the psychological benefits.

### Reconstructive Surgery

The topic of breast cancer reconstruction should also arise in the patient's pre-treatment discussions with their cancer specialists (Lang,

Shannon, Moberg, & Hjalmarson 1988), especially for those women who have not been offered a choice of breast conserving surgery (Morris & Royle, 1988). With the offer of an acceptable reconstruction prior to a mastectomy, the patient may be much more accepting of the prospect of the procedure.

Hailey, Lavin, and Hogan (1988) surveyed 27 post mastectomy patients who also perceived information about reconstructive surgery as helpful. Ninety percent of these women said they had a chance to ask questions about their treatment but some felt pressured and rushed by their physicians. However, over one-half of the women said the physician did not offer them any treatment option, other than mastectomy. Over two-thirds of women said they were informed about support groups for mastectomy patients; however, nearly one-quarter were not given any information about prostheses. Nearly one-half of women did not feel they were adequately prepared for what to expect from the mastectomy by health care professionals. The women wholeheartedly endorsed the idea of a coordinated program for mastectomy women that would ensure their needs would be met.

Reconstructive surgery is also not a straight forward issue. The

decision about whether or not to have reconstructive surgery should include the choice of synthetic implant versus breast construction from their own tissue. For those who consider a breast implant, decisions concern the location of incision and implant placement, and type of breast implant. When it comes to selecting the implant itself, the choices become particularly difficult. Because none of the devices available are problem-free, even the most conscientious consumer finds herself playing an unnerving game of implant roulette (Drawbridge, 1990). According to David Hidalgo, M.D., assistant professor at Cornell Medical College and assistant attending surgeon, Memorial Sloan- Kettering Cancer Centre, "There's a gradation of potential risk based on the type of implant" (quoted in Drawbridge, 1991).

Recently, these risks have become highly publicized with controversial findings relating to the Meme implant. The FDA ruling restricting use of these implants is viewed as a victory for many individuals, but for women who already have the implants anxiety, fear, and in some cases hysteria are the result. Unfortunately, the once believed psychological benefits of reconstructive surgery have been thwarted. Women with breast cancer considering breast reconstruction

now have yet another highly controversial decision to make.

As recent publicity has indicated, many women were not involved in these decisions regarding their breast implants. For women now alerted to the potential risks associated with reconstructive surgery and wishing to make informed choices about their treatment, information is virtually absent. According to Drawbridge (1990), the FDA has postponed publication on an "everything women ever wanted to know about" implants booklet, in part because of deep disagreement among members of the agency's breast augmentation advisory board.

### Summary

Although it is becoming generally accepted that cancer patients have the right to be adequately informed, many physicians either underestimate patients' desire for information or are not convinced that it is always in patients' best interests to be given full details of their cases. Nurses are often recognized for providing emotional support and information/advice about physical care rather than information about diagnosis, treatment options, and prognosis. Although nurses have a major role to play in the education of oncology patients and they are

gaining respect from patients, they do not always use their teaching opportunities effectively.

Despite patient requests and a shift to more open communication, the reviewed studies still cite communication problems with respect to the amount and kind of information patients are given. The impact of a cancer diagnosis and the need to make timely decisions creates enormous stressors that require the sensitivity and support of health care providers. Health professionals also need to take into account the information processing demands placed on the patient who attempts to present, to receive and to integrate ideas within a short space of time.

Several techniques have been or are being tried to remedy these information/communication difficulties: communication skills training in medical schools; inviting a close companion to be with the patient during the interview; utilization of good education aids (information sheets, booklets, posters, videos, and audiotapes). However, more attention has been paid to examining the way information is given than to the information itself. An essential prerequisite to each of these proposed strategies is a knowledge of the specificity and relevance of the information to the individual patient population.

## Literature Review

Although women with breast cancer have begun to articulate what information they would like to receive, existing research findings have not identified relative need for this information, considering differences within this particular patient population according to age, education, stage of disease and treatment option.

## CHAPTER III

## THEORETICAL FRAMEWORK

Concepts are defined and their meanings understood only within the framework of the theory of which they are a part (Hardy, 1973). This study begins with the premise that patients' information needs can be more accurately interpreted if the concepts chosen to represent the required or needed information are well defined within a theoretical framework. As well, the validity of these concepts is supported by logical and empirically based theoretical links postulated between them.

The theoretical framework underlying this study was constructed by Derdarian (1987) from theories of coping, appraisal, information seeking (Cohen & Lazarus, 1979; Folkman & Lazarus, 1980; Lazarus, 1966), needs (Heather, 1955; Hofer, 1972), and hierarchy of needs (Maslow, 1973). Lazarus's theory of coping forms the matrix of the framework. Certain components of the other theories are used to develop the conceptual links that are needed for a more comprehensive conceptualization of information needs.

Derdarian (1987a) provided a schematic representation of the theoretical framework (see Appendix A). The investigator also developed

a schematic representation of the theoretical framework as described by Derdiarian (1987a), in order to assist in conceptualizing the role that information plays in the coping process (See Appendix B). Within Derdiarian's (1987a) theoretical framework patients recently diagnosed with cancer are viewed as consumers of health care services with a right to participate in their own care. They are also portrayed as lacking in information about their diagnosis, treatment, hospitalization, remission, and prognosis, as well as about the implications of these factors for their physical, psychological, and social well-being. This lack of information about the immediate and future implications of cancer prohibits their anticipatory and effective adjustment to them.

Coping with the diagnosis of cancer and the post- diagnosis situation involves many cognitive, emotional, and behavioural responses aimed at alleviating the emergent concerns through problem-solving and minimization of emotions (Cohen & Lazarus, 1979). The theory of coping is chosen because it depicts the stresses brought on by the diagnosis of cancer, the individual's responses to them, and the relationship among the individual, the environment, and the stresses; all necessary to understand the role of information in the process of coping



(Derdiarian, 1987a).

Appraisal is the cognitive process through which an event is evaluated by the person according to what has been harmed, what is at stake, and what resources are available to cope with the perceived, actual or potential harm (Lazarus, 1966). Harm signifies the actual occurrence of an unpleasant or damaging event; such as a mastectomy, that may be consequential to the anticipated threat or could be antecedent to new threats. Threat refers to future harm and is therefore anticipated; it results from perception, learning, memory, and thought; and it is determined not by harmful stimuli that exist but rather by the cues indicating their approach; for example, recurrence of cancer (Lazarus, 1966). The evaluation of threat, therefore, is more subjective than that of harm. Resources are objects potentially capable of counteracting harms and threats; such as, a breast prosthesis.

Appraisal culminates in determination of power between harms and resources and between threats and resources. As a result of such cognitive processes, appraisals give direction to thought and behaviour. Appraisal comprises three cognitive processes; primary appraisal, or an assessment of the significance of the harmful or threatening stimuli;

secondary appraisal, or an assessment of the resources to contend with the perceived harm or threat; and reappraisal, both the appraisal of harm, threat, and resources and the choice of action and anticipated outcomes (Cohen, & Lazarus, 1979). The relationship between primary and secondary appraisal may or may not be sequential, although primary appraisal usually precedes secondary appraisal (Folkman & Lazarus, 1980).

Appraisal is believed to precede coping. Coping responses are made in response to the appraisal of a stressful situation. Appraisal and coping continuously influence each other throughout the stress response. Coping refers to the cognitive and behavioral effort of the individual to master, tolerate, or reduce external and internal demands and the conflict between them (Lazarus, 1966). Effective coping depends on the availability of either internal or external resources that aid in the mastery and control of harms and threats (Cohen, & Lazarus, 1979; Folkman, & Lazarus, 1980; Lazarus, 1966).

Although several modes of coping may be employed in a stressful event, information-seeking is the coping mode most pertinent to this study. Lazarus did not explicitly link information-seeking and appraisal or

coping. However, within Derdarian's framework (1987a), information is perceived to be functionally related to the processes of appraisal and coping, mediating both.

Inherent in the definition of information as factual knowledge relevant to a situation is the implication that a need for information derives from its lack (Derdarian, 1987a). Heather (1955) defined need as a perceived deficit that is requisite which, when fulfilled, achieves satisfaction of a goal. The need for information, therefore, is determined by the degree of lack of information and by the degree of relevance of the information to the situation (Derdarian, 1987a). A lack of relevant information may increase the motivation to seek it (Bandura, 1976).

According to Maslow (1973), basic needs rank higher and may energize behaviour more potently than secondary (acquired or learned) needs at times of high threat to survival. According to Derdarian (1987a) a hierarchy of relevant needs may be indicated by the relative importance of the information sought regarding those needs; for example, the importance of information sought may be equal to that associated with and necessary to survival. Concerns related to the harms, threats, and resources associated with survival are more likely to

prompt information-seeking behaviour than those unrelated to the individual's survival (Derdiarian, 1987a).

Since information-seeking is a mode of coping, it is assumed to have characteristics similar to coping: it exists in response to noxious stimuli; it aims at mastering novel situations by problem-solving and by controlling or reducing emotional distress; its nature may be determined by the relevance of harms, threats, and resources to survive; and it is influenced by person- and situation-related variables in the context in which it occurs (Cohen & Lazarus, 1979). Therefore, to understand the nature of the information sought, it is essential to understand the person- or situation-related variables as well (Derdiarian, 1987a).

Derdiarian used the described theoretical framework (1986) to investigate the information needs of 60 (age 18-70 years) recently diagnosed (1-18 days) cancer patients. Comparisons of information needs and their importance values among patients stratified by person- or situation-related variables indicated few differences by gender, age, and stage of cancer. The findings imply that information needs may be universal (Derdiarian, 1986). However, multivariate analysis of the data was not possible because of the small sample sizes of the subgroups.

Derdiarian (1987b) suggested that in future research, information needs should be investigated using measurements of hierarchy of needs concurrently with the measurement of information needs. This study followed Derdiarian's recommendation, generating profiles of priority information needs for different groups of women with breast cancer that could serve as a clinical guide to information sharing. Information seeking, as a mode of coping, was also assessed according to the patient's most preferred and actual sources of information about their disease.

Compared to breast cancer, no other single organ-site malignancy has been so often discussed with regard to the psychological consequences of its diagnosis and treatment (Schain, 1990). The particular coping responses adopted by cancer patients may, in fact, influence prognosis. Although most research studies have found information disclosure to have a salutary effect on the psychological adjustment of women diagnosed with breast cancer, these women consistently report that they do not receive the kind or amount of information they need.

Because Derdiarian's (1986) patient population was not

exclusively women with breast cancer, other person- and situation-related variables pertinent to the information needs of women recently diagnosed with breast cancer were identified in the literature.

The person-related variables reported to influence information needs of women recently diagnosed with breast cancer are those of age (Beisecker & Beisecker, 1990; Cassileth et al., 1980; Derdarian, 1986; Edlund & Sneed, 1989; GIVO, 1986; Greenfield et al. 1989; Hopkins, 1986; Leathar & Roberts, 1985; Ludwick, 1988; Newgarten, 1984; Rimer et al., 1983; Rudolph & McDermott, 1987; Vachon et al, 1990; Williams et al., 1987), education (Cassileth et al., 1980; GIVO, 1986; Jones et al., 1982; Ludwick, 1988; Rudolph & McDermott, 1987; Vachon et al., 1990; Waitzkin, 1984; ), and decision making control preference (Blanchard et al., 1988; Cawley et al., 1990; Cassileth et al., 1980; Degner & Russell, 1988; Fallowfield et al., 1989; Hack, 1991; Levy et al., 1989; Morris & Royle, 1987; Neufeld, 1986; Pierce, 1990; Schain, 1990; Sutherland et al., 1989; Ward et al., 1989).

Situation-related variables such as time since diagnosis (Keintz, & Glassman, 1985; Messerli et al., 1980; Northouse, 1989; Rimer, et al., 1983 ), stage of cancer (Abrams, 1966; Adams, 1991; Derdarian, 1986;

## Framework

Given & Given, 1989; GIVO, 1986; Greenfield et al., 1989; Hardy et al., 1980; Scott, 1983), and cancer treatment (Cawley et al., 1990; Drawbridge, 1990; Hailey et al., 1988; Lang et al., 1988; Larsy et al. 1987; Levy et al., 1989; Ward et al., 1989; were also considered to have a significant influence on information needs of women diagnosed with breast cancer.

Because previous research has shown a relationship between information needs and these variables in women recently diagnosed with breast cancer, the study of information needs can be refined by discriminating among groups that may differ on this characteristic. Therefore, eight groups were identified for this study based on their age, preferred role in decision making, education, and type of surgical intervention chosen. Previously reported theoretical and clinical knowledge about these groups of women recently diagnosed with breast cancer, resulted in the formulation of null hypotheses about profiles of information needs:

Hypothesis I-IV

- #1 Hypothesis: Women recently diagnosed with breast cancer who preferred active/collaborative roles in decision making about mastectomy versus lumpectomy/radiation will provide the same hierarchial profiles of information needs as women recently diagnosed with breast cancer who preferred passive roles in such decision making.
- #2 Hypothesis: Women recently diagnosed with breast cancer who have less than high school education will provide the same hierarchial profiles of information needs as women recently diagnosed with breast cancer who have high school or greater than high school education.
- #3 Hypothesis: Women recently diagnosed with breast cancer who had a mastectomy will provide the same hierarchial profiles of information needs as women recently diagnosed with breast cancer who had a lumpectomy.
- #4 Hypothesis: Elderly women (65-80) years, recently diagnosed with breast cancer will provide the same hierarchial profiles of information needs as those of younger women (18-64) years who are recently diagnosed with breast cancer.



CHAPTER IV

METHODOLOGY

Study Design

Survey methodology was used to describe information needs of women recently diagnosed with breast cancer. The method of paired comparisons derived from L. L. Thurstone's Law of Comparative Judgement (Dunn-Rankin, 1983a), a well recognized methodology for scaling a set of stimuli according to psychological preferences, was the major methodological approach. This chapter will include a description of this methodology as well as the other analytical methods used. The study setting, sample, subject recruitment, and protection of subject's rights will also be described.

Setting

The setting for this study was Winnipeg, Manitoba. The actual number of new cases of female breast cancer in Manitoba in 1991 was 743. The Manitoba Cancer Treatment and Research Foundation and the St. Boniface Hospital Outpatient Oncology Departments were chosen as

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the research sites because of their high number of breast cancer referrals. Approximately 50% of all breast cancer patients in Manitoba are seen at these two facilities.

Research approval was requested and received from the Director of the Clinical Investigations Office, at the Manitoba Cancer Treatment and Research Foundation (see Appendix C). Approval was also required and received from the St. Boniface General Hospital Nursing Research Department for access to St. Boniface Hospital patients (see Appendix D).

### Subjects - Patient Recruitment

A consecutive sample of 52 younger women (18-64) years and 22 older women (65-85) years, all within 131 days of diagnosis, were recruited from the Manitoba Cancer Treatment and Research Foundation and the St. Boniface Hospital Outpatient Oncology and Radiotherapy Departments.

