INFORMATION NEEDS AND DECISION MAKING PREFERENCES OF HUSBANDS OF WOMEN WITH BREAST CANCER

SUBMITTED BY : BRENDA JEAN DOZENKO

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BY

BRENDA JEAN DOZENKO

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University

of Manitoba in partial fulfillment of the requirements of the degree

of

MASTER OF NURSING

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ABSTRACT

To date, there has been minimal research that has measured husbands' information needs when their wives have recently undergone surgery for breast cancer. In addition, there has been no research that has examined husbands' surgical treatment decisional role preferences and the relationship between husbands' informational needs and their surgical treatment decisional role preferences when their wives have recently undergone surgery for breast cancer.

The purposes of this two phase descriptive survey were: to test a version of the Control Preferences Scale modified to index husbands' surgical treatment decisional role preferences (CPS-H) when their wives had recently undergone surgery for breast cancer; to describe husbands' informational needs and their decisional role preferences when their wives had recently undergone surgery for breast cancer, and to examine the relationship between husbands' information needs and decisional role preferences. Hanks' Structure of Knowledge Model of Family Decision Making was applied as the conceptual framework of this study.

In the first phase of the study, six husbands assessed the CPS-H for clarity and apparent internal consistency. Analysis in accordance with unfolding theory indicated that the CPS-H formed a unidimensional scale.

In the second phase of the study, a convenience sample of 70 husbands completed the Family Inventory of Needs-Husbands (FIN-H), the CPS-H, and a sociodemographic questionnaire. An open-ended interview was conducted with the participants to facilitate expression of concerns related to information needs and surgical treatment decision making.

Phase two results supported the unidimensionality of the CPS-H, with 70% of the participants indicating that they had systematic preferences about the degree of control they desired about their wives' surgical treatment decision making. The internal consistency of the FIN-H, as measured by Cronbach's standardized alpha coefficient was .95. Factor analysis suggested that there were five subdimensions to the FIN-H.

Results of this study indicated that the majority of husbands preferred a collaborative decision making role with their wives and the physician in their wives' surgical treatment decision making, with 50% of husbands achieving their preferred decision making roles. Husbands' decisional role preferences were not associated with demographic and disease related variables. Husbands' highest ranked informational needs were related to emotional and physical care needs, and their lowest ranked needs were related to family relationship issues. There was minimal variation in husbands' highest and lowest ranked needs according to demographic, disease, and decision making role variables. However, a profile of husbands a greatest risk for not having their needs met were identified.

Clinical implications and recommendations for future nursing research are presented on the basis of this study's findings.

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CHAPTER I

STATEMENT OF THE PROBLEM

Introduction

In 1996, there will be approximately 18,600 Canadian women diagnosed with breast cancer (Canadian Cancer Statistics, 1996). A cancer diagnosis not only affects the women but reverberates through the entire family unit (Baider & Kaplan De-Nour, 1988; Hilton, 1994; Howell, 1986; Kristjanson & Ashcroft, 1994; Lewis, 1990; Northouse, 1992; Sales, 1991). The fear, anger, uncertainty and helplessness that are engendered by a cancer diagnosis are not confined to the patient but extend to family members (Tringali, 1986). Both patients and families experience physical, psychological and social distress throughout the cancer experience (Burbie & Polinsky, 1992).

Hack, Degner and Dyck (1994) suggest that patients with cancer may gain a sense of control over their illness by acquiring information and participating in treatment decision making. Investigators have explored information needs and desire for participation in treatment decisions in women with breast cancer (Bilodeau, 1992; Hack et al., 1994; Luker et al., 1995). However, there is limited research about families' and in particular husbands' information needs and their desire for involvement in treatment decisions when their wives are diagnosed with breast cancer.

The aim of this research is to examine husbands' preferences for participation in treatment decisions and their needs for information when their wives have recently undergone surgery for breast cancer. The research problem chosen, the purpose of the study and the significance of the research will be addressed in this chapter.

Research Problem

The diagnosis of breast cancer has a ripple effect from patient to family and may have a long term impact on their lives (Hardwick & Lawson, 1995). Families "serve as the first line of support, nurturance and interpretation of the cancer diagnosis for the patient" (Lewis, 1986, p.269). The family in turn impacts on the patient's response and adaptation to the cancer experience (Cooper, 1984; Howell, 1986; Lewis & Bloom, 1978; Sholevar & Perkel, 1990; Tringali, 1986). The family is expected to provide the patient with emotional support, while attempting to deal with ramifications of the diagnosis for themselves (Gray-Price & Szczesny, 1985).

The diagnosis of breast cancer has a major impact on the patient's husband (Zahlis & Shands, 1991). Husbands are usually the closest family member and are frequently a major source of emotional support to the woman (Baider & Kaplan De-Nour, 1988; Chaitchik, Kreitler, Rapoport & Algor, 1992; Hannum, Giese-Davis, Harding & Hatfield, 1991). Husbands have a double duty of supporting their wives and other family members (Lewis, Ellison & Woods, 1985). However, empirical literature suggests that spouses of patients with cancer experience emotional distress similar to or greater than their partners (Baider & Kaplan De-Nour, 1988; Baider, Rizel & Kaplan De-Nour, 1986; Northouse, 1989; Oberst & James, 1985). Baider and Kaplan De-Nour's (1988) study of patients with breast, colon and testicular cancer and their spouses found that husbands of female cancer patients were more emotionally distressed than wives of male patients.

Northouse (1992) reviewed studies on the psychological adjustment of women with breast cancer and their families. Northouse found that the diagnostic period was extremely stressful for patients and their spouses. The diagnostic period was viewed as most stressful given the expectation of making treatment decisions, while coping with the emotional turmoil of the cancer diagnosis (Northouse, 1992).

Eighty percent of breast cancers are diagnosed at stage I or II (Waltman, 1994). A stage I or II breast cancer diagnosis presents options for local and systemic therapy, which may have far-reaching implications for the woman and her spouse (Hilton, 1994; Kalinowski, 1991). Treatment decisions that affect one member of the family have consequences for all family members (Blustein, 1993; Hardwig, 1990; Morra, 1985). Despite the current emphasis on family-centered health care, women with breast cancer tend to be treated as solitary decision makers and not as part of a family unit (Blustein, 1993; Lewis & Bloom, 1978; Nelson, 1992; Valanis & Rumpler, 1985).

Women's decision making abilities under stress may not be effective (Hack et al. 1994; Northouse, 1992; Valanis & Rumpler, 1985). Husbands, by virtue of their closeness and intimate knowledge of the patient, may act as a resource for helping women make treatment decisions (Blustein, 1993). In addition, they may act as an advocate and put women on a more equal footing with health care providers (Blustein, 1993; Nelson, 1992).

Empirical evidence has shown that patients who are involved in treatment decisions experience less anxiety and depression (Fallowfield, Hall, Maguire & Baum, 1990), improved role and physical functioning (Greenfield, Kaplan & Ware, 1985), increased satisfaction with treatment decisions and care received (Cassileth et al., 1989), and a higher degree of hope (Cassileth, Zupkis, Sutton-Smith & March, 1980). Morris and Royle (1988) found that husbands suffered less anxiety and depression when they participated in breast cancer treatment decisions.

Husbands have been shown to be influential in breast cancer treatment decision making (Hilton, 1993; Margolis, Goodman, Rubin & Pajac, 1989; Ward, Heidrich, & Wolberg, 1989) and often act as co-decision makers (Hilton, 1994). Hilton's (1994) examination of family decision making processes concerning early breast cancer treatment found differing degrees of family involvement in the decision making process. However, prediagnosis decision making patterns were carried into the cancer situation. Her study was not exclusive to the spousal role, but did place emphasis on couple decision making.

Hilton suggests that health care providers should recognize the importance of spousal involvement in decision making to support previous decision making patterns.

Assessing husbands' preferred roles in breast cancer treatment decisions is the initial step to providing husbands with an opportunity to be formally involved in treatment decisions. Husbands who want to be involved may then reap the benefits associated with participation in treatment decision making and may provide decisional support to their wives.

According to Lazarus and Folkman (1984) information seeking is a prime mode of coping with threatening events. Empirical literature indicates that information assists family members to cope with the anxiety and stress of the cancer experience (Adams, 1991; Meissner, Anderson & Odenkerchin, 1990; Northouse, 1989; Wingate & Lackey, 1989). Jassack (1992) and Meissner et al. (1990) suggest that the information needs of patients and family members are not necessarily identical. Each partners' concerns and information needs should be assessed rather than assuming that their concerns are identical (Northouse, 1989).

Kilpatrick (1995) examined the information needs of husbands of women newly diagnosed with breast cancer. The highest ranked information needs were related to immediate care needs and communication issues. Husbands wanted honest specific information about the disease and treatment, and wanted to know that the best possible care was being given to their wives. Addressing the information needs of husbands of women with breast cancer enhances their feelings of control, decreases their anxiety, prepares them for their supportive role and facilitates participation in decision making (Adams, 1991; Brandt, 1991; Tringali, 1986; Zahlis & Shands, 1991).

Studies that have examined the relationship between patient's preferences for control over treatment decisions and patient's desire for information report inconsistent findings. Cassileth et al. (1980), Dennis (1987) and Hack et al. (1994) suggest that information preference and desire for decisional control are correlated; a greater desire for control indicating a greater desire for information. However, other researchers found no correlation between information seeking and decision making preferences (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Ende, Kazis, Ash, & Moskowitz, 1989; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till,1989). The inconsistency of these findings highlights the need for assessment of husbands' information needs and their preferred roles in decision making.