Manitoba Cancer Treatment and Research Foundation

After receiving research approval, the investigator met with the Director of Nursing of the Manitoba Cancer Treatment and Research Foundation, who identified the weekly Conjoint Breast Cancer Clinic as the best access point to recruit patients. The Director of Nursing then introduced the investigator to the senior clinic nurse. The clinic nurses were given a copy of the study questionnaire and were encouraged to review it for their expert opinion. On the subsequent visit the investigator and clinic nurses discussed the questionnaire.

The senior clinic nurse agreed to being called by the investigator the day prior to the weekly clinic to identify patients according to the inclusion criteria. The investigator then attended the weekly clinic at the identified patient's appointment time. The clinic nurse gave the patient a brief explanation of the study and asked her if she would be willing to speak with the investigator to discuss it further. If the patient was in agreement the clinic nurse then introduced the investigator.

Approximately three months later the investigator discovered that breast cancer patients were being seen by doctors in clinics other than

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the Conjoint Breast Cancer Clinic. The investigator then approached the Director of Nursing for further access to these patients. The investigator was then invited to a meeting with the entire nursing department, in order to present the study and request further assistance with patient identification. Each clinic nurse was given a copy of the questionnaire as well as the investigator's telephone answering machine number. The investigator followed up with periodic telephone calls and personal visits to the clinic.

### St. Boniface Hospital Outpatient Oncology Department

After receiving research approval, the investigator initially met with the head nurse of the department and then attended two separate nursing staff meetings to explain the study and to identify the best method of patient identification. The nurses were encouraged to ask questions and review the study for their expert opinion. One senior nurse from each of the departments volunteered to be the main contact person. Each of these nurses was given a copy of the questionnaire as well as the investigator's telephone answering machine number. The

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investigator followed up with periodic telephone calls and personal visits to the clinic.

### Protection of the Rights of Human Subjects

This research proposal was reviewed by the Nursing Ethical Review Committee, School of Nursing, University of Manitoba, Winnipeg, Manitoba (see Appendix E). All potential study participants were identified (according to the criteria) and approached about participation in the study by the nurse in each oncology clinic. All subjects were informed that participation in the study was entirely voluntary and that they had the right to withdraw from the study at any time (see Appendix F). A written consent form was obtained for all subjects participating in the study (see Appendix G). Further consent was sought for access to the medical chart of those subjects who did not know their stage of disease. All consenting subjects were ensured of confidentiality. The subjects were asked not to write their name on the questionnaire and their consent forms were stored separately from their questionnaire.

Hierarchical Profiles of Information Needs of Women Recently  
Diagnosed With Breast Cancer: Questionnaire

A questionnaire was developed based on previous work by Derdarian (1986, 1987a, 1987b) and other clinical and theoretical literature. The questionnaire contained four parts (see Appendix H).

A. Control Preference Scale: Women were asked to indicate which of five potential roles in Treatment Decision Making, ranging from active to passive, was their preferred role, and which was the role they actually assumed in decision making at the time of their diagnosis. Subjects were shown a series of cards which describe and illustrate, with a cartoon, different roles in decision making. The set of five cards showed roles that the patient and physician could play, ranging from the patient making the decision, through a collaborative model, to a situation where the physician alone makes the decision (see Appendix I).

Subjects were asked to compare cards in subsets of two until their preference order across the set of five cards was unfolded. This measure was developed as a result of a pilot study (Degner & Russell, 1988) and tested subsequently in a survey of 436 newly diagnosed

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cancer patients (Degner & Sloan, 1992). Once the subject's preference order was recorded, she was asked to select the one card that best represented the role she had actually played in initial treatment decision making.

B. Sociodemographic Variables: The literature and clinical experience suggested the following variables could influence patient information needs: age, educational level, time since diagnosis, stage of disease, and treatment plan (mastectomy versus lumpectomy). Therefore, subjects were asked for data pertaining to these variables.

C. Informational Resources: As identified in the literature an important concern of cancer patients is obtaining the appropriate source of disease-related information. Patients were asked to identify their actual and preferred sources of information about their disease (for example: friends, literature, family, health professional).

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D. Information Needs: Nine questions (identified in the literature) that women might want to ask their physician/ nurse about their disease and treatment were arranged in every possible subset of two and presented in a specific order (see Appendix J). Ross's (1974) method of optimal orders was used to determine the order in which the paired items will be presented to the women (see Appendix K). Ross's method ensures that the maximum spacing for the maximum number of items is obtained to avoid selection bias. From each of these pairs of questions, women were asked to select the question they wanted answered first. After completion of the questionnaire, the women were asked if they could suggest any other informational needs they may have about their disease.

## Data Analysis

### A. Control Preference Scale

Part A of the questionnaire identified the individual's preferred and actual role in treatment decision making about their recent diagnosis of breast cancer. Data from the patient card sorts were analyzed using



unfolding theory (Coombs, 1970). Unfolding theory is a scaling theory designed to construct a space with two sets of points, one set for the individuals and one set for the objects of choice, the stimuli; the individual's preference orderings are reflected in the order relations on the distances between corresponding points (Coombs, Dawes, & Tversky, 1970). This scaling method is based on the theory of preferential choice. In preferential choice the data consist of, or are converted to, each individual's rank order of preferences for a set of alternate stimuli.

The model associates a point with each stimulus, called a stimulus point, and a hypothetical stimulus point with each individual, called the ideal point of the individual. The hypothetical stimulus corresponding to an individual's ideal point is that which he/she would prefer to endorse over all the others in the stimulus set. An individual's preference ordering, then, is taken to correspond in the model to the rank order of the stimulus points from the individual's ideal point (Coombs, Dawes, & Tversky, 1970).

In the real world of preferential choice, an individual's preferences

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may depend on considerations of many aspects of a stimulus, aspects that in the model would correspond to dimensions of the space. Any real stimulus may differ from the hypothetical stimulus that is the ideal in one or more aspects, and in the model these differences correspond to differences in the projections of the corresponding points on the dimensions of the space. What is meant by "considerations of many aspects" is captured in the model by the concept of a distance in a multidimensional space between the ideal point and a stimulus point (Coombs, Dawes, & Tversky, 1970).

In unidimensional unfolding theory, the stimuli and the ideals of the respondents are represented by two corresponding sets of points on a line representing an attribute continuum. This line is called a J scale, a joint distribution of two sets of points. Each respondent's I (individual) scale is obtained from the J scale by folding it at the ideal point of that respondent so the respondent's preference ordering of the stimulus is represented by the rank order of the stimulus points in order of increasing distance from the ideal point.

The analysis of data rests on the fact that the existence of a J

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scale places great constraints on the variety of I scales that can occur. Analysis of such data requires unfolding the I scales and constructing a J scale.

According to Coombs, Dawes, and Tversky (1970), another feature of real world preferences is that for any given set of stimuli an individual may not have a clear concept of a hypothetical stimulus that would be his/her ideal in that set. Many breast cancer patients, for example, may not have formulated an exact statement of how they would like to be involved in treatment decision making with their physician. Also, a given statement might not be interpreted or perceived as corresponding to a precise position on the issue. This uncertainty or ambiguity about an ideal point or about a stimulus point is captured in the model by a probability distribution in the spirit of the distribution of discriminial processes hypothesized by Thurstone in his model of comparative judgement (Coombs, Dawes, & Tversky, 1970).

A computer program utilizing the analytic methodology of Coombs unfolding theory was used to construct J scales from the individual participant's I scales about their preferred role in treatment decision

making with their physician.

The mean values of the study participant's preferred role in deciding upon treatment for their recent diagnosis of breast cancer were determined by a computer program which utilized the analytic methodology of Case V of Thurstone's law of comparative judgement. This methodology more clearly depicted the participant's priority ranking about treatment decision making.

#### B. Sociodemographic Variables

Part B of the questionnaire identified participant's sociodemographic data such as age, education status (less than high school, high school diploma, greater than high school), treatment plan (mastectomy versus lumpectomy), time since diagnosis, and illness severity (Stage I, II, III, or IV). These variables served as dependent or independent variables depending on which other variable was included in the statistical test. Statistical analysis was carried out with Wilcoxon's rank sum tests, Kruskal-Wallis ANOVA procedures, Bonferroni multiple-comparison procedure and chi-square tests.

C. informational Resources

Part C explored the participant's preferred and actual sources of information about their disease. Descriptive statistics as well as the Spearman rank correlation coefficient test for nonparametric data were used to identify any differences in the ten hypothesized groups. The Spearman rank correlation coefficient was used to measure the degree of association between the ranked sources of information and the variables of age, education, treatment plan, and time since diagnosis.

D. Information Needs

The analytic methodology chosen to identify the ranking of information needs of women recently diagnosed with breast cancer was Case V of Thurstone's Law of Comparative Judgement. The paired comparison data was collected in Part D of the questionnaire when the nine stimuli were judged in every possible combination of two. The data was compiled using the methodology described in Edwards (1957) and Dunn- Rankin (1983a, 1983b). A summary of this methodology by (Paton, 1990) was used in part by the investigator for the following

description.

#### Thurstone's Law of Comparative Judgement - Case V

Thurstone (1974) postulated that given a set of  $n$  stimuli such as the nine pieces of information, each will possess in varying but unknown degrees some attribute, for example, a sense of relevance. The only restriction on stimuli is that the subjects be able to rank one item above the other according to some attribute (Dunn-Rankin, 1983a). He assumed that the  $n$  stimuli could be ordered along an unknown psychological continuum with respect to the identified attribute. The more any two stimuli are separated on the continuum the more frequently subjects would identify one item as containing more of the attribute under investigation (Bock & Jones, 1968). In this study the attribute under investigation was perceived relevance. It is important to note that each of the stimuli may vary with respect to more than one attribute and thus the stimulus order within the continuum will vary depending on the attribute being measured (Edwards, 1957).

It is assumed that for each stimulus and amongst all participants,

there is a most frequently aroused perception of relevance. Thurstone called this the modal discriminial process. For each stimulus, the "perception of relevance" will be normally distributed around that stimuli's most frequent or modal response. For any normal distribution the mean, median and mode have exactly the same value. The identification of this mean/modal numerical value forms the scale of the stimulus items.

The full mathematical equation used to express Thurstone's Law is

$$\underline{S}_i - \underline{S}_j = z_{ij} \sqrt{\sigma_i^2 + \sigma_j^2 - 2r_{ij}\sigma_i\sigma_j}$$

where  $S_i$  and  $S_j$  are the mean responses to the stimuli,  $Z_{ij}$  is the normal deviate equivalent to an empirically determined proportion,  $p_{ij}$ ,  $\sigma$  is the standard deviation around each stimuli and  $r$  is the correlation between stimuli. This equation states that the normal deviate,  $z_{ij}$ , is a function of the difference between the mean responses to the stimuli, the standard deviation around the stimuli and the correlation between the stimuli.

In this study of perceptions of relevance, there were nine pieces of information or stimuli. The determination of the scale values describing

the ranking of the nine stimuli required application of Thurstone's Law equation for each of the possible pairs (36). However, these 36 equations had 54 unknowns; nine scale values, nine standard deviations and 36 inter-correlations. Since it was possible to only have nine known values, the  $z_{ij}$ 's, the solution of the system of 36 equations was impossible (Edwards, 1957).

In order to approximate the solution to this system of equations Case V methodology was chosen in which

$$\sqrt{\sigma_i^2 + \sigma_j^2 - 2r_{ij}\sigma_i\sigma_j}$$

is assumed to be a constant and is made equal to 1. That is, the Case V approximation requires assumptions of equal dispersion of reactions around each stimuli and uncorrelatedness between judgements of the different items (Dunn-Rankin, 1983a). Based on these assumptions, Case V of the Law of Comparative Judgement then becomes

$$\underline{s}_i - \underline{s}_j = z_{ij} \cdot$$

Case V is the simplest of the various cases Thurstone and other researchers explored. It has been applied successfully to data collected from a number of subjects to determine the ranking of independent



stimuli on a psychological continuum (Bock & Jones, 1968).

#### The Scale Value: Determination of the Modal Discriminal Process

Utilizing a computer program the numerical value of the modal discriminial process was determined by finding the mean of all the comparative judgements about a given stimuli.

First, the subjects made all possible comparative judgements about the "n" stimuli. From this, an empirical frequency was counted corresponding to the number of times that each stimulus was judged more relevant than the other. For example, the comparative judgements of all the 74 women between the stimuli i (Si) "information about the diagnostic stage and extent of involvement of the disease" and stimuli j (Sj) "information about the likelihood of cure from the disease" identified the number of times that each stimuli was judged more relevant than the other. Let

$$f_{ij} = i > j$$

where  $f_{ij}$  was the frequency of i being judged more relevant than j. This frequency was then expressed as a proportion by dividing frequency by

the total number of subjects making the judgement. With N equalling the number of subjects

$$p_{ij} = f_{ij}/N$$

where  $p_{ij}$  was the proportion of times that  $i$  was judged more relevant than  $j$ . The proportion  $p_{ij}$  was then expressed as a normal deviate  $z_{ij}$  by means of a normal deviate table.

Schematic representation of the paired comparisons

The data collected from Part D of the questionnaire was initially summarized to identify the frequency with which each information statement was perceived more relevant than each of the other information statements. A frequency, proportion and normal deviate matrix was then developed for each of the subject groups under investigation.

The fundamental appearance of the matrix was that of nine columns and nine rows. Each of the columns represented one of the nine information statements used in the paired comparative judgements as did each of the rows (see Figure 4-1). Each cell entry corresponds to the number of times that the row item was judged to be more relevant

than the column item.

A series of three matrices, one for frequencies, one for proportions and one for normal deviates were required to determine the scale of perceived relevance for each information statement. See the format of the Matrix in Figure 4-1.

The cells on the diagonal of the matrix involve a comparison of each stimuli item with itself. By convention, they were assumed to be equal  $N/2$ , half the total number of subjects making the judgements. By convention the diagonal of the frequency matrix is filled in with zeros, and the diagonal of the proportion matrix with 0.50. The normal deviate corresponding to the proportion 0.50 is 0.00 (Edwards, 1957).

Figure 4-1

The Fundamental Matrix

	STG	CUR	SOC	EMO	S.C.	SEX	TX	RIS	S.E.
STG									
CUR									
SOC									
EMO									
S.C.									
SEX									
TX									
RIS									
S.E.									
STG		the diagnostic stage and extent of involvement of the disease.							
CUR		the likelihood of cure from the disease.							
SOC		how the treatment may affect ability to carry on usual social activities.							
EMO		how to handle the physical and emotional impact of the disease on family and others.							
S.C.		caring for self at home (nutrition, support groups, home care, social worker, etc.)							
Sex		how the treatment may affect usual feelings of physical and sexual attractiveness.							
TX		different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks.							
Ris		how at risk children and/or other family members are of developing the disease.							
S.E.		possible unpleasant side effects of treatment (nausea, pain, change in physical appearance).							

### Test of Hypotheses

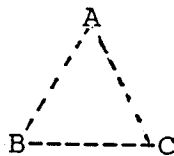
No method short of examining the entire population parameter enables us to determine with absolute certainty whether a hypothesis about a population parameter is true (Shott, 1990). We can only assess whether data provide evidence against a hypothesis. If the data provide evidence against a hypothesis, we reject the hypothesis. If the data do not provide evidence against a hypothesis, we cannot reject the hypothesis.

The null hypotheses about the hierarchical profiles of information needs of the different groups of women recently diagnosed with breast cancer were tested by the pooled variance t-test. The t-test compares the information needs relative scale values (means) of two groups and examines the probability of getting this magnitude of difference by chance alone. A 0.05 significance level was used to test the four null hypotheses.

### Internal Judge Consistency (Circular Triads)

In making paired comparison judgements, a subject may sometimes be inconsistent. Inconsistencies in an individual subject's comparative judgements may have occurred through disinterest, lack of a distinguishable difference between stimuli, or a general personality or ability trait (Edwards, 1974; Dunn-Rankin, 1983b). An inconsistency in judgments occurs whenever there is a circular triad present in the  $n(n-1)/2$  judgements. This can affect the assessment of the internal consistency of the questionnaire.

For example, if a subject was presented with all possible pairs of any three stimuli; A, B, and C; it would be expected that if A was judged to be more relevant than B and B more relevant than C, then A would be judged more relevant than C. If C, on the other hand, was judged more relevant than A, these three comparative judgements would constitute a circular triad.



## Methodology

Judge inconsistency was identified by computing the number of circular triads present in the results of each subject. The number of circular triads was determined by looking at each subjects' responses within the schematics of another matrix. Again the columns and rows are identified by the nine stimuli. Each time a column stimulus is judged more relevant than a row stimulus a "1" is entered into the matrix cell. When the row stimulus is judged more relevant than the column a "0" is entered into the cell. The number of circular triads is then determined by

$$d = (1/12) (n) (n - 1) (2n - 1) - 1/2 \sum a^2$$

where  $n$  is the number of stimuli and  $a$  is the squared sum of all the column stimuli. For nine stimuli, the maximum number of circular triads that can occur is 84. A summary of where the circular triads occurred and which participants were responsible was also completed.

The coefficient of consistence, zeta, is defined as

$$\text{zeta} = 1 - (24d/n^3 - n)$$

when  $n$  is odd. If a subject was totally inconsistent, zeta would equal 0; if he or she was totally consistent, zeta would equal 1.

Agreement Between Judges: Homogeneity  
and Kendall's Coefficient of Agreement

Edwards (1974) suggested that even though individual judges may demonstrate few circular triads (coefficient of consistence near one), they may not agree amongst themselves. Dunn-Rankin (1983b) described a statistic,  $u$  the coefficient of agreement, developed by Kendall in 1948. This statistic provided a means of determining the agreement between judges. This was applied to the judgements of all ten hypothesized subject groups.

First  $T$  must be defined.

$$T = (\sum f_{ij}^2 - m \sum f_{ij}) + (mC_2)(nC_2)$$

where  $\sum f_{ij}^2$  = the sum of the squared  $f_{ij}$  entries below the diagonal of the frequency matrix

$m$  = the number of subjects

$\sum f_{ij}$  = the sum of the  $f_{ij}$  entries below the diagonal

$mC_2$  = the number of combinations of  $m$  judges taken 2

at a time or  $m(m - 1) / 2$



$nC_2$  = the number of combinations of  $n$  stimuli taken 2  
at a time or  $n(n - 1)/2$

Kendall's coefficient of agreement can then be defined as

$$u = (2T / (mC_2) (nC_2)) - 1$$

If  $u$  takes any positive value whatsoever there is a certain amount of agreement among the judges; maximum  $u$  is 1, minimum  $u$  is -1.

The chi-square test for the coefficient of agreement is

$$x^2 = (4/m - 2) (T - (1/2 (mC_2) (nC_2) (m - 3) / (n - 2))).$$

The degrees of freedom are

$$df = (nC_2) (m(m - 1) / (m - 2)^2).$$

Coombs, Dawes and Tversky (1970) suggested that the larger the scale range the more homogeneity amongst the judges concerning the attribute under study. The range of the scales of the ten hypothesized subject groups were compared to identify the existence of a difference in the homogeneity towards the perception of relevance of the nine information statements.

Summary

This chapter has outlined the methods used in conducting a study of the perceived relevance of information to women recently diagnosed with breast cancer. The study design was based on Thurstone's Law of Comparative Judgement. The Case V Methodology of Thurstone's Law of Comparative Judgement formed the basis of the analysis.

Chapter V

RESULTS

The results of this descriptive study will be presented in this chapter. These results will be described and illustrated using tables, graphs, figures, and appendices. The format will follow that of the methodology chapter. First, the sociodemographic data are described in terms of frequency distributions. Next, the study participants' control preference scale results are described and illustrated in graph and figure form. Third, the participants' preferred and actual information resources are presented in relationship to their age, education, and time since diagnosis. Next, the participants' priority information needs are described and illustrated, by way of the Thurstone scale values. The degree of internal consistency of the individual judges (participants) is also described. Finally, the test of the hypotheses are presented, noting significant differences in the information needs profiles.

Sociodemographic Data

From July 1991 to March 1992 a total of 74 women from the outpatient oncology clinics at the St. Boniface General Hospital and the

## Results

Manitoba Cancer Treatment and Research Foundation, who were recently diagnosed with breast cancer, agreed to participate in the study. Fifty-two women were age (18-64) years and 22 women were age (65-83) years, with a median age of 59 years and a mean age of 57.5 years (s.d.=11.62) (see Table 5-1).

Table 5-1

### Number of Subjects Participating in the Study

Age Group	Frequency	Percent
(18-64) years	52	70.3
(65-83) years	22	29.7
Total	74	100.0

Mean age 57.5 years (s.d. 11.6).

## Results

Approximately 6 women who were approached did not participate in the study. No attempt was made to determine if the non-participants systematically differed from the participants.

The length of time from the subject's diagnosis of breast cancer to study participation ranged from 5-131 days with an average of 58 days (s.d.=25.7). Of the 74 women who participated in the study 27 (36.5%) had less than high school education, 21 (28.4%) had high school education and 26 (35.1%) had greater than high school education (see Table 5-2).

Table 5-2

### Education Level of Study Participants

Education	Frequency	Percent
<High School	27	36.5
High School	21	28.4
>High School	26	35.1
Total	74	100.0

## Results

Forty-six (66.7%) of the women in the study sample had a lumpectomy compared to 23 (33.3%) of women who underwent mastectomy. The higher proportion of women who received lumpectomy is not representative of the target population and is thought to be due to the fact that patients were recruited from oncology referral centres only. Patients who have a lumpectomy performed are routinely referred to these centres for radiation while patients who have a mastectomy may be referred to an oncologist for further treatments. However, referral may not be to either of these clinics (see Table 5-3).

Table 5-3  
Treatment Plan of Study Participants

Tx - Plan	Frequency	Percent
Mastectomy	23	33.3
Lumpectomy	46	66.7
Frequency missing	5	
Total	74	100.0

## Results

Of the 23 women who had a mastectomy 15 (28.8%) were between (18-64) years of age compared to 8 (36.4%) who were between (65-83) years of age. Of the 46 women who had a lumpectomy 34 (65.4%) were between (18-64) years of age compared to 12 (54.5%) who were between (65-83) years of age.

The severity of the participant's disease (i.e., tumor stage) ranged from Stage I-IV. Most women (60.3%) had Stage I breast cancer (see Table 5-4).

Table 5-4  
Stage of Disease of Study Participants

Stage	Frequency	Percent
I	44	60.3
II	22	30.1
III	4	5.5
IV	3	4.1
Frequency missing =	1	
Total	74	100.0

## Results

### Control Preference Scale

The preference orders of 28/54 (51.85%) of the subjects unfolded unto the psychological dimension of preferences about keeping, sharing, or giving away control over decision making to the physician. The highest frequency ordering for these preferences was EDCBA (see Figure 5-1). In other words, the participants that preferred this control preference order most preferred leaving all decisions regarding their treatment to their doctor and least preferred making the final selection about their treatment themselves.



Figure 5-1

Psychological Dimension of Treatment Decision Making (n=28)

ACTIVE ROLE - Patient Control

\_\_\_\_\_0\_\_\_\_\_5\_\_\_\_\_10\_\_\_\_\_

ABCDE	
BACDE	X X X X
BCADE	X X
BCDAE	
CBDAE	X X
CDBAE	X X X X
CDBEA	X X X X X
CDEBA	
DCEBA	X X X X
DECBA	X
EDCBA	X X X X X X

\_\_\_\_\_0\_\_\_\_\_5\_\_\_\_\_10\_\_\_\_\_

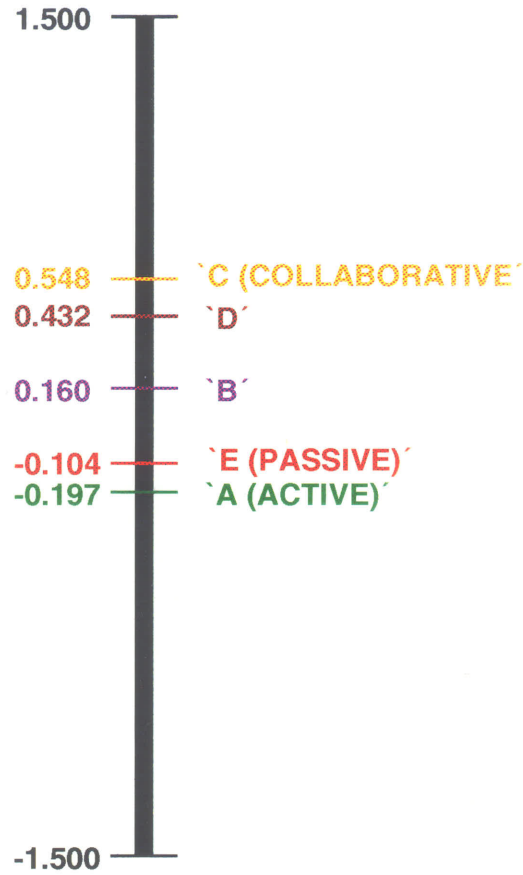
PASSIVE ROLE - Physician Control

The analytic methodology of Case V of Thurstone's Law of Comparative Judgement identified the rank ordering of the women's treatment decision making preferences as illustrated in graph form in Figure 5-2. Overall, participants in this study would have most preferred a collaborative role in treatment decision making about their diagnosis of breast cancer and would have least preferred an active role in such decision making.

FIGURE 5-2

# THURSTONE SCALE

## BREAST CANCER (N=74) TREATMENT CONTROL PREFERENCES



## Results

The patient's responses to the treatment decision making card sorting procedure were recorded in proximities matrices. These matrices indicate the treatment decision making role that patients preferred and the treatment decision making role that they actually assumed during their initial treatment decision making interview with their physician after their diagnosis of breast cancer.

The findings revealed 50% agreement in frequency between the subject's most preferred role and their actual role assumed in treatment decision making relative to their recent diagnosis of breast cancer (see Table 5-5). Agreement was evident between those women who preferred (20.3%) and actually assumed (24.3%) an active role (category A & B).

Results

Table 5-5  
Treatment Decision Making: Preference Role By Actual Role  
PREFROLE ACTROLE(ACTUAL ROLE)

Frequency Percent Row Pct Col Pct	A	B	C	D	E	Total
A	1 1.35 50.00 16.67	0 0.00 0.00 0.00	1 1.35 50.00 7.14	0 0.00 0.00 0.00	0 0.00 0.00 0.00	2 2.70
B	2 2.70 15.38 33.33	7 9.46 53.85 58.33	2 2.70 15.38 14.29	2 2.70 15.38 9.09	0 0.00 0.00 0.00	13 17.57
C	3 4.05 11.11 50.00	5 6.76 18.52 41.67	7 9.46 25.93 50.00	6 8.11 22.22 27.27	6 8.11 22.22 30.00	27 36.49
D	0 0.00 0.00 0.00	0 0.00 0.00 0.00	4 5.41 20.00 28.57	12 16.22 60.00 54.55	4 5.41 20.00 20.00	20 27.03
E	0 0.00 0.00 0.00	0 0.00 0.00 0.00	0 0.00 0.00 0.00	2 2.70 16.67 9.09	10 13.51 83.33 50.00	12 16.22
Total	6 8.11	12 16.22	14 18.92	22 29.73	20 27.03	74 100.00

37/74 = 50% perfect agreement  
( $\chi^2 = 56.70$ ,  $df=16$ ,  $p=0.000$ )

## Results

However, the findings revealed different distributions relative to collaborative (category C) and passive (category E) roles in treatment decision making (see Table 5-5). Twenty-seven percent of women actually assumed a passive role while only 16.2% of women indicated that they would prefer this role. Inversely, 36.5% of women preferred a collaborative role, whereas only 18.9% of women actually assumed this role. These findings indicate that almost twice as many women would have preferred a collaborative role than those who actually assumed such a role.

A further analysis of these treatment decision making roles was accomplished by collapsing the assumed roles into active (category A and B), collaborative (category C), and passive (category D and E). The chi-square analysis indicated a significant ( $\chi^2 = 35.14$ ,  $df=8$ ,  $p=0.000$ ) difference in the subjects preferred role in treatment decision making and their assumed role in such decision making.

An examination of the relationship between treatment decision making role preference and age (age category), education, illness severity, treatment plan, and time since diagnosis was conducted.

## Results

One-way analysis of variance indicated that there were significant differences in age by treatment decision making role preference ( $F = 4.26, p = 0.0039$ ). The bonferroni multiple-comparison procedure indicated that those subjects who preferred either an active (category A) or collaborative (category C) role in treatment decision making were significantly younger in comparison to those subjects who preferred a passive role (category E).

A subsequent chi-square analysis of the preferred treatment decision making role by the age categories (18-64) years and (65-83) years found no impact of age on role preference.

Examination of the differences in the actual treatment decision making role assumed by age (age category), education, illness severity, treatment plan, and time since diagnosis revealed one difference. The chi-square analysis indicated a significant ( $\chi = 11.24, df = 2, p = 0.004$ ) difference in the participant's assumed treatment decision making role category (active, collaborative, or passive) and their age category (18-64) years or (65-83) years. A greater proportion of women from the age category (65-83) years than from the age category (18-64) years assumed a passive role (category D & E) in treatment decision making.

## Results

### Informational Resources

The subjects were asked to rank order the listed information sources according to those from which they would have most preferred to get information after their diagnosis of breast cancer. Subjects most frequently ranked these sources in the following order from most preferred to least preferred: physician, nurse, friend/relative, brochure, medical journal/text, videotape, television/radio, women's journal, and newspaper.

The association between each of the preferred sources of information and the variables of age, treatment plan, education and time since diagnosis was examined. Each individual score for the preferred source of information was correlated with each of these person- and situation-related variables.