Purpose of the Study

Investigators have examined the relationships between women's preferences for involvement in breast cancer treatment decisions and their desire for disease/treatment information (Degner et al., 1997; Hack et al., 1994). However, to date, there has been no work to measure decision making preferences of husbands of women with breast cancer and no work to examine the relationships between husbands' information needs and their desire for involvement in breast cancer treatment decisions. A review of the literature related to instruments useful for measuring these constructs revealed several instruments that had been used and tested in a variety of populations.

The tool chosen for measuring decision making preferences is Degner and Sloan's (1992) Control Preferences Scale (CPS). The CPS is a valid and reliable measure of preferred roles in health care decision making (Davison, Degner & Morgan, 1995; Degner, Sloan & Venkatesh, 1997). The tool is theoretically based, as it was developed on the basis on Degner and Beaton's (1987) descriptive theory of life-death decision making. The tool has been used for patients with cancer, for the general public, (Degner & Sloan, 1992) and for women with breast cancer (Hack et al., 1994).

Degner (1984) suggests that previous tools utilized to measure control over health care were not designed to specifically elicit preferences for control over treatment decisions. The CPS offers greater variability for responses about roles in treatment decision making than previous tools which offered subjects only two dichotomous alternatives (Hack et al., 1994). Subjects found the tool to be simple and interesting (Degner & Sloan, 1992).

The tool consists of five cards which describe roles that the patient and physician can assume. The cards offer varying degrees of patient involvement in treatment decisions (active, collaborative, passive). In the active role, patients are the major determiners of treatment decisions. The collaborative role depicts a shared responsibility for treatment decisions by the patient and the physician. The physician is the major determiner of treatment in the passive role. This tool is specific to the patient's preferred role, so the tool will be modified to index the husband's preferred role in decision making.

The tool chosen for measuring husbands information needs is Kilpatrick's (1995) FIN-Husband (FIN-H). This tool was chosen as it is the only tool that specifically addresses the information needs of husbands of women with breast cancer. However, this tool has not been used to examine the relationship between husbands' information needs and their desire for involvement in breast cancer treatment decisions.

The FIN-H is based on the Family Inventory of Needs Scale (FIN) developed by Kristjanson (1993) to address the needs of family members of terminally ill patients. The FIN-H was found to be internally consistent, clear, content valid and stable over a short time interval (24 hours) (Kilpatrick, 1995). Kilpatrick found that FIN-H to be succinct and easily administered in a short time frame. The FIN-H consists of thirty items addressing husbands' concerns and need for information. The tool assesses the degree of importance of the thirty items and the extent to which husbands perceive that their identified needs are met.

The purposes of this study are to: (a) modify Degner and Sloan's (1992) Control Preferences Scale to index husbands' preferences for participation in treatment decisions when their wives have recently undergone surgery for breast cancer, (b) pilot test the modified control preferences scale to determine the reliability and validity of this modified scale (CPS-H), (c) describe husbands' role preferences for participation in treatment decisions when their wives have recently undergone surgery for breast cancer, (d) examine information needs of husbands of women who have recently undergone surgery for breast cancer, utilizing Kilpatrick's (1995) FIN-Husband tool, and (e) examine the relationship between husbands' desire for information and their preferences for participation in decision making.

Research Hypothesis

On the basis of previous empirical research that has shown a relationship between information needs and treatment decision making preferences in oncology patients, the following hypothesis has been formulated:

1. Husbands who prefer an active role in their wives' surgical treatment decision making will have a greater need for information (on the basis of number of identified priority needs and means of priority needs) than husbands who prefer a collaborative or passive role in their wives' surgical treatment decision making.

Significance of the Study

Although there is a paucity of literature related to families' involvement in cancer treatment decisions, existing literature suggests that many families are involved in decision making (Hilton, 1993; Hilton, 1994; Stetz, 1993). However, families are not always formally acknowledged by health care professionals as having a role in decision making, and as such are not always included in patient-physician treatment discussions. Hilton's (1994) examination of family decision making processes concerning early stage breast cancer treatment found varying degrees of family participation in decision making. However, pre-diagnosis decision making patterns were maintained in the cancer situation; couples were usually congruent in their participation, both either participating passively or actively. Hilton suggests that breast cancer treatment decisions are not usually solely patient matters, so health professionals must recognize the importance of family involvement. Health care professionals should assess and respect husband's wishes regarding involvement in treatment decisions.

Literature reviews of families' cancer experiences report that families feel ignored by health professionals (Sales, 1991), rely on indirect routes to obtain information (Northouse & Northouse, 1987), and continue to have difficulty obtaining desired information (Kristjanson & Ashcroft, 1994). Assessing and addressing husband's information needs assists them to cope with stress, prepares them for their supportive role and facilitates their participation in decision making (Adams, 1991; Tringali, 1986; Zahlis & Shands, 1991).

Research Questions

The research questions to be addressed in this study are:

1) What is the reliability and validity of the modified Control Preferences Scale?

2) What are husbands' preferred roles for participation in treatment decisions when their wives have recently undergone surgery for breast cancer?

3) What are the information needs of husbands of women who have recently undergone surgery for breast cancer?

4) What is the relationship between husbands' desire for information and their preferences for participation in decision making when their wives have recently undergone surgery for breast cancer?

Summary

To date, there is a dearth of literature in the areas of information needs and preferred roles in treatment decision making of husbands of women who have recently undergone surgery for breast cancer. This study will contribute to an understanding of husbands' information needs and their preferred roles in breast cancer treatment decisions.

Awareness of husbands' information needs and their preferred roles in decision making is the initial step to designing and testing appropriate interventions for this population.

CHAPTER II

CONCEPTUAL FRAMEWORK

Introduction

According to Lobiondo-Wood and Haber (1990), a conceptual framework provides a context for examining a problem and serves as a guide for interpretation, evaluation, and integration of the research findings. This section includes a brief review of research that has examined family decision making, and a description and rationale for choice of the proposed framework.

Family Decision Making

The search for a conceptual framework that would include the variables: husbands' need for information and husbands' preferred roles in breast cancer decision making lead to exploration of family decision making literature. Family decision making literature focuses on couple's decision making and the variables that influence this joint decision making process.

Family decision making has been examined from a variety of perspectives that include: spousal response consistency (Monroe, Bokemeier, Kotchen & McKean, 1985), communication patterns (Krueger & Smith, 1982), power (Corfman & Lehmann, 1987) decision making norms (Houlihan, Jackson & Rogers, 1990) and gender roles (Scanzoni & Szinovacz, 1980). One study was guided by equity theory, others had frameworks that were exclusive to home purchase decision making, and some did not have an explicit conceptual framework. The majority of the reviewed studies implicitly or explicitly were guided by Scanzoni and Szinovacz's (1980) family decision making model (Gerrard, Breda & Gibbons, 1990; Haber & Austin, 1992; Kinsbury & Scanzoni, 1989; Qualls, 1987; Wagner, Kirchler, Clack, Tekarslan & Verma, 1990).

Scanzoni and Szinovacz's family decision making model acknowledges that variation in spouse's decision making roles affects the process of family decision making. However, this model does not attend to the significance of information in the decision making process.

Structure of Knowledge Model of Family Decision Making

The framework chosen for this study is Hanks' (1993) Structure of Knowledge Model of Family Decision Making (Appendix A). Hanks states that family decision making is a complex process that includes multiple decision makers, variable access to information, unpredictable outcomes, and individual and family variation among styles of inquiry and structure of knowledge.

Within the family, member's individual learning styles influence individual decision making styles and in turn influence decision processes and outcomes. Individual learning and decision making styles are mediated by socialization. Variations in learning and decision making styles among family members can either strengthen or hinder the decision making process.

As family members interact during decision making they create a shared system of inquiry that results in a structure of knowledge characteristic of the family. Individual family members differ in their perceptions of the components of a decision (time to make the decision, amount of information needed, and potential risk). The impact of any single component on a decision is determined in part by the role acted out by the family member presenting his/her perceptions of that component to the family. Family members may have different roles in decision making. Individual family members may be deemed experts in certain areas or may have assumed decisional responsibility for specific types of decisions.

As family members interact in their various roles and with their various perceptions of decision to be made, they come to a collective definition of the decision. Once a collective definition has been determined, the family will either pursue additional information or adopt a course of action on the basis of available information.

Hanks suggests that the complexity of family decision making is compounded when the family (a social organization) interacts with other organizations (health, education) that have dissimilar orientations toward decision making. Hanks suggests that families are at a disadvantage due to the following differences in the interacting systems.

The tradition of professional supremacy places the family in a situation of unequal power and control in decision making. Families and organizations often differ in levels of experience with a particular decision and vary in the values and rules that guide decision making. Family members often have no experience in the organizational context, and have minimal or no knowledge of the organizational decision making processes, rules or goals. Conversely, organizational participants have minimal knowledge of family decision making beyond the assumptions that they bring from their own family life. Families and organizations have differential access to and understanding of decisional information. Organizations often justify decisions on the basis of rational choice, whereas family decision making has an emotional component and cannot be achieved using only rational criteria.

Hanks suggests that communication between family participants and organizational participants is key to facilitating family/organizational decisions. Decision making requires a free exchange of information. Both organizational units involved in decision making need equal access to: "(1) the information necessary to make a rational choice and (2) knowledge of the values and feelings that may make non-rational choice more appropriate" (Hanks, 1993, p.235). Both units need to understand the perceived values of outcomes that may result in different weighting of those values by each participant in the family/organizational decision process.

This framework was chosen because it depicts a common process of family decision making, but also acknowledges a structure of knowledge/decision making that is unique to each family. The framework recognizes that family members vary in their informational requirements and their decision making roles. This supports the need for individualized assessment of family members' information needs and preferred roles in decision making. The contextual variables involved when a family interacts with an organization in decision making highlights the importance of communication and information sharing between health care professionals and family members.

The tool (FIN-H) that will be used to measure husbands' information needs is not exclusive to decision making information. However, Kilpatrick (1995) found that communication issues and immediate care needs were the highest ranked information needs of husbands of women newly diagnosed with breast cancer. Husbands wanted honest specific information about the disease and treatment (Kilpatrick, 1995). One can only assume that this type of information was required to facilitate their involvement in treatment decision making.

Husbands also wanted to know that the best possible care was being given to their wives (Kilpatrick, 1995). Empirical literature indicates that family members require information that will help them cope with the stress and anxiety of the cancer experience and information to prepare them for their supportive role in addition to information that facilitates decision making (Adams, 1991; Northouse, 1989; Tringali, 1986; Wingate & Lackey, 1989; Zahlis & Shands, 1991).

Summary

The conceptual framework of the proposed research and the framework's applicability to the issues of husbands' information needs and preferred roles in breast cancer treatment decision making have been described. The contextual variables that influence family/organizational decision making have been explored. The proposed framework will guide the study as the researcher attempts to identify husbands' preferred roles in breast cancer treatment decision making and the types of information they desire about their wives' illness. By identifying husbands' preferred roles in breast cancer treatment decision making, health care professionals may be able to enhance families' decision making processes. By identifying husbands' information needs, health care professionals may be able to provide information that will facilitate husbands' involvement in treatment decision making, decrease their anxiety and enhance their ability to support their wives.

CHAPTER III

LITERATURE REVIEW

Introduction

This literature reviewed for this study will be presented under the following four main topic areas: breast cancer treatment choices, spouse/family responses to illness, significance of information for the family/spouse, and decision making.. Each area will be examined separately.

Treatment Choices

"Treatment of breast cancer is based on the stage of disease at diagnosis: approximately 80% of breast cancers are diagnosed at Stage I or II..." (Waltman, 1994, p.15). Treatment of Stage I and II breast cancer includes surgery and adjuvant systemic therapy for some patients (Waltman, 1994). Modified radical mastectomy and the breast conserving treatment of lumpectomy plus radiation have been shown to be equivalent in terms of local control and overall survival for the majority of women with Stage I and II breast cancer (Kalinowski, 1991; Kinne, 1990; Long, 1993; Margolis, Goodman, Rubin & Pajac, 1989; Waltman, 1994).

The majority of women with Stage I and II breast cancer make their initial treatment decision with respect to the type of surgical intervention. This section of the literature related to treatment choices is categorized into three subgroups: (1) factors that influence a woman's choice of surgical treatment, (2) psychosocial outcomes related to type of surgical treatment for women and their husbands, and (3) the effect that participation in treatment choice has on the psychosocial adjustment of women and their husbands.

Factors Affecting Choice

Although many women are medically eligible for either lumpectomy or mastectomy, survivorship is not the only factor considered by women when selecting surgical treatment

(Schain, 1990). Valanis and Rumpler (1985) postulate that a woman's choice of treatment is influenced by four factors. The four factors are: media, physician, family and friends, and the woman's resources and her feminine identification.

Empirical studies have also examined factors that influence women's choice of surgical treatment. Sample sizes in the six reviewed studies ranged from 20 to 119, with only two studies having greater than 50 subjects. Factors that influenced choice of surgical intervention were assessed by questionnaires or semi- structured interviews.

The majority of the studies reported that women who chose breast conserving surgery showed greater concerns about maintenance of body integrity than women who chose mastectomy (Ashcroft, Leinster & Slade, 1985; Margolis et al., 1989; Morris & Royle, 1988; Ward, Heidrich & Wolberg, 1989; Wolberg, Romsaas, Tanner & Malic, 1989). Women who chose modified radical mastectomy were influenced by their concerns about the efficacy of lumpectomy, the side effects and inconvenience of radiation therapy, and the possibility of a second surgery (Ashcroft et al . 1985; Margolis et al., 1989; Morris & Royle, 1988; Ward et al., 1989; Wilson, Hart & Dawes, 1988).

Two of the aforementioned studies examined the influence of partner's feelings on the woman's choice of surgical treatment. Ward et al. (1989) found that a greater percentage of women who chose lumpectomy were influenced by their partner's feelings. In contrast, Margolis et al. (1989) found that a greater percentage of women who chose mastectomy were influenced by their partner's feelings. Although these studies are limited by small samples (n = 22 & 70, respectively), the findings suggest that spouses are influential in women's surgical treatment decisions.

Choice of surgical treatment has been related to women's concerns about body integrity, survivorship, convenience of treatment, and partner's feelings. Providing husbands with the information they desire and respecting their desire for involvement in treatment decision making may enhance communication of feelings about treatment options between a woman and her husband and facilitate treatment decision making.

Psychosocial Outcomes of Different Treatment Choices

According to Schain (1990), the psychological consequences of breast cancer treatment have been examined more than any other single organ site malignancy. Schain suggests that it may be attributable to the high incidence of breast cancer and "to the fact that the female breast is imbued with special nurturant and sexual connotations" (p.917). One of the reasons for breast conservation treatment was that the psychological sequalae would be less severe than after breast amputation (Fentiman, 1995). However, the following empirical studies do not fully support this hypothesis.

The six reviewed studies that have compared the psychosocial outcomes of women who had a lumpectomy to women who had a mastectomy had sample sizes that ranged from 52 to119 (Fallowfield, Baum & Maguire, 1986; Hughes, 1993; Omne-Ponten, Holmberg, Burns, Adami & Bergstrom, 1992; Steinberg, Juliano & Wise, 1985; Taylor et al., 1985; Wolberg et al., 1989). Five studies had more than 65 subjects. These studies examined various psychosocial outcomes (overall global adjustment, anxiety, depression, self-image, sexual function, uncertainty, and functional status) and employed a variety of instruments. The time frames for data collection ranged from 8 weeks to16 months post surgical intervention.

All of the studies indicated that there were minimal differences in the various psychosocial dependent variables between women who had a lumpectomy and women who had a mastectomy. Taylor et al. (1985), Steinberg et al. (1985), and Wolberg et al. (1989) reported that women who underwent a lumpectomy reported better sexual relations than women who underwent a mastectomy. However, Omne- Ponten et al. (1992) found a higher rate of sexual disturbances for women who had a lumpectomy than women who had a mastectomy.

Four recent literature reviews suggest that there are minimal differences in overall psychosocial outcomes between modified radical mastectomy and lumpectomy (Carlsson & Hamrin, 1994; Meyerowitz, 1993; Royak-Schaler, 1991; Wainstock, 1991). However, the majority of reviewed studies indicated that women who chose breast conservation surgery had a more positive body image than women who chose mastectomy.

Only two of the reviewed studies compared psychosocial outcomes of husbands of women who had breast conserving surgery to husbands of women who had a mastectomy. A retrospective study by Baider, Rizel, and Kaplan De-Nour (1986) compared couples' psychosocial adjustment post lumpectomy (n = 21) and post mastectomy (n = 20). Comparisons of women's responses showed no differences in anxiety, depression and overall psychosocial adjustment.

There were no significant differences in depression or overall adjustment between husbands of women who underwent lumpectomy and husbands of women who underwent mastectomy. Husbands of women who had undergone lumpectomy were somewhat more anxious than husbands of women who had undergone mastectomy. Husbands in both groups reported more adjustment problems than their wives and were less satisfied with the care their wives had received than were the women.

Omne-Ponten, Holmberg, Bergstrom, Sjoden, and Burns (1993) examined the psychosocial adjustment of husbands of women who had a mastectomy (n = 36) and husbands of women who had breast conserving surgery (n = 20) at four and thirteen months post surgery. Results were marginally more favourable for husbands in the breast conserving group, with husbands reporting slightly less anxiety and depression than the husbands in the mastectomy group. Emotional distress was high in both groups and for both groups, increased over time. The investigators suggest that type of surgery is not the major determinant of husbands' psychosocial outcomes. Anecdotal information from the study showed that husbands felt disregarded by medical staff, and lacked information about their wives' disease and treatment.

Although these studies of husbands' psychosocial adjustment are limited by small samples, findings are consistent. Type of surgical intervention does not appear to affect the psychosocial outcomes of husbands of women with breast cancer. The literature suggests that women and their husbands experience psychosocial distress irrespective of the type of surgical treatment for breast cancer. Ganz (1992), suggests that the key to psychosocial adaptation may be related to the opportunity to participate in choice of treatment.

Choice and Outcomes

The third sub-category related to treatment choices explores the effect that participation in treatment choice has on the psychosocial adjustment of women with breast cancer and their husbands. Empirical evidence has shown that patients who are involved in treatment decision making experience less anxiety and depression (Fallowfield, Hall, Maguire & Baum, 1990), improved role and physical functioning (Greenfield, Kaplan & Ware, 1985), increased satisfaction with treatment decisions and care received (Cassileth et al., 1989), and a higher degree of hope (Cassileth , Zupkis, Sutton-Smith & March, 1980). The following studies compared psychological outcomes of individuals who were provided an opportunity to choose treatment to individuals who did not have an opportunity to choose treatment.

Levy, Herberman, Lee, Lippman, and d'Angelo (1989) examined mood states and functional status of Stage I and II breast cancer patients at three to five days and three months post surgery. Ninety-three women were randomly assigned to mastectomy or lumpectomy treatment and ninety-eight women were given a choice of surgical treatment. Seventy percent of the women given a choice opted for mastectomy.

Results indicated there were minimal differences in mood states and no differences in functional status between women randomly assigned to surgical treatment. In the group offered a choice, functional status was similar, but women who had a lumpectomy demonstrated overall higher levels of emotional distress three months post surgery than women who had a mastectomy. In addition, women who had a lumpectomy reported less emotional support from significant others than did women who had a mastectomy. Emotional distress was not attributable to adjuvant therapy or extent of disease.