The Spearman Rank Correlation Coefficient Test showed a significant negative correlation ( $Rho = -0.348$ ,  $p = 0.002$ ) between level of education and the use of a medical journal as a preferred source of information about breast cancer. The higher the level of education of women in this sample the more relevant a medical journal as a source of disease related information became.

## Results

Subsequently subjects were asked to circle, from the same list of informational resources, only those sources from which they actually did get information about their diagnosis of breast cancer. The frequency that women actually utilized any of these resources is shown in Table 5-6. As was expected, physicians were the most frequently utilized source of information for women in this study, whereas, nurses were the third most frequently utilized source. Interestingly, friends/relatives were identified as people these women approached for information about their diagnosis of cancer slightly more frequently than nurses. Videotapes were identified as the least utilized source. Overall, people sources of information ranked higher than written sources.



Table 5-6

## Informational Resources: Actually Used by Study Participants

Information Source	Frequency	Percent
Physician	72	97.3
Friend/Relative	48	64.9
Nurse	45	60.8
Brochure	42	56.8
Television/radio	22	29.7
Women's Journal	19	25.7
Medical Journal	16	21.6
Newspaper	12	16.2
Videotape	3	4.1

The relationship between the actual sources of information used by this sample of women recently diagnosed with breast cancer and their age, level of education, time since diagnosis, and the role they actually assumed in treatment decision making was examined using a variety of statistical tests. No correlations between these variables were found.

## Results

### Information Needs: Thurstone Scale Values

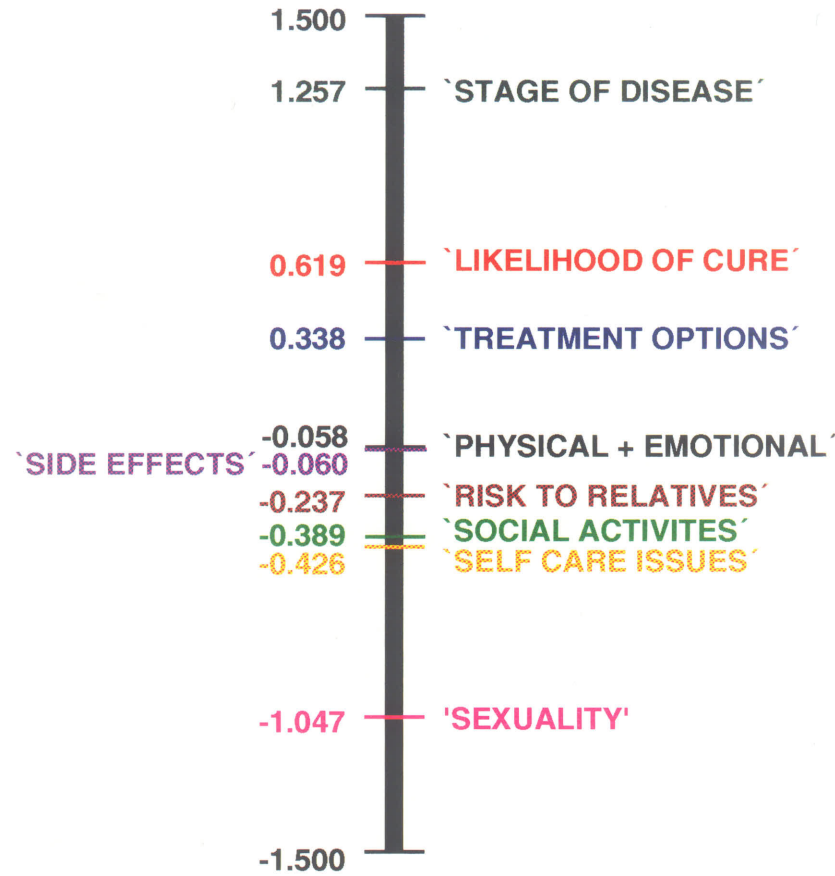
The frequency, proportion and normal deviate matrices for the total sample of breast cancer patients can be found in Appendix L, M, and N respectively. The relative scale values (means) for each of the nine patient information needs are identified in the last row on the normal deviate matrix.

Figure 5-3, shows the rank ordering of the nine patient information needs, for the total patient sample, based on the relative scale values (means). Overall, these patients ranked having information about the stage of disease, the likelihood of cure, and the treatment options available to them as the three most important needs. Information about how the treatment may affect their usual feelings of physical and sexual attractiveness was least relevant. The remaining information needs were fairly evenly distributed in the middle of the scale.

FIGURE 5-3

### INFORMATION NEEDS OF WOMEN RECENTLY DIAGNOSED WITH BREAST CANCER

All Women  
N = 74



## Results

This scale is also shown in Figure 5-4, in combination with relative scale values (means) for each of the hypothesized breast cancer patient groups. These comparative scales help to illustrate the trends between and among patient groups. For example, as patients' desire for an active role in treatment decision making decreased, so too did their desire for information about the diagnostic stage and extent of involvement of their disease. The same downward trend in relevance is evident among this group of patients for information about how the treatment may affect their usual feelings of physical and sexual attractiveness. Inversely, as patients' desire for an active role in treatment decision making decreased, their desire for information about how at risk children and/or other family members were of developing the disease appeared to increase.

Another example illustrating a downward trend in relevance of particular information needs is evident among the two different age group categories. There was a downward trend in the need for information about the stage of disease and about how the treatment will affect their body and their sexual attractiveness for those women who were in the (65-83) year age group compared to those women in the (18-64) year

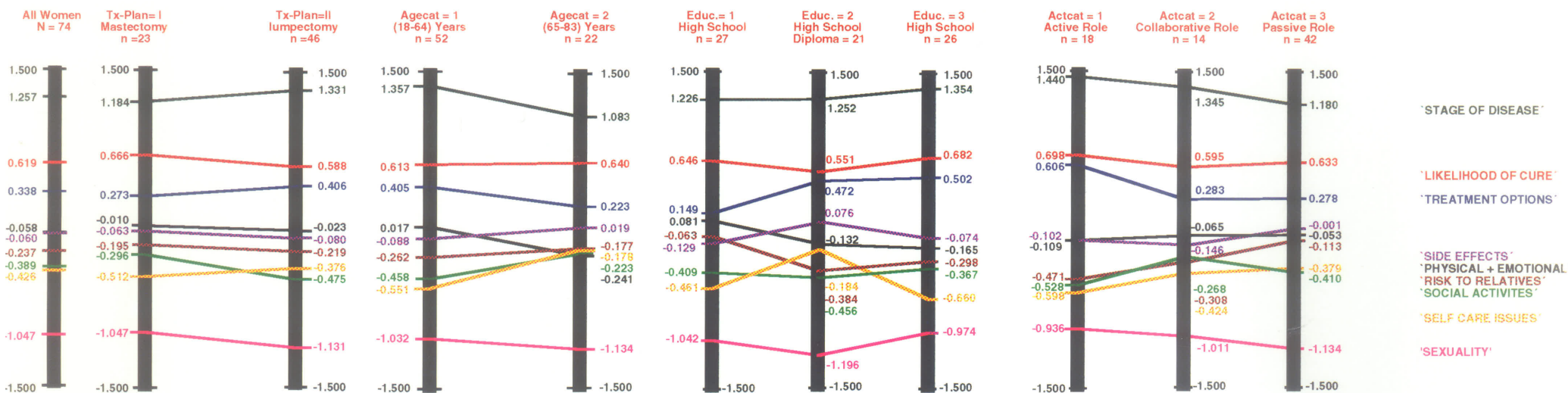
## Results

age group. There was also a slight downward trend in the relevance of information about how treatment will affect the body and sexual attractiveness of women who had a lumpectomy compared to those women who had a mastectomy.

Despite these few visual trends, the rank ordering by all 10 hypothesized patient groups are remarkably similar. The first three and last ranked information needs are the same for all 10 hypothesized patient groups, as well as for the overall sample.

FIGURE 5-4

# INFORMATION NEEDS OF WOMEN RECENTLY DIAGNOSED WITH BREAST CANCER



## Results

### Test of Hypotheses

The pooled variance t-test was used to test the null hypotheses about the hierarchial profiles of information needs of women recently diagnosed with breast cancer (See Appendix O, P, Q, R, and S).

#1 Hypothesis: Women recently diagnosed with breast cancer who preferred active/collaborative roles in decision making about mastectomy versus lumpectomy/radiation will provide the same hierarchial profiles of information needs as women recently diagnosed with breast cancer who preferred passive roles in such decision making.

The data do not provide evidence against the hypothesis, therefore, it cannot be rejected ( $p < 0.05$ ).

#2 Hypothesis: Women recently diagnosed with breast cancer who have less than high school education will provide the same hierarchial profiles of information needs as women recently diagnosed with breast cancer who have high school or greater than high school education.

## Results

Women who had a high school diploma education ranked information about caring for themselves at home significantly ( $t= 2.53$ ,  $p<0.02$ ) more important than women who had greater than high school education.

Therefore, the hypothesis that the hierarchical profiles of information needs are the same for these two groups of women must be rejected.

#3 Hypothesis: Women recently diagnosed with breast cancer who had a mastectomy will provide the same hierarchical profiles of information needs as women recently diagnosed with breast cancer who had a lumpectomy.

The data do not provide evidence against this hypothesis, therefore, it cannot be rejected ( $p<0.05$ ).

#4 Hypothesis: Elderly women (65-83) years, recently diagnosed with breast cancer will provide the same hierarchical profiles of information needs as those of younger women (18-64) years who are recently diagnosed with breast cancer.



## Results

Elderly women (65-83) years of age ranked information about caring for themselves at home as significantly ( $t= 2.47, p<0.02$ ) more important than younger women (18-64) years of age. Therefore, the hypothesis that the hierarchical profiles of information needs are the same for these two groups of women must be rejected.

### Internal Judge Consistency - Circular Triads

#### The Coefficient of Consistence

Circular triads describe the internal consistency of the individual judges, in this case, the participants diagnosed with breast cancer. The maximum number of circular triads for a set of nine stimuli is 84. Table 4-8 shows the frequency of circular triads for the total sample. The maximum, average, and minimum number of triads shown by any one participant in this study was 17, 4, and 1, respectively. A total of 18 participants had no circular triads; in other words, they were completely consistent in their judgements of relevance of paired comparisons of information needs about their recent diagnosis of breast cancer. Ten participants made 10 or more circular triads in their paired comparative judgements. In other words 13.5% of the respondents were responsible

## Results

for almost 3/4 (71.&%) of the circular triads.

Inconsistencies in comparative judgements may occur for a number of different reasons. In an attempt to identify the possible reasons for the identified inconsistencies a further analysis of the circular triads data was completed. Table 4-8 shows a profile of person- and situation-related variables of those participants who had 10 or more circular triads in their judgements of the paired comparisons. For these participants, no apparent correlations were evident for the variables age, stage of disease, education level, type of surgery, and treatment decision making role.

Table 5-7

### Individual Participation Profiles

Patient#	# of Triads	Age	Tx_Plan	Stage	Education	Role
6	17	59	Mast.	II	2	E
8	17	63	Lump.	I	2	C
52	16	53	Lump.	I	1	E
54	15	33	Lump.	I	3	C
15	13	50	Mast.	II	3	B
44	13	83	Lump.	I	3	D
39	12	60	Lump.	I	1	C
38	11	71	Mast.	III	1	D
56	10	81	Lump.	I	2	D
62	10	71	Mast.	III	2	D

## Results

According to Edwards (1974), the statements that are being judged in comparative judgements, may in fact, cause inconsistencies in these judgements. For example, statements may fall so close together on the psychological continuum that the judgements are exceedingly difficult to make. Still another possibility is that the statements do not fall along the single dimension on which they scaled. If statements differ with respect to attributes or dimensions other than the one of interest, these additional attributes may play a part in influencing the comparative judgements. Considering these possible influences, a further analysis of where the study participant's circular triads occurred was completed.

The greatest number of circular triads that occurred for an individual person, among the same trio - of information need statements, was nine. This number of circular triads, although not large, occurred in two different combinations of statements. These information need statement combinations were as follows:

TRIO:

- A. 1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
- B. 2. Information about the likelihood of cure from the disease.

## Results

- C. 8. Information about how at risk my children and/or other family members are of developing the disease.

### TRIO:

- A. 1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
- B. 3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.).
- C. 7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the advantages and disadvantages associated with each treatment.

The single information need statement involved in the most number of circular triads overall is #4 - information about how to handle the physical and emotional impact of the disease on family and significant others.

The test for Kendall Zeta showed a mean value of 0.992. Therefore, the study participants were found to be consistent, despite a lack of perfection, in their comparative judgements of the importance of

## Results

the nine information needs about their recent diagnosis of breast cancer.

The group that was the most consistent in their judgements of the paired comparisons of the information needs about their recent diagnosis of breast cancer was the group of women who played an active role in treatment decision making with their physician. In contrast, the group of women that were the least consistent in their individual judgements of the paired comparisons were those women who assumed a collaborative role in treatment decision making.

### Agreement Between Judges -

#### Homogeneity and Kendall's Coefficient of Agreement

The coefficient of agreement,  $u$ , indicates the extent to which the study participants agreed in their comparative judgements. The coefficient of agreement of the total sample was found to be 0.348, indicating there was agreement between the participants, although it was not great. The subgroup that showed the greatest extent of agreement in their comparative judgements of the information needs about their recent diagnosis of breast cancer were the group of women who assumed an active role in treatment decision making with their physician.

## Results

In contrast, the subgroup of women that showed the least amount of agreement in their comparative judgements were the group 65 years of age and over

A comparison of the range of scale values of the subgroups, as suggested by Coombs, Dawes, and Tversky (1970), confirmed these findings. The overall range of the scales differed, with the scales of the group of women who assumed an active role in treatment decision making ranging to 1.44, in comparison to the maximum scale value of 1.08 for the group of women 65 years of age and over. These combined findings suggested that the group of women who assumed an active role in treatment decision making had the greatest degree of homogeneity in their attitudes toward the perception of relevance of information from the nine information needs statements.

Participant's responses to the question, at the end of the information needs, about other kinds of information they would like to have access to included the following: earlier access to mammogram, breast self examination, tamoxifen, how chemotherapy works, care of hemovac, and the cause of breast cancer. Participants also expressed concern about lack of communication between family physician and

## Results

consultants. Others expressed a need to talk to a health professional during the diagnostic stage, as well as after.

### Summary

The study sample was not representative of the target population in relation to proportions of participants in the following categories: treatment plan, stage of disease and age category. Using unfolding theory for data analysis the majority of participants were found to prefer a collaborative role in treatment decision making about their recent diagnosis of breast cancer. However, those subjects who preferred either an active or collaborative role in treatment decision making were significantly younger in comparison to those subjects who preferred a passive role. Likewise, a greater proportion of women from the age category (65-83) years than from the age category (18-64) years actually assumed a passive role in treatment decisions regarding their recent diagnosis of breast cancer.

Overall, people as sources of information were found to be more important to participants than written sources. The participant's level of education was found to influence their preferred sources of information.

## Results

Case V Methodology of Thurstone's Law of Comparative Judgement was used to analyze the information needs, paired comparisons, according to the perception of relevance to participants. The results demonstrated a clear picture of how the participants prioritized their information needs from most important to least important. Visually, the rank order and the scale values (means) of the information needs were very similar for each of the hypothesized patient groups. The pooled variance t-test, used to test the null hypotheses, compared each of the nine information need scale values within each profile. This analysis found two significant differences in the individual scale values of the hypothesized patient groups, causing Hypotheses #2, and #4 to be rejected. It is important to note however, that these differences were in individual scale values not the overall profile of values. The data did not provide evidence to refute Hypotheses #1, and #3.



Chapter VI

DISCUSSION

Guided by Derdarian's (1987a) theoretical framework, this study used a four part questionnaire to investigate the preferred and actual treatment decision making roles, the preferred and actual sources of information, and the priority information needs of women recently diagnosed with breast cancer. Four hypotheses about these women's profiles of priority information needs were tested.

The final chapter of this thesis includes discussion of the study results in relation to previous research findings, the theoretical framework, and the implications for nursing practice and research. Limitations of the study are also addressed.

Sociodemographic Data

The proportion of women in the 18 to 64 year age group and the 65 to 83 year age group were not representative of the target population. According to 1991 statistics, 48.3% and 42.1% of women diagnosed with breast cancer in Manitoba were in the respective age groups. As in

## Discussion

Degner and Sloan's (1992) study approximately one third of the breast cancer patients had less than high school education. In contrast, the Manitoba needs study found that approximately one half of the cancer patients surveyed (n=526) did not have high school (Vachon et al., 1990).

Of the 743 women who were diagnosed with breast cancer in Manitoba in 1991, 288 (38.8%) had a lumpectomy compared to 518 (69.7%) who had a mastectomy (Whittaker, 1992, personal communication, Manitoba Cancer Foundation Registry). The total number of lumpectomies and mastectomies surpasses the total number of diagnosed cases due to the fact that some patients had both procedures performed. The study sample proportions for each of these treatments are almost the exact opposite of the 1991 statistics. Therefore, this study sample is not representative of the target population. The higher proportion of women who had lumpectomy compared to mastectomy is thought to be due to the fact that patients were recruited from referral centres only. Patients who had a lumpectomy performed are routinely referred to these centres for radiation therapy; patients who have a mastectomy may be referred to

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an oncologist for further treatment, but referral may not be to either of these clinics.

The proportion of women in the 18 to 64 year age group who had a mastectomy (28.8%) or lumpectomy (65.4%) are not representative of the respective target population proportions of 71.3% and 28.7% respectively. The proportion of women in the 65 to 85 year age group who had a mastectomy (36.8%) or lumpectomy (54.5%) are also not representative of the respective target population proportions of 76% and 24% respectively.

Of particular interest is the finding that 54.5% of the women who were 65 to 83 years of age had a lumpectomy. This result, like that of Fallowfield et al., (1989) does not support the assumption that elderly women do not mind losing a breast. They found that 13 of 21 (61.9%) women over 60 years of age who were able to choose their treatment opted for lumpectomy. However, this same conclusion cannot be made for this study sample as the researcher does not know whether the patient or the doctor made the decision about type of treatment.

Since a greater proportion of women from the 65-83 year age category than from the 18-64 year age category assumed a passive role

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in treatment decision making, one might conclude that the decision for a lumpectomy was made by the physician. In contrast, this finding might lend support to those researchers who contend that some physicians tend to treat elderly cancer patients less aggressively (Chu et al., 1987; Samet, Hunt, Key, Humble, & Goodwin, 1986; Mandelblatt, & Fahs, 1988). These interpretations are made cautiously, keeping in mind the non-representativeness of the sample proportions for type of surgical intervention.

## Control Preference Scale

As the time from diagnosis to treatment is usually short, a patient's decision making abilities may be impaired and may lead to uninformed decisions that are regretted later. The impact of a cancer diagnosis and the need to make timely decisions creates enormous stressors that require the sensitivity and support of health care providers. The most effective decision consistent with the patient's value system is less likely to cause regrets and negative psychological outcomes (Cawley, Kostic, & Cappello, 1990).

The findings from the control preferences scale revealed that twice

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as many women would have preferred a collaborative role in treatment decision making than those women who actually stated they had assumed this role. These findings may suggest three possible influences. Firstly, the women may have been overtly or covertly discouraged or prevented from articulating their questions and opinions and thus were not able to participate in a collaborative manner with their physicians. Secondly, the women may have initially assumed a passive role because they were emotionally upset and new to the health care system; whereas, by the time they were interviewed they were more in control and more familiar with the system and thus able to assume a more collaborative role. Another possible reason for the change in roles may be the presence of a social desirability factor. For example, the patient may feel it is more socially acceptable to choose the collaborative role, which depicts the patient and physician shaking hands and being in agreement, over the other possible roles.

In a study by Degner and Sibon (1992) in which the preferences about roles in treatment decision making of 431 (half male and half female) patients recently diagnosed (average 75 days) with cancer were determined, 12.5% preferred an active role, 28.7% preferred a

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collaborative role, and 58.7% preferred that the physician make treatment decisions on their behalf. In comparison, a greater percentage of women in the current study preferred an active (20%) and collaborative (36%) role in treatment decision making. These results may be influenced by the all female sample. Degner and Sloan (1988) found that the men in their study preferred less control than the women.

This trend for women with breast cancer to want a more active or collaborative role in treatment decision making is further supported by an even more recent study of 35 women with breast cancer whose preferences for treatment decision making were assessed using the same control preference cards. Hack (1991) found that 23% of the women preferred an active role, 57% preferred a collaborative role, and 20% preferred a passive role in treatment decision making. Similarly, Hayter et al. (1991) found that although there were no specific questions dealing with alternative forms of treatment, the 7th ranked question was: May I seek a second opinion before consenting to treatment? The authors suggested this importance of seeking a second opinion may indicate the strong desire of most patients to hear about alternatives.

This increasing trend in breast cancer patients' desire for a

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collaborative role in treatment decision making provides a clear message for health care professionals.

### Informational Resources

The participants' three most preferred and actual sources of information about their diagnosis of breast cancer were people sources compared to the written sources of information. These findings are supported by Messerli et al. (1980) who found that 86.2% of 58 mastectomy patients placed greater importance on discussion, counselling, and professional services of mental health workers; while surgeons considered these less important. Similarly, the 58 breast cancer patients in Hopkin's (1986) study most frequently reported receiving verbal information about their disease and treatment from the oncologist, television programs, and the oncology nurse.

Not surprisingly, the physician was the most preferred source of information and the person from whom the study participants most frequently sought information about their diagnosis of breast cancer. Although the nurse was the second most preferred source of information, she/he was the third most frequently sought source of information from

whom patients actually received information about their diagnosis of breast cancer. Friends/relatives were utilized slightly more frequently than the nurse. Previous studies support the important role that friends/relatives play in the overall support system for women diagnosed with breast cancer (Bloom, Pendergrass, & Burnell, 1984; Callwood, 1986; Dierdiarian, 1989; Rice & Szopa, 1988; Smith, Redman, Burns, & Sagert, 1985; and Siegel, 1986). Some of these friends/relatives may have in fact been nurses, as some patients in this study verbalized this while they were checking this category.

Likewise, the following two studies found physicians were more frequently reported as sources of information for breast cancer patients than were nurses. Hopkins (1986) study of 58 breast cancer patients receiving chemotherapy reported the physician in the majority (61.4%) of reported communications, while nurses constituted 29.7% of the communicated messages about their disease, treatment, illness and other information.

Cawley et al. (1990) also found the physician was the primary information provider to the 160 women prior to their lumpectomy surgery. In this same study only 23% of the women reported receiving information



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about their surgery from nurses. In contrast, 56% of the respondents who were given special instructions regarding care of their affected arm after surgery received this information from the nurse while, 43% listed the physician as the information provider.

The findings on the different context and content of communications from nurses and physicians raise some interesting points. Thorne (1988) suggested that since information-giving is basic to nursing practice, patients may not perceive the information from the nurses the same way they perceive information from physicians. This may not be surprising since nurses have historically been viewed in a supportive role to physicians.

People as sources of information were also rated as more important than written or visual materials in Ward et al.'s (1989) study of women who underwent either mastectomy or lumpectomy. An equal percentage (82%) of mastectomy and lumpectomy patients identified the physician among the three most important sources of information in treatment decision making. However, 46% of the women who underwent lumpectomy compared to 18% of those women who underwent mastectomy identified the nurse among the three most important sources

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of information. In other words, the nurse was identified as an important source of information twice as often by women who underwent lumpectomy compared to those women who underwent mastectomy.

Brochures were the fourth ranked preferred and actual source (56.8%) of disease related information after the people sources. The higher the level of education of women in this sample, the more relevant a medical journal as a source of disease related information became. Similarly, Jones et al. (1982) found that more educated cancer patients and their relatives were more likely to prefer information in writing.

## Information Needs: Thurstone Scaling

Likelihood of cure and extensiveness of the disease were the two highest ranked information needs of women in this study. Cassileth et al. (1980) found that more than 50% of the 256 cancer patients also said they needed information about likelihood of cure and the extensiveness of the disease. Having information about different types of treatments was ranked number three by the women in this study. The increasing desire for this kind of information by cancer patients was also evident in other recent studies ( Barton, Fowble, & Wickerman, 1987; Levy,

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Herberman, Lee, Lippman, & d'Angelo, 1989; Pierce, 1988). The findings clearly demonstrated that these women with breast cancer wanted honest, direct and complete information about their disease from the physician.

Slevin (1987) suggested that physicians avoid communicating bad news for the following reasons: talking to patients about diagnosis and prognosis would precipitate a state of depression; because of limited time, communicating may be considered low priority when competing with medical treatment; and physicians who have not come to terms with their own feelings about illness and dying may experience considerable embarrassment and feel ill at ease when discussing the subject.

Although the commonest complaint that patients make about the medical profession is not being told what is wrong, patients are reluctant to criticize their physicians and consequently physicians get little feedback (Slevin, 1987). These results provide physicians with important feedback, in a positive manner, about what kind of information this sample of women considered most important after hearing about their diagnosis of breast cancer.

Contrary to much of what has been written about the importance

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of sexual issues in cancer treatment, this group of women recently diagnosed with breast cancer ranked information about how their treatment would affect their body and sexual attractiveness as least important. The low ranking of the need for information about sexuality and self care may be due to the fact that these participants, all within 131 days of diagnosis, were still dealing with the life and death concerns associated with a new diagnosis of cancer. This rationale is supported by the following authors.

According to Griffith-Kenny (1986), in the early phases of treatment an emotional dichotomy often prevails and the woman experiencing a mastectomy deals with either the cancer or the breast loss. Weisman and Worden (1976) suggested the first 100 days of the cancer experience is a distinct phase through which all patients pass. They refer to this period as a time of "existential plight," when the impact of becoming a cancer patient takes precedent over all other aspects of daily life. Similarly, Gordon et al. (cited in Edlund & Sneed, 1989), who studied the concerns of 308 patients with cancer over a six month period following diagnosis, found that the most frequent concern during initial hospitalization was worry about the disease. At three and six month

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intervals, subjects' concerns were more broadly distributed among physical, psychosocial, and financial issues. Since the current study participants' average length of time from diagnosis to testing was 58 days, it may have been too early for participants to start dealing with concerns about their sexuality.

The possible significance of timing in relation to patients' expressed concerns about sexuality was also evident in the study by Fallowfield et al. (1989) which tested patients at two weeks, 3 months, and 12 months. Irrespective of surgical treatment, the results of a single self report item on the Rotterdam symptom checklist showed well over one quarter of the total sample (n=269) experienced loss of sexual interest. Although the authors do not clarify if this is a cumulative or single point result, one might conclude that the 12 month assessment point influenced these findings.

In the current study, another factor possibly influencing the low ranking of the information statement about their body and their sexual attractiveness is the wording of the statement. Ward et al. (1989) noted that although their participants' second frequently expressed reason for type of surgical choice was concern about body integrity, they did not

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speak spontaneously of concern about breast loss in terms of sexuality. Therefore, patients in this study may have identified more with this item if it had been worded more generally; for example, information about the possible effects of treatment on the body.

The hierarchial ranking of these women's information needs are also congruent with Derdarian's (1987) theoretical framework based on Lazarus's postulation that the information needed may be relevant to the amount, imminence, and likelihood of occurrence of anticipated harm. For example, information related to stage of disease, likelihood of cure, and treatment options was deemed more important than the physical and emotional impact of the disease on family and friends or the side effects of treatment. These events are more imminent and likely to occur than those related to how to handle family and friends or the side effects of treatments. Furthermore, the hierarchial rankings are congruent with Maslow's hierarchy of needs. Information about stage of disease and likelihood of cure were more definitive of the patient's survival than information about family and friends; therefore, they were ranked higher.

Participants ranked information about the side effects of treatment and the impact of the disease on family and friends as more important

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than information about how the treatment may affect their social activities. Therefore, the degree of relevance of information about these personal concerns may also be congruent with the importance, imminence, and likelihood of occurrence of anticipated harm and with the degree of association of the harm with the patient's physical and psychological survival. For example, the threats related to side effects of treatment and the impact on family and friends were more important, imminent, and likely to occur and likewise, more closely associated with survival than those concerns related to social activities. These findings suggest that recently diagnosed breast cancer patient's informational needs may be determined by the hierarchy of needs as well as the amount, imminence, and likelihood of harm.

Thurstone's method of paired comparisons has been successful in eliciting the rank ordered profiles of information needs for these women recently diagnosed with breast cancer, thus eliminating the "ceiling effect" of patients desire for maximal information about every item. The "ceiling effect" was controlled for by asking women to make forced choices between the pairs of information needs.

Internal Judge Consistency - Circular Triads

Discussion of possible reasons for the circular triads will follow, guided by Edward's (1974) suggested reasons for such inconsistencies in comparative judgements. The trio - of information need (#1), (#2), and (#8), will be considered first. Information about (#1) and (#2) would assist women in clarifying the seriousness of their disease. Edwards (1974) suggested that statements may fall so close together on the psychological continuum that the judgements are exceedingly difficult to make. Although these statements do not fall close together on the value scale, this rationale may be partially true as they are the two top ranked information needs.

The reason that participants in this study were inconsistent in their comparative judgement of information need (#8), and (#1) and (#2) is less clear. Perhaps this statement did not fall along the same single dimension on which it was scaled. In other words, this statement involves information about how this disease will affect someone other than the participant herself. Only one other statement, (#4), also relates to how the disease will affect someone other than the participant herself. Interestingly, this (#4) statement was the single statement that was



involved in the most number of circular triads.