The investigators suggest that making a choice within the context of a perceived unknown is threat producing. Post surgical monitoring of the conserved breast and knowledge of the need for radiation therapy may suggest to women who have undergone a lumpectomy that they are still harboring a malignancy in the spared breast.

In another study by Fallowfield, Hall, Maguire, and Baum (1990) comparisons of the psychological outcomes of women (n = 269) treated by surgeons who offered a choice whenever possible and women treated by surgeons who favoured breast conserving or mastectomy surgery were made. In contrast to Levy's et al. (1989), Fallowfield et al. found that women treated by surgeons who offered a choice, irrespective of treatment choice, showed less depression and anxiety than women treated by surgeons who did not offer a choice. Sixty-two of the 118 women treated by surgeons who offered a choice were eligible to choose their surgery, forty-three chose breast conservation. There was no significant difference in anxiety or depression between women who were eligible to choose and those who were not eligible to choose surgical treatment. The researchers suggest that surgeon type and the manner in which treatment decisions are made are as influential as surgical choice on psychological adjustment.

Thirty women and their husbands were studied prospectively to assess whether choice of surgery (mastectomy or wide excision plus radiotherapy) affected anxiety and depression pre and post operatively (Morris & Royle, 1988). Twenty couples were given a choice, and ten were not offered a choice because tumor position mandated a mastectomy. Preoperatively and at two months postoperatively, women and husbands offered a choice suffered less anxiety and depression than couples not offered a choice of surgery. Although the trend continued until one year post surgery, the differences between the groups were statistically insignificant.

There was no significant difference in anxiety and depression between women who chose mastectomy or wide excision plus radiotherapy. Anxiety and depression were lower in the seven women who chose mastectomy compared to the ten women who had received mastectomy for medical reasons. Morris and Royle conclude that choice may be beneficial for both women and their husbands. However, they recommend that treatment choice should only be offered after treatment counseling and in conjunction with written information.

Wallston et al. (1991) explored the interaction between patients' level of desire for control over treatment decisions and the effect of choice of antiemetic treatment for cancer chemotherapy (n = 78). Thirty one percent of the patients had breast cancer. Patients were randomly assigned to choice and no choice groups. The Krantz Health Opinion Survey and a seven item desire for control scale were combined to assess the patients' level of desire for control (high, moderate, low) over health care. Emotional distress (anxiety and negative mood states) was assessed pretreatment and after each chemotherapy treatment. Physical distress (pain and nausea) was assessed immediately after each treatment.

Patients with moderate levels of desire for control (DFC) demonstrated less anxiety, negative mood, and nausea when given a choice than when not given a choice. Emotional distress was the most significant variable. There were no significant differences in physical or emotional distress in patients with high and low DFC, irrespective of opportunity for choice.

Wallston et al. (1991) suggest that the impact of choice depends on the relevance of control and how much control the choice provides. Thus, in patients with low DFC, choice is not relevant and may have minimal impact on their outcomes. In contrast, patients with high DFC may need to take control rather than be given it. The findings of this study highlight the need for individual assessment of degree of involvement desired in treatment decisions.

The aforementioned studies suggest that an opportunity to make a choice about treatment when an individual desires to do so may have a positive effect on psychological and physical outcomes. Knowledge of husbands' desire to participate in breast cancer treatment decisions is the initial step to affording husbands the benefits associated with participation in treatment decision making.

Spouse/Family Responses to Illness

A diagnosis of breast cancer not only affects the woman but reverberates through the entire family unit (Baider & Kaplan De-Nour, 1988; Hilton, 1994; Howell, 1986; Kristjanson & Ashcroft, 1994; Lewis, 1990; Northouse, 1992; Sales, 1991). The fear, anger, uncertainty, and helplessness that are engendered by a cancer diagnosis are not confined to the patient but extend to family members (Tringali, 1986). Both patients and families experience physical, psychological, and social distress throughout the cancer experience (Burbie & Polinsky, 1992). Previously cited literature has shown that spouses are not protected from the psychological impact of their wives' cancer treatment. The following studies will expand on the responses experienced by spouses and families of cancer and chronically ill patients.

Early studies of spousal responses to chronic illness (Klein, Dean & Bogdonoff, 1967) and mastectomy (Baiber & Kaplan De-Nour,1984; Wellisch, Jamison & Pasnau, 1978) reported that spouses experience emotional, physical, and vocational distress. Wellisch et al.(1978) found that husbands' symptom distress occurred prior to mastectomy and continued during treatment. Baider and Kaplan De- Nour (1984) found that husbands and wives reported similar problems with their vocational and domestic environments, sexual relations and psychological distress. Couples' scores were highly correlated, with the level of distress of one partner being indicative of the level of distress of the other partner. Husbands' adjustment became worse over time and with the addition of treatment. **Table 1** presents studies that have examined spousal/family responses to cancer and studies that have compared couples' psychosocial adjustment to cancer.

Table 1

Spouse/Family Responses to Illness

Author, Year	Purpose	Sample	Variables
Cassileth, Lusk, Strouse, Miller, Brown, and Cross, (1985)	To determine the degree of compatibility between the psychosocial status of patients and their relatives. To elucidate factors associated with psychosocial status and distress in patients and in their relatives.	n = 201 oncology outpatients and their next-of-kin from one clinic. 67% were spouses.	Anxiety Mood Disturbance Global Mental Health

Major Findings: Patients' and relatives' scores for each variable were found to be significantly correlated : anxiety ($r = 0.28$, $p = <0.0001$), mood disturbance ($r = 0.42$, $p = <0.000001$), and global mental health ($r = 0.40$, $p = <0.00001$). Mutuality of psychological response between patients and their relatives were found through all phases (active treatment, follow-up, and palliative therapy) of the cancer experience. Psychological distress was higher in active treatment than follow-up and highest during palliative care.

Author, Year	Purpose	Sample	Variables
Oberst and James (1985)	To describe the magnitude and pattern of crisis development experienced by both patient and spouse.	n = 40 patients with newly diagnosed bowel and genitourinary cancer and their spouses (40) from a large urban cancer center.	Emotional Distress Physical Symptoms

Major Findings: The primary concern voiced by both patients and spouses prior to discharge and 10 days post discharge was the patients' health. However, spouses' anxiety during the hospital period was significantly higher than patients' anxiety. Spouses had a higher incidence of emotional problems at each post discharge interview (10, 30, and 60 days post discharge) than did the patients. The anxiety seen in spouses before discharge was replaced by depression in the post discharge periods. All patients reported physical symptoms (wound discomfort, bowel problems, fatigue, anorexia , and insomnia) at 10 days post discharge. 75% of patients reported the same symptoms at 60 days post discharge. During the hospital period, spouses reported fatigue and anorexia. By 30 to 60 days post discharge, spousal incidence of illness escalated and included reports of vague diffuse pain , indigestion, exacerbation of preexisting medical conditions, and a variety of minor ailments. Spouses reported distress, anger and frustration about the lack of support they received from health care professionals.

Table 1 (cont'd)

Author, Year	Purpose	Sample	Variables
Lovejoy (1986)	To describe family members' responses to patient hospitalization in cancer units.	n = 105 family members of adult patients with cancer in two major teaching hospitals. 56% were spouses.	Emotions Physical Symptoms

Major Findings : Patients were in hospital at various stages of their illness: diagnostic (41%), complications (39%),and palliation (18%). Content analysis of the interview data indicated that families' responses to hospitalization of patients with cancer were: shock, uncertainty, accommodation, immersion, and awareness. Uncertainty produced the negative emotions (guilt, fear, anxiety, and depression) and the physical symptoms (fatigue, insomnia, and eating disturbances) reported by family members.

Author, Year	Purpose	Sample	Variables
Northouse and Swain (1987)	To examine the psychosocial adjustment of women who undergo mastectomy and their husbands during the initial and adaptation phases of breast cancer.	n = 50 women who were hospitalized after their initial mastectomy and their husbands (50) from four hospitals.	Mood Symptom Distress Role Functioning

Major Findings: Patients' and husbands' mood adjustment scores did not significantly differ ($F(1, 49) = 1.33$, $p = .25$). In addition, patients' and husbands' symptom distress scores did not significantly differ ($F(1, 49) = 0.02$, $p = .90$). However, there were significant differences between patients' and husbands' role functioning scores ($t(49) = 4.43$, $p < 0.0001$). Patients had more problems in domestic, vocational, and social roles than did their husbands.

Author, Year	Purpose	Sample	Variables
Baider and Kaplan De-Nour (1988)	To examine the interaction and adjustment of couples in which one partner has cancer.	n = 117 patients with breast, colon, or testicular cancer and their spouses (117). 62 couples were adjusting to breast cancer.	Psychosocial Adjustment

Major Findings: Couples within each of the diagnostic groups reported similar numbers of problems on all psychosocial domains (health ,vocational, domestic, sexual, extended family, social, and psychological distress). Correlation of patients' and husbands' scores indicated that either both partners coped well together or had many problems together. An interesting finding from the study was that husbands of female patients were more distressed than wives of male patients.

Table 1 (cont'd)

Author, Year	Purpose	Sample	Variables
Northouse (1989)	To assess the psychosocial adjustment of women with breast cancer and their husbands over an extended period of time. To compare couples' levels of adjustment at 18 months post surgery with their levels of adjustment 3 days and 30 days post surgery.	n = 41 couples who had participated in a previous study that had assessed their psychosocial adjustment at 3 and 30 days post mastectomy.	Mood Symptom Distress Role Functioning

Major Findings: Approximately 35% of the women and 24% of the husbands reported moderate to severe distress levels at 18 months post- surgery. Patients' and husbands' mood scores did not significantly differ from one another ($F[1, 40] = 1.59$, $p = 0.22$) across all three data collection times. Comparison of patients' and husbands' symptom distress scores over the three time points, found no significant difference between the partners ($F[1, 40] = 0.06$, $p = 0.80$). There was a difference between patients and husbands in the number of role adjustment problems reported across time. Patients reported more role problems than husbands ($F[1, 40] = 14.69$, $p < 0.001$). There were no significant relationships between demographic factors (age, education, length of marriage) or medical factors (type of surgery, recurrence, current treatment)and mood and symptom distress among women. However, younger husbands ($r = 0.42$, $p < 0.01$) and those who had been married for shorter periods of time ($r = 0.33$, $p = 0.03$) had less positive mood states than older and longer married husbands.