The study participants rank ordered these two statements, (#4, #8), as their fourth and fifth most important information needs. Verbal comments from several participants about their need to be selfish and consider themselves first lends support to the possible dilemma between concern for self or others.

Another possible reason that may have caused participants to be inconsistent in this comparative judgement is that it is the only judgement that involves information that may not need to be considered until a future date. For example, women who have only young children may not consider this information important at this time, as they may think the children are too young to be at risk.

The trio - of information needs (#1), (#3), and (#7) will now be discussed as to possible reasons for participants' inconsistencies in their judgements of these items. Since information need (#1) and (#7) were rank ordered as the first and third most important needs of study participants, it would suggest they were fairly equal in importance, and therefore it was difficult to make consistent choices between them. Although information need #3 was rank ordered as the seventh most

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important information need by study participants, information need #3 and #7 both relate to type of medical treatment. The fact that information need #3 is ranked less important than #7 makes sense in the logical sequence of events in the patient's disease trajectory.

## Test of Hypotheses

Overall, the profiles of information needs for each of the hypothesized patient groups were remarkably similar. Women who preferred active/collaborative roles in decision making about mastectomy versus lumpectomy/radiation ranked the information needs the same. In other words, even though some patients preferred that the physician make the decision about their surgical intervention they valued the same information as those patients who preferred a more active role. These findings support Sutherland et al.'s (1989) conclusion that patients may desire information, not only to enable them to participate in treatment decision making, but also to maintain psychological autonomy.

This study also found that a greater proportion of women from the age category (65-83) years than from the age category (18-64) years

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assumed a passive role (category D & E) in treatment decision making. Since this older age group of women may also be less likely to communicate their information needs nurses/physicians should take particular note of this finding.

The overall profiles of information needs were the same for women who had less than high school education as they were for women who had high school education or greater than high school education. However, one scale value involving information about caring for oneself at home differed among these groups. Women with high school education valued this information more than did the women with greater than high school education.

Similarly, elderly women 65 to 83 years, ranked this information need as more important than did women 18 to 64 years. Otherwise, their profiles of information needs were the same. For the elderly women at risk of facing other physical and financial losses at this time in her life, concern about caring for oneself at home is valid.

Interestingly, women who had a mastectomy provided the same profiles of information needs as women who had a lumpectomy.

Previous research studies (Ward et al., 1989; Fallowfield et al., 1990;

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and Larsey et al., 1987) suggested there might be differences in the need for information about how the treatment may affect their feelings about their body and their sexual attractiveness.

## Implications For Practice

The implications of this study for practice are numerous. Although the study has implications for many health professionals, the focus of this discussion will be on those implications for nursing practice.

For the woman who has doubts about a proposed treatment, the nurse can serve as a client advocate. Despite the seriousness of the illness, the time constraints, and expense involved, the woman may need to be supported in her desire to seek a second opinion. A consultation with a plastic surgeon, an oncologist, and a radiologist prior to a decision about treatment is the ideal, rather than the usual. The nurse may assist the woman in clarifying her values, defining her alternatives, and seeking additional information. The study results confirmed that women recently diagnosed with breast cancer ranked information about different types of treatments and the advantages and disadvantages of each treatment as a priority.

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The professional nurse who is responsible for inpatient or outpatient primary care can often be instrumental in initiating and/or supporting a multidisciplinary treatment focus that involves the woman and her partner. The nurse should also be available to patients and/or their family members when their physicians visit. This support may bolster the women's confidence to pursue questions they want answered and reinforce information they may not have fully grasped. Recognizing and supporting such assertiveness relevant to patient care is of extreme importance. Nurses must feel comfortable and confident in their role before they can help patients assert their rights. According to Deck and Palmer (1987), a feedback loop is created wherein nurses first give themselves permission to act assertively, then give this permission to patients who, by asserting themselves successfully, in turn enable nurses to feel an increased measure of growth.

The personal experience of illness has long been known to stimulate feelings of helplessness and fear. According to Wilson (1979), during crisis, the female patient will be more receptive to those interventions which promote growth and change. Physicians/nurses can use the crisis state of a recent diagnosis of breast cancer for patient

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growth, by collaborating with patients during the treatment decision making process. Patients take cues about appropriate role behaviour from doctors and others with whom they interact. Therefore, doctors' and nurses' perceptions of acceptable patient participation in the interaction will be consciously or unconsciously evaluated by the patient, and will very likely influence their information seeking behaviour.

Nurses and physicians must keep in mind how much these patients value their personal contribution in the information sharing process. Therefore, they should be selective about personally providing that information which patients most highly value. The less important information could then be included in written and/or visual form.

Nurses often do not distinguish between nursing generated information and advice, and physician generated information and advice. Nurses also often incorporate their information-giving into their routine nursing care rather than identifying a separate information-giving event. In contrast, the interaction with the physician is seen as a specific event, as patients make a specific appointment to seek information from the physician. Regardless of whether nurses wish to be recognized for their unique or collaborative professional contribution in the area of patient

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information sharing, perhaps they need to be more articulate about their source of information. For example, nurses may need to clarify between physician driven information and advice and information given as a result of clinical/research nursing experience and knowledge.

The high useage of brochures as actual and preferred sources of information signifies the single most popular method of providing women with written information about breast cancer. If women are relying on this form of educational material, the health care professional must ensure the information is current, complete and clear. Health professionals must also ensure the principles of adult education and appropriate literacy reading levels are incorporated into the development of such brochures. In preparing materials and presenting programs to the elderly female population, nurses need to pay special attention to specific strategies to overcome certain barriers. For example, written brochures should be in large print to better accommodate the loss of visual acuity of this particular group.

Availability and accessibility of such information are two important issues. The study participants as well as many cancer patients in the Manitoba needs study expressed "unmet" needs in these areas (Vachon

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et al., 1990). The challenge of meeting these needs involves not only increased availability, but also increased accessibility. Physician's offices, day surgery departments and mammography units are crucial areas for women to access this information. Physicians and nurses must work collaboratively to ensure patients have the opportunity to avail themselves of a variety of current educational material.

The frequency with which subjects reported getting information from television, newspapers, and women's magazines suggests nurses also acknowledge these as potential sources of information and try to influence their content and quality. Nurses can empower women while they are well, offering their speaking services at women's groups and clubs. Nurses can further increase public awareness of treatment alternatives by writing articles in popular women's magazines and participating in health fairs. This increased exposure will heighten the public's awareness of nurses' sensitivity, caring, and commitment to meeting the information needs of women.

Traditionally, cancer related information has been conveyed in written form, through pamphlets and brochures. However, the Manitoba needs study suggested that more attention should be paid to alternate



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ways of dispensing information; for example, video or audio tapes, telephone information lines, illustrated books with low-vocabulary captions (Vachon et al. 1990). The importance of audio-visual information sharing programs was also supported in this current study; as the age of women increased so too did the value of television/radio as a source of disease related information. Availability, decreased visual acuity, and reduced information processing ability may be contributing factors in older women's preference for audio-visual information compared to written information.

Interestingly, there was not strong support for use of videotapes in either the preferred or actual sources of information. This may in fact be due to lack of supply of appropriate videos and also the uniqueness of the idea. Although only three women indicated they had utilized video material to acquire information about their breast cancer diagnosis, it was ranked as the sixth most preferred source of information. Increased development and exposure of pertinent video material in our society may influence these preferences in the near future.

Since the content of an educational program is equally important as the type of equipment used, the profiles of information needs will

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provide direction for the critique of current educational programs for newly diagnosed breast cancer patients as well as for development of more up to date programs.

Keeping in mind the tentativeness of these study findings and the proposed shift in the focus of health care to the community, health professionals must recognize that the professional followup of these women in the community could be a crucial aspect of their total care and long range recovery. Nurses in outpatient oncology clinics can be instrumental in identifying and meeting the continuing information needs of women who may or may not require further adjuvant therapy. Prior understanding of the priority information needs of women recently diagnosed with breast cancer will assist physicians and nurses to meet these needs more effectively. In times of cost restraints, increased patient workload, and shorter patient stays, an advanced understanding of the needs of this patient population could be rewarding for both the patient and the health professional.

When patients recover from surgery for a malignant breast cancer, they leave hospital care, but their battle with cancer is just beginning. The road to recovery can be long. Nurses can be instrumental in

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providing these women with a friend for this journey: a Reach to Recovery visitor. The Reach to Recovery program should include lumpectomy patients and should likewise have visitors who have had the same type of surgery. The findings from this study serve to heighten nurses' awareness of including older women in this program as well. Their information needs differ from those of younger women only in the area of ranking information about caring for themselves at home as more important. Encouraging and supporting older women to become Reach to Recovery visitors could be very reassuring for newly diagnosed patients of their own age group and could also be very rewarding for the elderly visitor herself.

This apparent universality of information needs among this particular population of cancer patients would certainly facilitate the information sharing process. However, further research with a larger sample size is required to confirm or refute these findings.

## Implications For Research

Although study participants did not rank videotapes as an important source of disease related information, many current

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educational programs are advocating this type of information sharing technique. According to Marchant (1982), visual aids in teaching are helpful not only to dispel any unnecessary fears but also to give the patient and her partner an idea of what changes to expect either in anatomy or function. However, in Ward et al.'s (1989) study, although 36% of the women who underwent mastectomy (n=11) found the clinic videotape among the three most important sources of information, none of the women who underwent lumpectomy (n=11) did so. Since the authors offered no discussion about this finding, one can only guess about possible reasons for such marked differences in this patient population. Perhaps those patients who chose not to have a mastectomy did so because of what they saw on the video. However, they may not have consciously realized this or wanted to admit this fact. This may be a plausible explanation, considering the concern about body integrity was the participants' second most frequently expressed reason for surgery choice. Although a small study sample, these previous findings, in combination with this study's current findings, suggest further research is necessary to determine the desire for and effectiveness in providing women recently diagnosed with breast cancer with information

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by video.

Study results identify the types of information that are most important to women recently diagnosed with breast cancer, but the exact amount and content of this type of information requires further investigation.

Current and proposed changes to the health care system pose implications for the ways nurses reach and communicate with the breast cancer patient and her family. For example, patients are going home from hospital sooner and sooner, decreasing the amount of time nurses have to assess and assist in meeting the information needs of patients in relation to their physical and emotional adjustment. Just as the type of teaching strategy must differ at different periods in the patient's adjustment period (Fredette, 1990) so too might the patient's information needs. A longitudinal study would better enable health professionals to understand these patients' ongoing information needs.

The study sample did not have enough patients in the Stage III and IV categories to assess differences in information needs of patients with different stages of breast cancer at time of diagnosis. Therefore this variable as it relates to information needs requires further research.

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The study findings support previous research that found that elderly patients prefer a passive role in treatment decision making. However, the elderly women in this sample had virtually the same information needs as younger women. Despite the fact that surprisingly little is known about the biological or psychological response of the elderly to cancer as a disease or to the effect of cancer treatments (Given, & Given, 1989), many studies have found that age is a strong determinant of professionals' choices of cancer treatment (Celentano, Shapiro, & Weisman, 1982; and Foster, Long, Costanza, Worden, Haines, & Yates, 1978). Delay in seeking diagnosis has been attributed to lack of knowledge of the importance of the symptom (attributing it to normal aging), educational and attitudinal barriers to obtaining information about proper care, social isolation, and pessimistic and fatalistic attitudes about disease and treatment (Holland, & Maisse, 1987; Rimer et al., 1983; Weinrich & Weinrich, 1986). This combination of findings suggests that systematic knowledge about age-related management of elderly patients with cancer is needed. Specifically, further research about information needs and appropriate sources of information for elderly women diagnosed with breast cancer is required.

### Study Limitations

The participants were asked to rank order the kinds of information needs judged to be important by the researcher as a result of previous research studies. Although these information needs were identified in the literature as important, they may reflect a certain degree of bias and preconceptions by the researcher. Therefore, the participants were given an opportunity to describe the kinds of information they would have liked to have access to.

The readability level of the information needs statements was found to be Grade XIV according to the SMOG methodology. In view of the fact that one third of the participants had less than a high school diploma education, this readability level may have been a limitation of the study. This limitation may have been partially controlled for by the researcher's presence during the completion of the questionnaire. If participants did not understand the information needs, one would expect they might be inconsistent in their comparative judgements of these items. However, the mean coefficient of consistence (zeta) of 0.99 suggests that the participants were consistent in their selection of the paired comparisons.

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Although the researcher was present during the completion of the questionnaire and told participants to ask if there was anything they did not understand, few questions were asked. This lack of questions provides further evidence that study participants had no difficulty understanding these information items.

The presence of the researcher may have in some way created general psychological reassurance and thus prompted the participants to respond to the questions differently than if they had been alone. The researcher's presence may also have influenced the participants to respond to the questionnaire in what they thought was a socially desirable manner. For example, participants may have over rated their preference for information from the nurse in hopes of pleasing the nurse researcher. Many patients believe that they must be seen by therapeutic staff as non-demanding, non complaining, non-assertive, and compliant if they are to receive optimal attention (Reynolds, Samson-Fischer, Poole, Harker, & Byrne 1981).

The health care setting in which the interview took place may also have had some unknown effect on how they responded to the questionnaire. For example, the participants may have been attending



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the clinic for the first time and may, therefore, have been reluctant to express their true opinions. In contrast, some participants may have viewed this as an opportunity to express their opinions more freely as this clinic visit may be a one time only consultation.

When interpreting and comparing these study findings to those of previous studies, one must keep in mind that although previous research findings have suggested that certain information was important to this patient population, the actual degree of importance may not have been investigated.

The retrospective nature of the identification of priority information needs may have been a limitation to the accuracy of the study findings. Participants were asked to think back to when they were first told about their diagnosis of breast cancer when choosing the most important information between the paired comparisons. However, they may have been influenced by their immediate information needs and these needs may have been different than those immediately after diagnosis.

The large number and repetitious nature of the paired comparisons of information needs may have been a study limitation.

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Participants were told about the repetitious nature of the paired comparisons, and that each pair was a different comparison and must be considered independently of previous comparisons. However, some participants may have tried to remember what they had answered previously in order to appear consistent in their choices, or they may have altered their selection trying to avoid being repetitious. Others may have become disinterested and therefore inaccurate in their selections.

The rank ordering for information about how at risk children and/or other family members are of developing the disease is difficult to interpret as patients were not asked if they had children or family members to whom this information might apply.

The non-representativeness of the sample in relation to the proportion of women in the age, treatment, and stage III and IV categories is also a study limitation. The generalizability of the study findings is limited because of the non-probability sampling technique used.

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A. DERDIARIAN

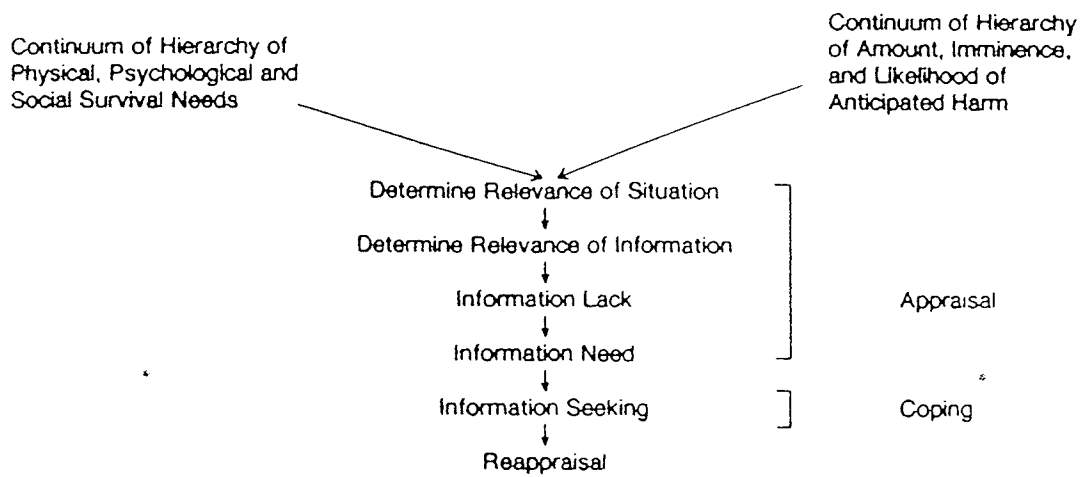
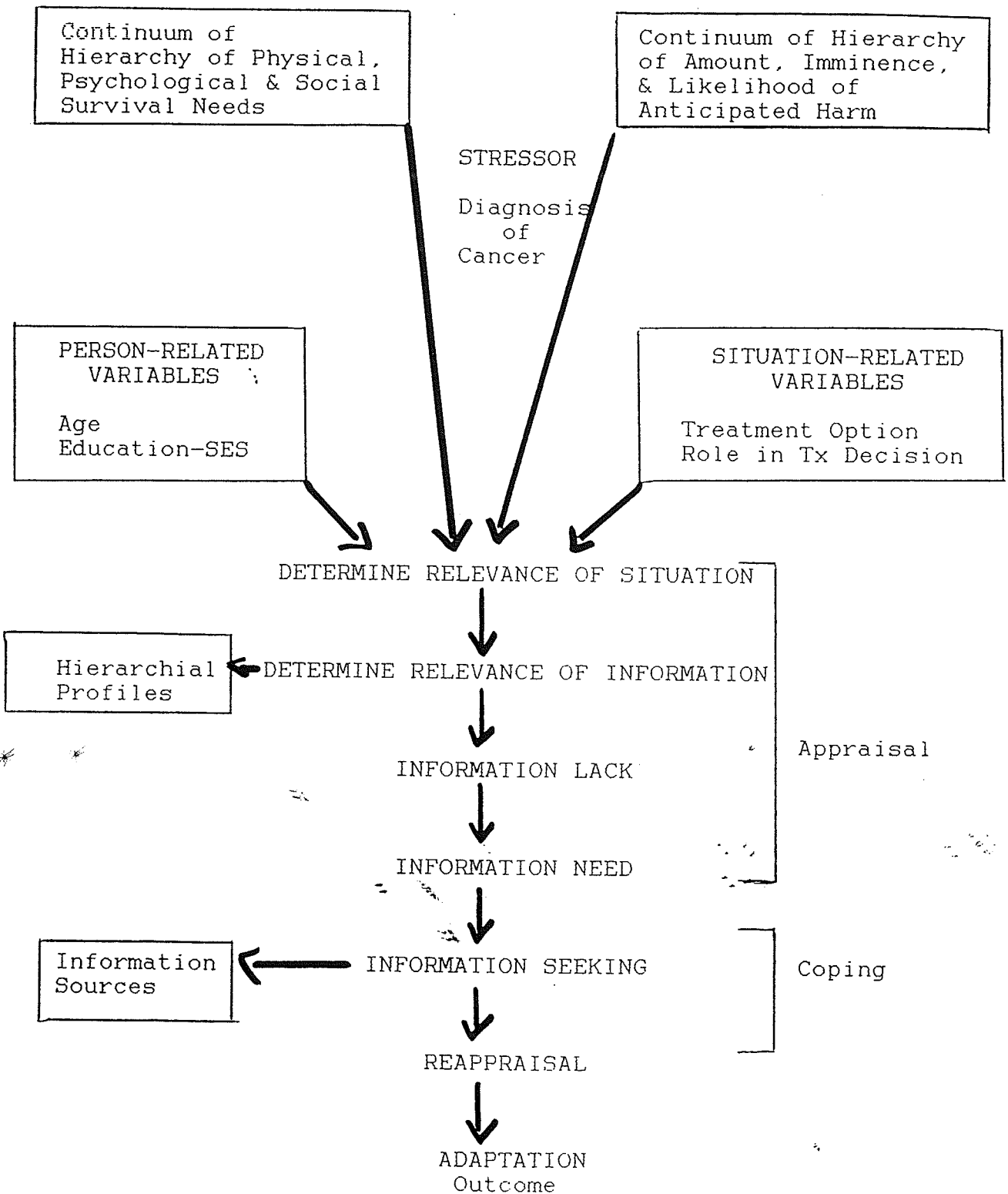


FIG. 1. The relationship of hierarchy of needs and hierarchy of amount, imminence, and likelihood of anticipated harm and informational needs.



Adapted from Derdiarian, A. (1987a). A theoretical framework.



**Manitoba Cancer Treatment and Research Foundation**  
M.R. MacCHARLES UNIT  
100 Olivia Street • Winnipeg, Canada R3E 0V9

July 15, 1991

Barbara Bilodeau R.N. - B.N.

Winnipeg, Manitoba

Dear Barbara,

RE: HIERARCHIAL PROFILES OF INFORMATION NEEDS OF WOMEN RECENTLY DIAGNOSED  
WITH BREAST CANCER.

---

On behalf of Dr. Martin Levitt, Director of the Clinical Investigations Office,  
approval has been given for you to proceed with the above mentioned project.

We wish you success in your endeavours.

Sincerely,

Erna Stiles  
Office Manager  
Clinical Investigations Office

es





Hôpital général St-Boniface General Hospital

August 13, 1991

Ms. Barbara Bilodeau  
62 Carlotta Crescent  
Winnipeg, MB R3R 2L7

Re: Access to SBGH Approval

Dear Ms. Bilodeau:

I am pleased to inform you that your project:

Hierarchical profiles of information needs of women recently diagnosed with cancer

has been approved for access to St. Boniface General Hospital patients, according to the protocol you have outlined. Approvals have been received from the nursing and medical heads of Medicine and Gynecology, myself, and Ms. Jan Dick, VP Nursing.

Your findings will be of interest and value to SBGH, and we look forward to the knowledge it may add to patient care.

Please feel free to access the facilities of the Nursing Research Space when you are on site. We will be happy to facilitate your project in any way possible.

Contact me at 235-3480 with any questions you have now or as the work proceeds.

Sincerely,

Eleanor J. Adaskin, RN, PhD  
Director of Nursing Research

EA/mj

The University of Manitoba  
SCHOOL OF NURSING  
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number #N91/17

Proposal Title: "Hierarchical Profiles of Information Needs of Women  
Recently Diagnosed with Breast Cancer."

Name and Title of  
Researcher(s): Barbara Bilodeau  
Master of Nursing Graduate Student  
University of Manitoba School of Nursing

Date of Review: June 03, 1991.

APPROVED BY THE COMMITTEE: JUNE 03, 1991.

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Date: June 12, 1991 \_\_\_\_\_  
Erna J. Schilder, RN, DNS                      Chairperson  
Associate Professor  
University of Manitoba School of Nursing  
Position

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

Revised: 91/01/11/se

### Explanation of the Study to Subjects

My name is Barbara Bilodeau. I am a graduate student in nursing at the University of Manitoba. I am inviting you to participate in a research study that I am conducting as part of my thesis. I have worked in the area of women's health care for several years. From this past experience, I have developed a keen interest in the information needs of women, like yourself, who have been diagnosed with breast cancer. My study will look at what information would be most helpful to women within the first three months of finding out they have cancer. The intent of this study is to find out what patients want to know about first, so that physicians/ nurses and other health professionals will be able to provide this information more quickly and completely.

Prior to collecting this information I would like to have a brief discussion with you to explain the details of the study, to give you an opportunity to ask questions, to review the consent form, and to help you make your decision about whether or not you would like to participate in the study. If you decide to participate you will be asked to read and sign a consent form.

Then you will be asked to complete a four part questionnaire which will take about thirty minutes. I will assist you with Part A of the questionnaire which asks you which of five potential roles in Treatment Decision Making, you prefer and which role you actually assumed. You will then be asked to complete the remaining three parts of the questionnaire on your own, although, I will be present if you have any questions. Parts B and C ask you for background information, such as your age and from whom you received information about your disease. These particulars will help me understand the information needs of the patients who consent to participate.

Part D of the questionnaire presents you with several different pairs of questions which women might want to ask their physician/nurse about their disease. You will notice that several of the questions are the same but are presented in different pairs. From each of these pairs of questions you will be asked to select the question that you want answered first. There is no right or wrong answer as this is your own personal opinion. This method has potential for identifying which of these questions different groups of women would want answered first by their physician/nurse. Lastly, you will be asked if you have any other important information needs.

It is important that you understand that you are under no obligation to participate in this study. If you decide to participate, you may refuse to answer any of the questions, and you may withdraw at any time. There is no anticipated benefit to you if you do choose to participate; however, in the future, women diagnosed with breast cancer may in some way benefit.

## Patient Consent Form

The present research project entitled "Hierarchical Profiles of Information Needs of Women Recently Diagnosed With Breast Cancer," is being conducted to gain knowledge about the priority information needs of women recently diagnosed with breast cancer. Barbara Bilodeau, a graduate student in nursing, University of Manitoba, is conducting this research as the basis for her thesis. Dr. Lesley Degner, Professor, School of Nursing, University of Manitoba, is the thesis advisor.

If you decide to participate in this study, you will be asked to complete a questionnaire designed to obtain your opinion of the most important information needed about your recent diagnosis of breast cancer. The questionnaire will take approximately 30 minutes to complete. You will also be asked to indicate which of five possible roles in treatment decision making is your preferred role, and which is the role you actually assumed in decision making. How you would prefer receiving information about your disease will also be asked. The questionnaire is not a test of your knowledge, but rather, is asking your opinion of what information about your disease is most important.

To ensure confidentiality, you will be asked **not** to write your name on the questionnaire, and your consent form will be kept separate from your questionnaire. Therefore, your name will not be listed in any research paper that may be written for this study.

You are under no obligation to participate in this study. Your participation or non-participation will have no influence on your medical treatment. If you decide to participate, you may refuse to answer any of the questions, and you may withdraw at any time.

If you have any questions now, please feel free to ask. If you have any questions or concerns about the research at a later date, again please ask. You may contact the researcher Barbara Bilodeau at 895-9551 or her advisor Dr. Lesley Degner at 235-3482.

---

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

---

Signature of Patient

---

Date

---

Signature of Investigator

---

Date

Hierarchical Profiles of Information Needs of Women Recently Diagnosed with Breast Cancer.

Instructions: Please read all the questions and answer them as directed in each section. Your response to all of the questions is very valuable. The survey will take 30 minutes of your time.

---

A. Control Preference Scale:

PREFERRED ROLE IN TREATMENT DECISION MAKING: \_\_\_\_\_

ACTUAL ROLE IN TREATMENT DECISION MAKING: \_\_\_\_\_

(Choose your answer from the choices below; mark the number of your choice on the line.)

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

B. Sociodemographic Data:

1. What is your age? \_\_\_\_\_ years. (Fill in the blank)
2. Time since diagnosis \_\_\_\_\_ days. (Fill in the blank)

Circle the correct answer for each of the following:

2. Educational level: a) less than high school diploma  
c) high school diploma  
d) greater than high school
3. Stage of disease: Stage 1, 11, 111, or 1V.
4. Treatment plan: mastectomy or lumpectomy.

C. **Informational Resources:**

1. From which of these sources would you **most prefer** to get information about your disease? Please put number 1 beside your first choice, number 2 beside your second choice and so on to number 9 for your last choice.

Womens Journal	_____
Friend/Relative	_____
Physician	_____
Medical Journal/Text	_____
Nurse	_____
Television/radio	_____
Newspaper	_____
Brochure	_____
Video tape	_____

2. From which of these sources **did you get** some information about your disease? Please **circle** each one that you used.

Womens Journal
Friend/Relative
Physician
Medical Journal/Text
Nurse
Television/radio
Newspaper
Brochure
Video tape

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D. **Information Needs:**

From each of the following pairs, circle the one that you would want to know about first.

- Information about the diagnostic stage of the disease and the extent of involvement of the disease.
- Information about the likelihood of cure from the disease.
- Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
- Information about possible unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).
- Information about how to handle the physical and emotional impact of the disease on the family, and significant others.
- Information about how at risk my children and/or other family members are of developing the disease.

5. Information about caring for myself at home (for example: nutrition, support groups, home care, social worker, mental health worker).
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.
6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
2. Information about the likelihood of cure from the disease.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).
4. Information about how to handle the physical and emotional impact of the disease on family, and significant others.
8. Information about how at risk my children and/or other family members are of developing the disease.
5. Information about caring for myself at home (for example: nutrition, support groups, home care, social worker, mental health worker).
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.
6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
4. Information about how to handle the physical and emotional impact of the disease on family, and significant others.
2. Information about the likelihood of cure from the disease.

5. Information about caring for self at home (for example: nutrition, support groups, home care, social worker, mental health worker).
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).
6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
8. Information about how at risk my children and/or other family members are of developing the disease.
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.
1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
4. Information about how to handle the physical and emotional impact of the disease on family, and significant others.
2. Information about the likelihood of cure from the disease.
5. Information about caring for myself at home (for example: nutrition, support groups, home care, social worker, mental health worker).
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).
6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
8. Information about how at risk my children and/or other family members are of developing the disease.
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.
1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
4. Information about how to handle the physical and emotional impact of the disease on family, and significant others.



5. Information about caring for myself at home (for example: nutrition, support groups, home care, social worker, mental health worker).
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
2. Information about the likelihood of cure from the disease.
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).
8. Information about how at risk my children and/or other family members are of developing the disease.
1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
4. Information about how to handle the physical and emotional impact of the disease on family, and significant others.
5. Information about caring for myself at home (for example: nutrition, support groups, home care, social worker, mental health worker).
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
2. Information about the likelihood of cure from the disease.
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).
8. Information about how at risk my children and/or other family members are of developing the disease.

1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
5. Information about caring for myself at home (for example: nutrition, support groups, home care, social worker, mental health worker).
6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
4. Information about how to handle the physical and emotional impact of the disease on family, and significant others.
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3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
8. Information about how at risk my children and/or other family members are of developing the disease.
2. Information about the likelihood of cure from the disease.
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).
1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
5. Information about caring for myself at home (for example: nutrition, support groups, home care, social worker, mental health worker).
6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prosthesis, reconstructive surgery).
4. Information about how to handle the physical and emotional impact of the disease on family, and significant others.
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.