Author, Year	Purpose	Sample	Variables
Northouse, Laten, and Reddy, (1995)	To examine the differences in psychosocial adjustment of patients and spouses during the recurrent phase of breast cancer. To examine the differences in patients' and spouses' perceptions of the recurrence.	n = 74 women who had a first recurrence of their breast cancer and their husbands (74).	Hopelessness Uncertainty Social Support Symptom Distress Role Functioning Perception of Recurrence Emotional Distress

Major Findings: There were similarities (role functioning, hopelessness, assessment of symptom distress) and differences (perceptions of the recurrent illness, uncertainty, emotional distress, and perceptions of support from family and friends) in partner's responses to recurrent breast cancer. The majority of

husbands (56%) . in contrast to their wives, found the time of initial diagnosis was more distressing than the time of recurrence. Women reported more emotional distress than their husbands.
Husbands reported more uncertainty than their wives and lower levels of social support from family and friends. The investigators suggest that husband's uncertainty may be related to their limited contact with health care professionals and their indirect access to illness information.

The literature indicates that spouses of cancer patients experience physical symptoms and psychosocial distress as a result of the illness experience. Studies have reported both intracouple similarities and intracouple differences in psychosocial responses to cancer. In some instances, spouses' psychosocial distress has been greater than patients' psychosocial distress. Husbands of women with breast cancer have been shown to experience psychosocial distress. Husbands are usually the closest family member and as such are frequently the major source of emotional support (Baider & Kaplan De-Nour, 1988; Chaitchik, Kreitler, Rapoport & Algor, 1992; Hannum, Giese-Davis, Harding & Hatfield, 1991). Husbands are expected to support their wives while coping with their own responses to the illness experience (Lewis, Ellison & Woods, 1985). Illness should be viewed as a marital rather than individual issue (Baider & Kaplan De Nour, 1984). As such, both patients and their spouses should be considered and supported by health care professionals throughout the cancer experience.

Inclusion of spouses in treatment decision making provides spouses with the opportunity to communicate with the health care professionals. Spouses may be more inclined to discuss their own concerns and seek information and assistance if they have established an initial relationship with health care professionals.

Significance of Information for Family/Spouse

This section will explore literature related to the significance of information for families/spouses of patients with cancer and the information needs of husbands of women with breast cancer. Empirical evidence in the previous section has suggested that spouses of patients with cancer have difficulty obtaining information. Information is "one mechanism for coping cognitively with change, uncertainty, disability, and crisis; and for gaining control over health related events" (Lenz, 1984, p. 59). Empirical literature indicates that information assists family members to cope with the anxiety and stress of the cancer experience (Adams, 1991; Gotay, 1984; Meissner, Anderson & Odenkerchin, 1990; Northouse & Northouse, 1987; Northouse, 1989; Wingate & Lackey, 1989; Wright & Dyck, 1984). Information also facilitates families' participation in decision making (Adams, 1991; Tringali, 1986; Zahlis & Shands, 1991).

Early research related to the significance of information for the family suggests that families utilize information as a coping mechanism; families desire information about treatment options; and families have difficulty obtaining information (Gotay,1984; Morra, 1985; Wright & Dyck, 1984). Gotay (1984) examined coping mechanisms of spouses of women with early and late stage breast and gynecological cancer. Spouses of early stage patients coped by seeking information and direction from physicians.

Wright and Dyck (1984) interviewed the next of kin of hospitalized patients with cancer (n = 45) to determine family members' concerns. One concern was difficulty obtaining information. Forty-nine percent of the participants indicated that they had difficulty obtaining information from physicians and nurses. Lack of information contributed to their uncertainty and anxiety.

Morra (1985) analyzed 2,500 calls from a Cancer Information Service and found that the majority of family members asked questions about treatment. She suggests that questions about treatment may be related to the fact that family members are often not present when treatment information is provided, as they have not been included in initial treatment decision making discussions. **Table 2** presents further studies that have examined the significance of information for families/spouses of patients with cancer.

Table 2

Significance of Information for Family/Spouse

Author. Year	Purpose	Sample	Design
Tringali (1986)	To identify the cognitive, emotional and physical needs perceived as important by family members of patients with cancer during three phases of illness (diagnostic and treatment, follow-up and recurrence).	n = 25 family members of oncology outpatients from one clinic. 18 were spouses.	Descriptive

Major Findings: Cognitive (informational) needs were important to family members throughout the cancer experience. 76% of the needs identified as most important in all three phases of illness were cognitive and 24% were emotional needs. Families in the initial and recurrent phases of illness wanted to know facts about the disease, treatment, expected symptoms, patient progress, and probable outcomes. Families in follow-up treatment indicated that information about patients' progress and probable outcomes was most important. Tringali suggests information facilitates families' participation in decision making and prepares them for their supportive role. In addition, information allows for clarification of information given to the patient but not retained by the patient due to anxiety.

Author. Year	Purpose	Sample	Design
Northouse (1989)	Two of the fourfold purposes were : To identify factors that helped husbands of women who had undergone mastectomy to cope with the illness. To determine which phase of illness (before surgery, during hospitalization, or at home after surgery) was most stressful to husbands of women who had undergone mastectomy.	n = 50 husbands of women who had undergone mastectomy at four hospitals.	Descriptive

Major Findings: Emotional support from family and friends was the most important factor that helped husbands cope with their wives' illness. Health care professionals were seldom regarded as sources of emotional support. Information was another important factor identified as helpful in coping with their wives' illness. Husbands wanted detailed information about procedures and wanted to have their questions answered in understandable terms. The majority of husbands (50%) found the preoperative period most stressful, while 44% found the hospital phase most stressful. The preoperative phase was considered stressful due to uncertainty, insufficient information and the need to make treatment choices with minimal contact or guidance from health care providers. The hospital phase was considered stressful due to the uncertainty of the surgical outcome.

Author . Year	Purpose	Sample	Design
Meissner, Anderson, & Odenkirchen, (1990)	To examine the information needs of significant others of patients with cancer.	n = 189,755 calls to a Cancer Information Service from significant others.	Telephone Survey

Major Findings: The three most frequent subjects of inquiry were : information on specific cancer sites , treatment information, and advice on how to get a second opinion. The fourth ranked information need was information on counseling services for patients and significant others. There was a significantly larger volume of calls from significant others (189,755) than diagnosed patients (89,876) during the data collection time frame. The investigators suggest that this difference in volume indicates that significant others feel they have insufficient information, which may be due to lack of communication with health care professionals. In addition, the investigators believe that the number of calls from significant others reflects their desire to be active participants in the patient's care and act as patient advocates.

Author . Year	Purpose	Sample	Design
Zahlis and Shands (1991)	To identify the demands that a diagnosis of breast cancer placed on the patient's partner.	n = 67 male partners of women diagnosed with breast cancer within the previous 2 1/2 years. Recruited from a various facilities in a large city.	Qualitative

Major Findings: One conceptual domain identified by partners of women with breast cancer was "negotiating the illness experience". This domain included becoming educated about the illness, arriving at a treatment decision, and dealing with physicians. Men felt they lacked knowledge about the disease, but felt pressured to understand the disease so they could assist in treatment decision making. Treatment decision making was identified as a stressful time due to lack of information from physicians and / or a diversity of opinions.

Author . Year	Purpose	Sample	Design
Hilton (1993)	To examine the issues, problems, and challenges of families of women newly diagnosed with breast cancer from the time of diagnosis to one year post diagnosis.	n = 12 partnered families of women newly diagnosed with breast cancer.	Qualitative

Major Findings: Being informed and making treatment decisions were two of the categories identified under one of the major themes "Taking Care of the Cancer". Being informed and making treatment

decisions were most significant in the diagnostic and treatment phases of the cancer experience, but were also relevant throughout the year. Most families wanted to be informed about all aspects of the cancer experience, while some families preferred minimal information. Families reported a lack of information about the disease, treatment, and prognosis. Several families did not know how to access information, were unsure of what to ask, and some were afraid to ask. Other families felt overwhelmed and could not think clearly when talking to the physician. Specific information problems were: lack of clarity of technical information, discrepant information, inability to understand information, and inappropriate timing of information. Families were very involved in treatment decision making. Some families had little difficulty making decisions, while other families found it a challenge. Decision making was most difficult when the families received differing opinions from their physicians.

An early literature review by Northouse (1984) indicated that families of cancer patients feel frustrated in their attempts to communicate with medical staff and feel excluded from the focus of medical care. More recent literature reviews report that families feel ignored by health professionals (Sales, 1991), rely on indirect routes to obtain information (Northouse & Northouse, 1987), and continue to have difficulty obtaining desired information (Kristjanson & Ashcroft, 1994). Northouse and Northouse (1987) suggest that the family's lack of contact with health professionals not only limits their access to information, but makes them feel peripheral to the treatment process. In addition, limited contact prevents families from developing rapport with, and seeking support from health care providers (Northouse and Northhouse, 1987).

In conclusion, the literature suggests: families want information throughout the cancer experience but especially in the diagnostic and treatment phases; families have difficulty obtaining information, particularly due to minimal contact with health care professionals; information assists families in coping with the cancer experience; and information facilitates families' involvement in treatment decisions.

Husbands of women with breast cancer found the peoperative period most stressful due to lack of information from health care professionals. Assessing and addressing husbands' information needs when their wives are diagnosed with breast cancer may assist them to cope with stress, prepare them for their supportive role, and facilitate their participation in decision making (Adams,1991; Tringali, 1986; Zahlis & Shands,1991).

Information Needs of Husbands of Women with Breast Cancer

Luker et al. (1995) state that there have been several problems in assessing information needs since individuals have a tendency to say they want as much information as possible about all aspects of their care. Luker et al. suggest that receiving the right amount and type of information is especially important for individuals with cancer, due to the emotional constraints on information processing. Investigators have explored the priority information needs of women with breast cancer (Bilodeau & Degner, 1996; Degner et al., 1997; Luker et al., 1995). However, there has been limited research on the types of information that families and in particular husbands of women with breast cancer desire during the cancer experience.

A study by Kilpatrick (1995) examined the information needs of husbands (n = 84) of women newly diagnosed with breast cancer. The sample was recruited from one tertiary care and three community hospitals. Kilpatrick developed a tool (Family Inventory of Needs-Husbands or FIN-H) which consists of thirty items that address husbands' concerns and information needs. The tool assesses the degree of importance of the thirty items and the extent to which husbands perceive that their identified needs are met.

The majority of husbands (62%) completed the tool from one to three days after their wives' surgical intervention (lumpectomy / mastectomy). Overall, husbands rated 28/30 needs as having some degree of importance . The highest ranked information needs were related to communication issues and immediate care needs. Husbands wanted honest specific information about the disease and treatment, and wanted to know that the best possible care was being given to their wives. Younger husbands (<60 yrs.) reported a greater mean number of information needs (29/30) than older husbands (>60 yrs.)(26/30). Husbands of women classified as clinical stage 0 reported a higher mean number of needs (29.5/30) than husbands of women classified as clinical stage 1, 2, 3, or 4. Husbands with less than high school education had a greater percentage of unmet needs (54%) than the percentage of unmet needs (29%) reported by husbands with greater than high school education. Husbands of women who had had a previous lumpectomy /mastectomy reported a smaller percentage (15%) of unmet needs than the percentage of unmet needs (43%) reported by husbands of women who had had an initial surgical intervention.

Kilpatrick found that most husbands wanted to be included in all discussions with health care professionals. However, several husbands stated that they felt disregarded by health care providers and lacked information about their wives' disease and treatment. Some husbands felt that the information they received had been filtered by their wives. Kilpatrick believed that many women did not want to worry their husbands, so may not have shared their concerns with their husbands.

Kilpatrick suggests that husbands have some of the same questions/concerns about disease and treatment as do their wives. However, they also have questions/concerns related to emotional support for and interaction with their wives. Jassack (1992), Meissner et al. (1990), and Northouse (1989) concur and suggest that the information needs of patients and family members are not necessarily identical. Therefore, each partner's concerns and information needs should be assessed rather than assuming that they are identical.

Decision Making

This section of the literature related to decision making is divided into three sub-sections. The first section provides a brief description and critique of rational decision making models. The second section, health care decision making, will describe how treatment decisions are made in life-threatening illness, and the relationship between desire for information and preferred roles in treatment decision making. The third section, the role of the family in health care decisions, will discuss the family's role and involvement in health care decisions and spousal involvement in breast cancer treatment decisions.

Rational Decision Making Models

The earliest decision theorists were mathematicians (Edwards & Tversky, 1967). However, decision making has been explored by several other disciplines such as psychology, sociology and political science (Zey, 1992). The various theoretical approaches have produced numerous normative models of decision making that prescribe what people ought to do (Pierce,1993). However, rational-choice models based on economic theory have been theoretically generalized to explain decision making behavior by nearly all social science disciplines (Zey,1992). Rational choice models assume that decision makers choose their course of action on a rational basis by evaluating the values and probabilities of the consequences of each available alternative (Janis,1982).

Decision Making Process

"Decision making is a process by which a person, group or organization identifies a choice or judgment to be made, gathers and evaluates information about alternatives, and selects from among the alternatives" (Carroll & Johnson, 1990, p.19) . Rational decision making models describe decision making as a process that occurs in a series of fairly well defined stages. Although authors label the steps differently, there is similarity in the sequence of the process (Janis & Mann, 1977; Marquis & Houston, 1987; Strauss & Clarke, 1992).

Carroll and Johnson (1990) outline seven assumed temporal stages of the decision making process. The stages are : recognition, formulation, alternative generation, information search, judgment and choice, action, and feedback. Recognition (recognizing there is a decision to be made), formulation (exploring and classifying the decision situation and understanding the relevant objectives of the situation), alternative generation (exploring possible alternatives), information search (identifying the attributes of the alternatives), judgment and choice (labeling the attributes of the alternatives and comparing of alternatives), action (acting on the decision), and feedback (receiving information about the outcome of the action)

Carroll and Johnson state that this process assumes decision makers follow a rational procedure for making decision. In addition, it assumes that individuals know their preferences and available alternatives and have access to information about the consequences of all alternatives. Carroll and Johnson suggest that the aforementioned assumptions are not necessarily true, and that actual decision making may frequently diverge from the rational model.

Zey (1992) concurs and outlines three limitations to the "rational" decision making process. The first being that the process assumes that individuals only make self-interested choices. She suggests that individual's choices are influenced by significant others and also have implications for significant others. The second limitation is the lack of focus given to the significant role that habit, values, and emotions play in decision making. The third limitation is that the rational decision making process is insensitive to the cognitive limitations of individuals. Attentional or memory limitations may cause the individual to act on insufficient or irrelevant information. Too much or too complex information can also limit comprehension.

Janis (1982) suggests that rational decision making models do not account for decision making that occurs in stressful situations. Rational decision making models reflect decision making for ordinary choices (Janis, 1982). A life threatening diagnosis creates stress and choosing a treatment alternative cannot be viewed as an ordinary choice. In addition, Janis suggests rational decision making models are valuable for "prescriptive" purposes, but run into difficulty when they are proposed as "descriptive" models that explain how people actually do make decisions.

The conceptual framework for this study, Hanks' (1993) Structure of Knowledge Model of Family Decision Making acknowledges the aforementioned criticisms of rational decision making models. Individual family members are viewed as having various learning and decision making styles that influence their decision making process. Decisions are made through family interaction and are influenced by individual decision making roles and individual perceptions of the decision. Decisions are influenced by family members' values and emotions. Family decision making is complicated when families interact with an organization such as the health care system. Hanks suggests that families are disadvantaged by unequal power and control, and differential access to and understanding of decisional information when they make decisions within an organizational context.

The following literature examines the "actual" decision behaviours of patients confronted with life threatening illness and the relationship between desire for information and preferred role in treatment decision making.

Health Care Decision Making

In the past, physicians made health care decisions with minimal or no input from patients. This paternalistic decision making model was believed to distinguish the professional from the lay person (Castledine, 1995). Patients were expected to assume a passive dependent role, while physicians were expected to utilize their medical knowledge and act in the best interest of their patients.

In recent years, the imbalance of health care decision making power has been challenged by ethical, legal, and social forces (Sutherland, Llewellyn-Thomas, Lockwood, Tritchler & Till, 1989). The present emphasis on patient autonomy and self-determination; the formal legal requirements concerning the exchange of information; and the consumer rights movement have fostered a trend for more patient participation in health care decision making. Health care professionals are expected to interact with patients, and provide adequate information in order that patients may participate in informed decision making. With the emphasis on patients' participation as informed decision makers, health care decision making research has focused on examining patients' desire for and use of health care information, and their degree of participation in health care decisions.

Treatment Decisions in Life-Threatening Illness

A qualitative study by Degner and Beaton (1987) contributed the foundational work in the area of decision behaviour when confronted with a life-threatening illness. Degner and Beaton (1987) examined how treatment decisions are made in life-threatening illness through a 4 year study of 14 health care settings in the province of Manitoba. Their descriptive theory was based on a qualitative analysis of life-death decisions from the perspectives of patients, families, and health care professionals. The theory described four patterns of control over decision making: provider-controlled decision making (the health care professional had final control over the treatment design), patient-controlled decision making (the patient had final control over the treatment design), family-controlled decision making (families exert control over the design of treatment for the seriously ill patient), and jointly-controlled decision making (a shared control over the treatment design).

Degner and Beaton found that patients and families exercised little, "if any, control over final decisions about treatment" (p.135). Participation in treatment decision making was limited by lack of information and assistance in interpreting provided information. The sequential process of decision making was not examined. However, the information barriers outlined would preclude patients from following the tenants of rational decision making models.

On the basis of Degner and Beaton's study, Degner and Russell (1988) utilized two card sorts to examine the preferences of sixty oncology outpatients about alternative roles they might want to play in treatment decisions. The patient-physician alternative and the patient-family alternative card sorts presented four vignettes which described various patterns of control over treatment decision making. Control patterns ranged from patient keeping control, through shared control, to giving away control. The majority of patients (66%) chose control patterns that were closer to keeping control than giving away control. The most preferred pattern in the patient-physician alternative was shared control. Patients were more willing to give decision responsibility to the physician than to family members.

On the basis of Degner and Beaton's (1987) and Degner and Russell's (1988) work, Degner and Sloan (1992) developed a card sort tool to measure preferences for participation in decision making along two dimensions (patient/physician, and family/physician). The purpose of the family/physician dimension was to elicit whom the patient would want to make treatment decisions if they became too ill to participate. Each dimension was evaluated by a card sort procedure which had five cards describing five potential roles in decision making. Role preference ranged from patient/family keeping control (active), through shared control with the physician (collaborative), to giving away control to the physician (passive). Degner and Sloan used the card sorts to compare the role preferences of newly diagnosed cancer patients (n = 436) and members of the general public (n = 482) in regards to cancer treatment decisions.