3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
8. Information about how at risk my children and/or other family members are of developing the disease.
  
2. Information about the likelihood of cure from the disease.
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, change in physical appearance).

Can you suggest any other information needs you may have about your disease?

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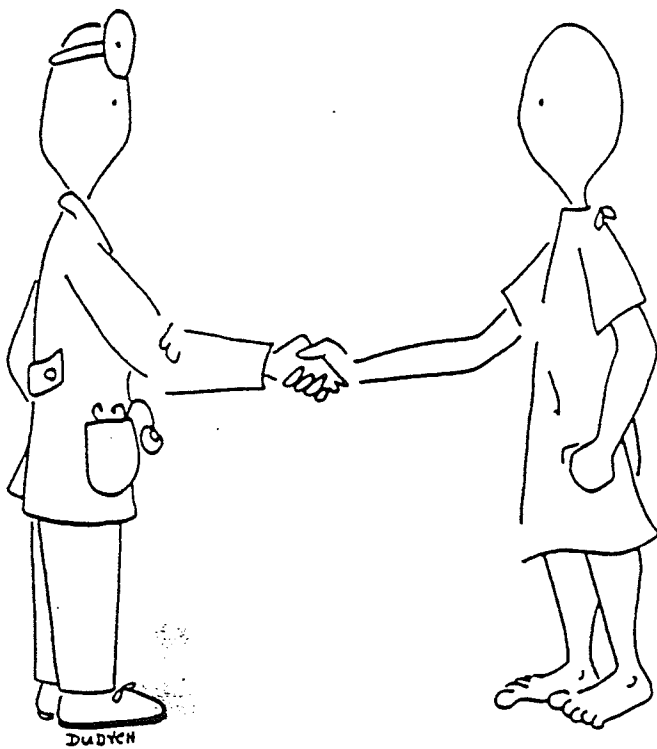
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I PREFER TO MAKE THE FINAL SELECTION  
ABOUT WHICH TREATMENT I WILL RECEIVE.



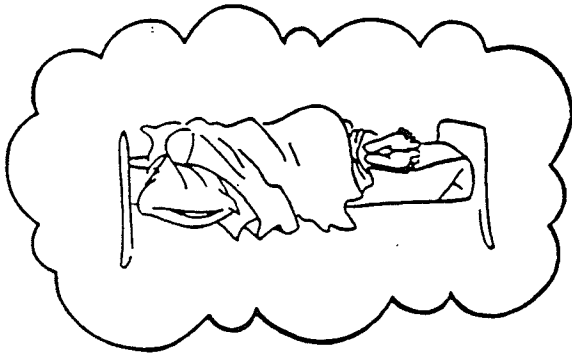
I PREFER TO MAKE THE FINAL SELECTION  
OF MY TREATMENT AFTER SERIOUSLY  
CONSIDERING MY DOCTOR'S OPINION.



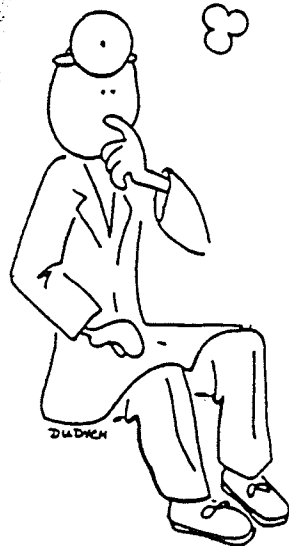
I PREFER THAT MY DOCTOR AND I  
SHARE RESPONSIBILITY FOR DECIDING  
WHICH TREATMENT IS BEST FOR ME.

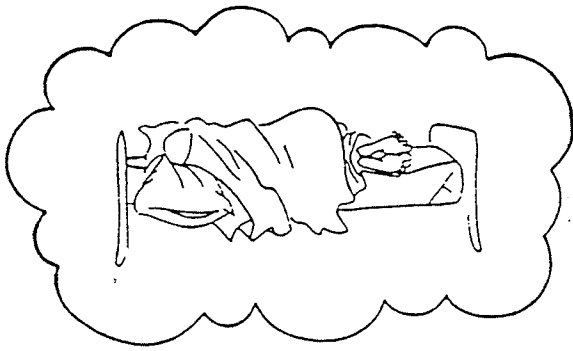


I PREFER THAT MY DOCTOR MAKES THE FINAL DECISION ABOUT WHICH TREATMENT WILL BE USED, BUT SERIOUSLY CONSIDERS MY OPINION.



I PREFER TO LEAVE ALL DECISIONS REGARDING MY TREATMENT TO MY DOCTOR.





I PREFER THAT MY PHYSICIAN ALONE  
MAKES ALL OF THE DECISIONS  
REGARDING MY TREATMENT.



I PREFER THAT MY DOCTOR MAKES  
THE FINAL SELECTION OF MY  
TREATMENT BUT CONSIDERS MY  
FAMILY'S OPINION.

Information Needs Of Women Recently Diagnosed With Breast Cancer:

1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
2. Information about the likelihood of cure from the disease.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
4. Information about how to handle the physical and emotional impact of the disease on family, and significant others.
5. Information about caring for self at home (for example: nutrition, support groups, home care, social worker, mental health worker).
6. Information about how the treatment may affect my usual feelings of physical and sexual attractiveness (breast disfigurement, breast prothesis, reconstructive surgery).
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.
8. Information about how at risk my children and/or other family members are of developing the disease.
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, alteration in physical appearance).



## ROSS'S METHOD OF OPTIMAL ORDERING

With a total of 9 items, the total number of possible pairs was 36. The order within the pairs and the overall order of all the pairs was determined using Ross's "Optimal orders in the method of paired comparisons". This method ensured that the maximum spacing for the maximum number of items was obtained. Whether or not the spacing or ordering makes a difference in the choices of subjects has not been proven. It seems reasonable to assume, however, that the further the items are separated the smaller the chance for a selection bias. A matrix provided the basis for ordering items for presentation.

First all items were numbered, in this case from 1 to 9. As determined by Ross's method, there were 5 rows and 8 columns in the matrix. In the fifth row, the first pair in the first column was an identical pair. Other identical pairs appeared in this row in all the odd numbered columns. The other pairs in the fifth row were repetitions of pairs already found on the matrix. Ross's rules that governed the use of the pairs in the fifth row were as follows: a) The second number in each identical pair was replaced with the number 1. b) The pairs occurring in the even columns of the fifth row were ignored. Finally, the order for the presentation was determined by reading down the column and then moving to the right column by column.

The Ross Matrix: The format

I	II	III	IV	V	VI	VII	VIII
1-2	2-3	1-3	3-4	1-4	4-5	1-5	5-6
3-n	n-4	4-2	2-5	5-3	3-6	6-4	4-7
4-(n-1)	(n-1)-5	5-n	n-6	6-2	2-7	7-3	3-8
5-(n-2)	(n-2)-6	6-(n-1)	(n-1)-7	7-n	n-8	8-2	2-9
6-(n-3)	(n-3)-7	7-(n-2)	(n-2)-8	8-(n-1)	(n-1)-9	9-n	

The Ross Matrix: Applied

I	II	III	IV	V	VI	VII	VIII
1-2	2-3	1-3	3-4	1-4	4-5	1-5	5-6
3-9	9-4	4-2	2-5	5-3	3-6	6-4	4-7
4-8	8-5	5-9	9-6	6-2	2-7	7-3	3-8
5-7	7-6	6-8	8-7	7-9	9-8	8-2	2-9
6-1		7-1		8-1		9-1	

## Order of Items

1. Information about the diagnostic stage of the disease and the extent of involvement of the disease.
2. Information about the likelihood of cure from the disease.
3. Information about how the treatment may affect my ability to carry on my usual social activities (sports, or hobbies etc.)
9. Information about possible unpleasant side effects of treatment (for example: nausea, pain, alteration in physical appearance).
4. Information about how to handle the physical and emotional impact of the disease on the family, and significant others.
8. Information about how at risk my children and/or other family members are of developing the disease.
5. Information about caring for self at home (for example: nutrition, support groups, home care, social worker, mental health worker).
7. Information about different types of treatments (surgical, chemotherapy, radiotherapy) and the possible benefits and risks associated with each treatment.

## Frequency Matrix for all Participants

	STG	CUR	SOC	EMO	S.C.	SEX	TX	RIS	S.E.
STG	0	47	59	60	63	74	74	74	74
CUR	27	0	61	58	62	70	39	54	61
SOC	15	13	0	24	42	53	12	26	19
EMO	14	16	50	0	42	63	21	45	30
S.C.	11	12	32	32	0	49	11	29	21
SEX	0	4	21	11	25	0	5	17	5
TX	0	35	62	53	63	69	0	48	56
RIS	0	20	48	29	45	57	26	0	31
S.E.	0	13	55	44	53	69	18	43	0

## Appendix M

## Proportion Matrix for all Participants

	STG	CUR	SOC	EMO	S.C.	SEX	TX	RIS	S.E.
STG	0.500	0.635	0.797	0.811	0.851	0.980	0.980	0.980	0.365
CUR	0.365	0.500	0.824	0.784	0.838	0.946	0.527	0.730	0.824
SOC	0.203	0.176	0.500	0.324	0.568	0.716	0.162	0.351	0.257
EMO	0.189	0.216	0.676	0.500	0.568	0.851	0.283	0.608	0.405
S.C.	0.149	0.162	0.432	0.432	0.500	0.662	0.149	0.392	0.284
SEX	0.020	0.054	0.283	0.149	0.338	0.500	0.068	0.230	0.068
TX	0.020	0.473	0.838	0.716	0.851	0.932	0.500	0.649	0.757
RIS	0.020	0.270	0.649	0.392	0.608	0.770	0.351	0.500	0.419
S.E.	0.020	0.176	0.743	0.595	0.716	0.932	0.243	0.581	0.500
SUM	1.486	2.662	5.742	4.703	5.838	7.289	3.263	5.021	3.879

## "Z" Score Matrix for All Participants

	STG	CUR	SOC	EMO	S.C.	SEX	TX	RIS	S.E.
STG	.000	0.345	0.832	0.881	1.042	2.042	2.054	2.054	2.053
CUR	-.345	0.000	0.932	0.785	0.986	1.607	0.068	0.612	0.931
SOC	-.832	-0.932	0.000	-0.456	0.170	0.571	-0.986	-0.382	-0.653
EMO	-.881	-0.785	0.456	0.000	0.170	1.042	-0.572	0.274	-0.239
S.C.	-1.042	-0.985	-0.170	-0.170	0.000	0.418	-1.042	-0.572	-0.571
SEX	-2.054	-1.607	-0.572	-1.042	-0.418	0.000	-1.494	-0.739	-1.494
TX	-2.053	-0.067	0.985	0.571	1.042	1.494	0.000	0.381	0.695
RIS	-2.053	-0.612	0.381	-0.274	0.274	0.739	-0.381	0.000	-0.204
S.E.	-2.053	-0.931	0.653	0.239	0.571	1.494	-0.695	0.204	0.000
Sum	-11.31	-5.574	3.497	0.534	3.837	9.407	-3.048	1.832	0.518
Mean	-1.25	-0.619	0.389	0.058	0.426	1.045	-0.338	0.237	0.058

## Test of Hypothesis # 1

Actual Role in Treatment Decision Making = 1 (Active)  
 Actual Role in Treatment Decision Making = 3 (Passive)

Scale Item	Actcat=1 Mean	Actcat=3 Mean	t value	Significance
Stage	-1.44	-1.18	-1.08	p>.20
Cure	-0.70	-0.63	-0.39	p>.60
Social	0.53	0.41	0.67	p>.40
Phy+Emo	0.11	0.05	0.32	p>.60
Self Care	0.60	0.38	1.16	p>.20
Sexuality	0.94	1.13	-1.00	p>.30
Tx	-0.61	-0.28	-1.10	p>.20
Risk	0.47	0.11	1.57	p>.10
Side E.	0.10	0.001	0.33	p>.60

## Test of Hypothesis # 2

Education = 1 (&lt; high school)

Education = 3 (&gt; high school)

Scale Item	Educ= 1 Mean	Educ= 3 Mean	t value	Significance
Stage	-1.35	-1.23	-0.52	p>.60
Cure	-0.68	-0.64	-0.22	p>.80
Social	0.37	0.40	-0.18	p>.80
Phy+Emo	0.16	-0.08	1.26	p>.20
Self Care	0.66	0.46	1.18	p>.20
Sexuality	0.97	1.04	-0.36	p>.60
Tx	-0.50	-0.14	-1.20	p>.10
Risk	0.30	0.06	1.04	p>.30
Side E.	0.07	0.13	-0.21	p>.80

## Test of Hypothesis # 2

Education = 3 (> high School)  
 Education = 2 ( high school diploma)

Scale Item	Educ= 3 Mean	Educ= 2 Mean	t value	Significance
Stage	-1.35	-1.25	-0.40	p>.60
Cure	-0.68	-0.55	-0.68	p>.40
Social	0.37	0.46	-0.47	p>.60
Phy+Emo	0.16	0.13	0.14	p>.80
Self Care	0.66	0.18	2.53	p<.02*
Sexuality	0.97	1.20	-1.09	p>.20
Tx	-0.50	-0.47	-0.09	p>.80
Risk	0.30	0.38	-0.33	p>.60
Side E.	0.07	-0.08	0.47	p>.60



## Test of Hypothesis # 3

Treatment Plan = I (Mastectomy)

Treatment Plan = II (Lumpectomy)

Scale Item	Tx_Plan I Mean	Tx_Plan II Mean	t value	Significance
Stage	-1.18	-1.31	0.62	p>.40
Cure	-0.67	-0.59	-0.50	p>.60
Social	0.30	0.47	-1.13	p>.20
Phy+Emo	0.01	0.02	-0.06	p>.80
Self Care	0.51	0.38	0.87	p>.30
Sexuality	1.05	1.13	-0.44	p>.60
Tx	-0.27	-0.41	0.52	p>.60
Risk	0.20	0.22	-0.09	p>.80
Side E.	0.06	0.08	-0.07	p>.80

## Appendix R

## Test of Hypothesis # 4

Agecat = 1 (18 - 64) years

Agecat = 2 (65 - 83) years

Scale Item	Agecat=1 Mean	Agecat=2 Mean	t value	Significance
Stage	-1.36	-1.08	-1.33	p>.10
Cure	-0.61	-0.64	0.19	p>.80
Social	0.45	0.23	1.57	p>.10
Phy+Emo	-0.02	0.24	-1.53	p>.10
Self Care	0.55	0.18	2.47	p<.02*
Sexuality	1.03	1.13	-0.56	p>.40
Tx	-0.40	-0.22	-0.69	p>.40
Risk	0.26	0.18	0.40	p>.60
Side E.	0.09	-0.02	0.42	p>.60