The majority of patients (59%) preferred the physician to make treatment decisions, 29% wanted a collaborative role and only 12% wanted an active role. In contrast, 64% of the general public preferred an active role in treatment decisions. The researchers suggest that a life threatening illness influences decision making preferences and leads to a less active role in treatment decisions. Both groups wanted the physician and family to collaborate in treatment decisions if they were too ill to participate.

Only 15% of the variance in preferences was accounted for by sociodemographic factors. Age was the most important predictor in both groups, with younger people wanting a more active role. Younger cancer patients also wanted more family involvement than the general public. Level of education only influenced the patient group, with increased educational level predicting increased decisional involvement. Women with reproductive cancers preferred a more active role than men with reproductive cancers. Gender effect was not seen in other types of cancer. Female cancer patients preferred more family involvement than the general public. Stage of disease and symptom distress were not related to role preferences. The investigators suggest that the best clinical approach is individual assessment of role preference.

A qualitative study by Pierce (1993) described the decision making of women (n = 48) facing treatment for breast cancer. She found five empirical indicators of decision behaviour: perceived salience of alternatives, decision conflict, information seeking, risk awareness, and deliberation. Perceived salience is the extent to which a person becomes aware of and is attracted to a particular alternative on the basis of information provided by the physician. Decision conflict occurs when the decision maker considers more than one option, and is motivated to take action (e.g., seeking information). Information seeking occurred when women were unable to discriminate between alternatives or experienced conflict. Risk awareness was the degree of uncertainty involved with each option. "Deliberation occurs while the decision maker seeks and evaluates the alternatives and gathers information required to make the choice" (p.25). Deliberation only occurred when women considered more than one option.

Pierce formulated three decision making styles on the basis of individual variations of the aforementioned empirical indicators. The three decision making styles are deferrer, delayer, and deliberator. Deferrers (41%) were influenced by the salience of an alternative, allowing them to make quick conflict-free decisions. Deferrers frequently deferred to physicians' judgments. Deferrers were older than women in the other groups, with an average age of 56 years.

Delayers (44%) considered and deliberated about at least two options, jumping from consideration of one option to another. When one option dominated, they made a choice. Like deferrers, delayers minimally sought information and were satisfied with their decisions. The mean age of delayers was 45 years.

Alternatives had more equal salience for deliberators (15%) and they sought specific and technical information. They processed large amounts of information before they were comfortable and several deliberators went against popular or professional opinion to get their preferred treatment. Deliberators experienced the greatest psychological distress and needed more time to make decisions. Pierce suggests that the deliberator is closest to rational models of decision making. However, this decision making style was only present in a small percentage of subjects.

Although Pierce (1993) found elements of the rational decision making process in her study, a large percentage of subjects did not conform to the sequential steps outlined in the rational decision making process. Patients varied in their preferences for type and amount of information, and the degree of control they exerted in the decision making process.

The literature on "actual" health care decision making suggests that individuals vary in their approach to treatment decision making and do not always utilize the criteria of rational decision making models. The following section examines the relationship between desire for information and preferred roles in treatment decision making.

Information and Treatment Decision Making

The basic notion of decision making purports that there are two essential elements to decision making: knowledge and preference (Levine, Gafni, Markham & MacFarlane, 1992). Health care professionals are required to provide patients with the information they need to participate as informed decision makers. In addition, health care professionals are expected to encourage patient involvement in decision making. However, the previously mentioned research suggests that there is individual variation in patients' desire for information and decisional control. Several studies have examined the relationship between information and decision making preferences. In addition, some of the studies have examined medical and sociodemographic characteristics related to information and decision making preferences. **Table 3** presents studies that have investigated the aforementioned variables.

Table 3

Information and Treatment Decision Making

Author, Year	Purpose	Sample	Instruments
Cassileth, Zupkis, Sutton-Smith, and March, (1980)	To explore the degree to which patients prefer to become informed about and participate in medical decisions. To determine medical and demographic characteristics related to information and decision making preferences. To determine if a relationship existed between hopefulness and informational and participation preferences.	n = 256 hospitalized and outpatient (59%) oncology patients.	Preference for participation: two dichotomous alternatives (leave the decision to the physician or participate in decisions) Information preferences: 1. five point scale with range from "no more details than needed" to "as many details as possible" 2. desire for "good "or "good and bad" information Hopefulness-Beck Hopelessness Scale

Major Findings: The majority of patients (67%) preferred to participate in treatment decisions, 71% wanted detailed information, and 85% wanted all information "good and bad". Participation in treatment was desired by patients who were younger ($p<0.001$) and better educated ($p<0.001$). Detailed information was sought by younger ($p<0.001$) and better educated patients. Patients who wanted "good and bad" information were younger ($p<0.05$) than patients who only wanted "good" information. Patients who wanted detailed information and wanted to be involved in decision making were more hopeful. There was a strong positive correlation between preference for detailed information and desire to participate in decisions ($p<0.0001$).

Table 3 (cont'd)

Author. Year	Purpose	Sample	Instruments
Blanchard. LaBrecque. Ruckdeschil,.and Blanchard. (1988)	To examine information and decision making preferences of hospitalized adult patients with cancer . To determine medical and demographic characteristics of patients who prefer to participate in their care versus patients who prefer a more authoritarian model of care.	n = 439 hospitalized adult patients with cancer in a teaching hospital.	Preference for information: desire for 'good" or "good and bad" information. Preference for participation: two dichotomous alternatives (leave decision to physician or participate in decision).

Major Findings: The majority of patients (92%) wanted all information (good and bad) and 69% of patients wanted to participate in decision making. 75% of patients who wanted all the information also wanted to participate in decision making. The investigators suggest that preference for information does not equate with preference for participation in decision making. Patients who participated in decision making were younger ($p<0.001$) and had a poorer prognosis ($p<0.05$) than patients who did not participate. Male gender ($p<0.01$) and a married status ($p<0.01$) were positively correlated with non-participation in decision making.

Author. Year	Purpose	Sample	Instruments
Ende. Kazis. Ash . and Moskowitz. (1989)	To examine decision making and information preferences. To identify characteristics that influence preferences.	n = 312 medical patients from a primary care facility.	Autonomy Preference Index: a fifteen item decision making scale and an eight item information scale (for both scales totals were adjusted to range from 0-100. with 0 corresponding to lack of desire for decision making or information)

Major Findings: The mean score for desire to participate in decision making was 33.2 + or - 12.6. The mean score for desire for information was 79.5 + or - 11.5. There was no correlation between patients' desire for information and their preferences for decision making. Younger age ($p<0.001$) and higher educational level ($p<0.01$) were positively associated with a desire for participation in decision making. Younger age ($p<0.001$) and higher educational level ($p<0.05$) were positively associated with a greater desire for information. Although less significant than the aforementioned variables, other demographic variables (higher income, higher occupational status, and unmarried status) were associated with a greater desire for decisional control.

Table 3 (cont'd)

Author, Year	Purpose	Sample	Instruments
Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, and Till, (1989)	To determine how actively patients seek information about their health status. To compare patient's "ideal" preference for participation in treatment decision making with their "actual" experience. To compare the desire for information with the actual role patients play in treatment decision making.	n = 52 oncology patients from a ambulatory care facility.	Krantz Health Opinion Survey Preference for Participation Questionnaire : 5 point scale ranging from physician assuming full responsibility to patient assuming full responsibility for decision making. Information Seeking Questionnaire : 18 linear analogue scales about type, amount, detail of information and degree of active information seeking.

Major Findings: The majority of patients (63%) believed the physician should assume responsibility for decision making, 27% desired a shared responsibility, and 10% wanted to assume responsibility for decision making. 77% of patients participated in decision making to their desired extent. 83% of the patients who reported a lack of congruence between actual and preferred participation indicated that their actual participation was less than their preferred participation. The mean of the summary score of the subscales of the information-seeking questionnaire was 72.6 with a range of 0-100 and a S.D.. of 29.5. There was a trend for increased information seeking with increased preference for decision making. However, 63% of patients who had high information seeking scores preferred minimal involvement in decision making. The investigators suggest that the need for information may be related to factors other than desire for active involvement in decision making.

Table 3 (cont'd)

Author.Year	Purpose	Sample	Instruments
Hack, Degner, and Dyck. (1994)	To examine the relationships between patients' preferences for involvement in treatment decision making and their preferences for information.	n = 35 women with stage I and II breast cancer from two oncology clinics.	Preference for Control Card Sort (Degner & Sloan, 1992) - Patient-Physician dimension. Preference for Information Card Sort: preferences for diagnostic,prognostic, and treatment-related information. Semi-structured interview patients elaborated on their preferences.

Major Findings: The majority of patients (57%) preferred a collaborative role in decision making, 23% wanted an active role, and 20% a passive role. Education was the only sociodemographic variable that correlated with decisional role preference. Better educated women preferred a more active role ($p<0.01$) than women with less education. There was a significant relationship between decision making preferences and information preferences. Active and collaborative patients consistently wanted detailed information. Passive patients varied in the amount of desired information. Some wanted minimal information and others wanted detailed information.

Table 3 (cont'd)

Author. Year	Purpose	Sample	Instruments
Davison. Degner.and Morgan. (1995)	To determine whether a relationship exists between preferences for involvement in decision making and type and amount of preferred information.	n = 57 men diagnosed with prostate cancer from a community urology clinic.	Preference for Control Card Sort (Degner &Sloan.1992) -Patient-Physician dimension. Categories of Information Preferences : 1. nine categories presented: importance ranked by presenting two choices at a time. 2. nine categories ranked by amount of information desired in each category (4 point Likert Scale 1= almost nothing. 4 = almost everything)

Major Findings: The majority of men (57.9%) preferred a passive decision making role. 23% a collaborative role. and 19% an active role. The three preferred categories of information were: information on disease advancement. likelihood of cure. and types of treatment available. The majority of men (>50%) wanted a fair bit of information to almost everything on eight of the information categories Men who chose the collaborative card and the card "physician to make treatment decision only after seriously considering my opinion" wanted significantly more information on the three preferred categories of information than men who chose the other three cards. Recent diagnosis($p<0.04$). less education($p<0.09$). married status($p<0.15$). and an earlier stage of disease ($p<0.49$) were correlated with a preference for a passive role in treatment decision making. The investigators suggest that the high percentage of men who chose a passive decision making role may have been related to the effect of their wives' attendance during clinic appointments. Wives asked physicians more questions than their husbands asked and may have assumed more of the decision making role for their husbands.

Table 3 (cont'd)

Author. Year	Purpose	Sample	Instruments
Degner. Kristjanson. Bowman. Sloan. Carriere, Bilodeau, Watson. and Mueller. (1997)	To determine the degree of control that women with breast cancer wished to assume in treatment decision making To determine the extent to which women believed they had achieved their preferred level of control. To determine the types of information judged to be most important by different groups of women.	n = 1012 women with breast cancer from 4 oncology clinics.	Preference for Control Card Sort (Degner and Sloan. 1992) -Patient-Physician dimension. Categories of Information Preferences: nine categories presented. information ranked by presenting two choices at a time.

Major Findings: The majority of women (44%) preferred a collaborative decision making role. 22% preferred an active role. and 34% preferred a passive role. Only 42% of women believed they had achieved their preferred level of control in treatment decision making. Women under the age of 50 (p=.000). with greater than high school education (p=.000). who were married (p=.011). who had a lumpectomy (p=.000), and whose first language was English (p=.029) were more likely to prefer active or collaborative roles in treatment decision making. The most important predicator of preferences was educational level: women who had greater than high school education were three times more likely to prefer an active role in decision making than were women with less than high school education. The highest priority information needs were: information related to chances of cure. stage of disease. and treatment options. There were no differences in information needs by educational level. stage of disease at diagnosis. or the role that the woman actually assumed in decision making.

Studies that involved patients as participants had sample sizes that ranged from 35-1012, with only four studies having less than sixty subjects. Six studies found that the majority of patients did want to participate to some extent in decision making (Blanchard et al, 1988; Cassileth et al., 1980; Degner et al., 1997; Degner & Russell, 1988; Hack et al., 1994; Pierce, 1993). In contrast, four studies found a greater percentage of patients who preferred that their physician make the treatment decision (Davison et al., 1995; Degner & Sloan, 1992; Ende et al., 1989; Sutherland et al., 1989). However, levels of decisional participation were based on different measurement tools, different medical decisions, and different patient populations. Studies that examined the discrepancies between actual and preferred roles found that the actual level of decision making participation was less than what patients desired (Degner et al., 1997; Sutherland et al., 1989). Based on reported levels of participation, patients with cancer may desire more involvement in medical decisions than other patient populations (Blanchard et al., 1988; Degner et al., 1997; Degner & Russell, 1988; Hack et al., 1994; Pierce, 1993).

Educational level was found to be the most predictive sociodemographic variable related to preference for decisional control, with patients with higher educational levels preferring greater control over decision making (Cassileth et al., 1980; Davison et al.,1995; Degner et al., 1997; Degner & Sloan, 1992; Ende et al., 1989; Hack et al., 1994). Age was also found to be related to preference for decisional control, with younger patients preferring greater control (Blanchard et al., 1988; Cassileth et al., 1980; Degner & Sloan, 1992; Ende et al., 1989; Pierce, 1993). The two studies that examined patients' desire for family involvement if they were too ill to participate reported different findings. Degner and Russell (1988) found that patients were more willing to give decision responsibility to the physician than to family members, whereas Degner and Sloan (1992) found that patients preferred the physician and family to collaborate in treatment decisions if they were too ill to participate. However, the wording of the role preference statements in the family/physician dimension in the two studies was not identical.

The majority of studies that examined preference for information found that all patients desire to be well informed. However, Hack et al. (1994) found that some patients desired minimal information. Cassileth et al. (1980) and Hack et al. (1994) suggest that desire for information and desire for decisional control are correlated: a greater desire for control indicating a greater desire for information. However, other researchers found no correlation between information seeking and decision making preferences (Blanchard et al., 1988; Ende et al., 1989; Sutherland et al., 1989).

In summary, patients desire disease and treatment related information, and some prefer to be involved to varying extents in treatment decision making. When decisional role and informational preferences are known, health care providers can respect patients' wishes and gear their communication and decision making accordingly. Individual assessment of preferences is key to promoting individualized care (Waterworth & Luker, 1990).

Empirical literature indicates that husbands of women with breast cancer are involved in treatment decision making to varying degrees, and have expressed a need for disease and treatment related information. Information assists husbands of women with breast cancer to cope with the stress of the cancer experience, prepares them for their supportive role, and facilitates their participation in decision. However, the literature on preference for control over treatment decisions and desire for disease related information is exclusive to the patient's preference or patient's preference for family involvement if they are too ill to participate . Husbands of women with breast cancer, like their wives, should have their preferences for information and decisional control assessed and respected by health care professionals.

Role of the Family in Health Care Decisions

The final section related to decision making will explore the family's role and involvement in health care decisions and spousal involvement in breast cancer treatment decisions. Consulting the family in health care decisions has generally been viewed as a medical courtesy, and the family is thought to have neither ethical or legal authority in treatment decisions (Jecker, 1990). Ethicists have suggested that the prevalent ethic of patient autonomy ignores family interests in treatment decisions (Blustein, 1993; Hardwig, 1990; Jecker, 1990; Nelson, 1992). Hardwig (1990) contends that the current individualistic model is isolating and destructive to both patients and their families. Constraints on patient autonomy such as anxiety, depression, and fear may affect the patient's ability to make decisions (Blustein, 1993). Families can act as resources and enhance the patient's decisional abilities because of their intimate knowledge of the patients' desires and values, and their shared history (Blustein, 1993; Hardwig, 1990; Jecker, 1990; Nelson, 1992). Families can also act as advocates and put patients on a more equal footing with health care providers (Blustein, 1993).

Individual decision making research overlooks the ways in which families enable autonomy to function meaningfully (Jecker, 1990). The patient's identity is constituted by family relationships, and the patient may be too enmeshed in their relationships to be singled out as the sole decision maker (Blustein, 1993). Brody (1978) (as quoted in Jecker, 1990) suggests that the family provides the patient with an avenue for "bouncing off" ideas and discerning the values that influence decisions. Values emerge from dialogue with people whose opinions and reactions are cared about (Brody, 1978).

Literature related to the familiy's role in health care decisions is often anecdotal in nature or related to the decision making role the family assumes for family members that are unable to make informed, competent decisions . The following studies examine the role of families in the health care decisions of competent adults.

Family Involvement in Health Care Decisions

Pratt, Jones, Shin and Walker (1989) examined perceptions of decisional autonomy and decision making processes among sixty-four caregiving daughters and their elderly single mothers. Decision areas investigated ranged from routine daily decisions to major health and financial decisions. Although mothers had the final say in all decisions, daughters were highly influential in major health and financial decisions. Daughters had the most significant influence in major health care decisions. The daughters' knowledge of the mothers' preferences was the most frequently cited reason for involvement in decision making. The investigators suggest that decisional values and preferences are embedded in social relationships and as such families play a role in supporting an individual's decision making autonomy.

Sims, Boland, and O'Neill (1992) used a grounded theory methodology to examine decision making from the perspective of family caregivers (n = 17) involved in a home health care program. Analysis showed that families tend to maintain previous roles in decision making to obtain a sense of comfort and support. When caregivers were forced to be sole decision makers, the loss of mutual decision making led to feelings of isolation and burden on behalf of the caregiver. Decision making processes did not resemble rational models of decision making. Values, experiences, and emotions provided the framework for decision making. Information was filtered through this framework and options were evaluated by this framework.

A study by Ebell, Smith, Seifert, and Polsinelli (1990) explored how patients (n =339) arrived at decisions regarding Do-Not-Resuscitate (DNR) orders. The majority of patients indicated that the physician, spouse, and children would be included in the decision making process. Spouses were ranked as the most valued advisors. Patients expressed a desire to consult with their physicians about DNR decisions. However, only eleven percent had discussed their wishes for DNR status with their doctors, while forty-four percent had discussed their wishes for DNR status with their family.

A qualitative study examined the experiences of patients and spouses undergoing experimental treatment for advanced liver cancer (Stetz, 1993). Spouses were found to be co-decision makers, and assumed shared responsibility in seeking out and entering treatment regimes. Three studies related to reproductive issues concur that spouses are co-decision makers (Bean & Egelhoff, 1984; Frank, 1989; Miller, Shain & Pasta, 1991). Couples were influenced by their spouse's feelings and beliefs and acted as a unit in making decisions.

The conclusions of this review are: families/spouses influence health care decisions; the family's knowledge of patient's preferences provides support in decision making; family health care decisions are influenced by values and emotions; spousal input into decision making is valued; and spouses often act as co-decision makers.

Spousal Involvement in Breast Cancer Decisions

The literature on spousal role in breast cancer decisions is limited. However, a few studies have documented the value of spousal involvement in treatment decisions and one study has examined family decision making processes with respect to surgical treatment for early stage breast cancer treatment.

Wellisch, Jamison, and Pasnau (1978) assessed factors related to husbands' adjustment post mastectomy (n = 31). One aspect of the study examined the husband's degree of involvement in treatment decisions. Fifty-six percent of the husbands viewed themselves as being involved to quite or a very considerable extent. Twenty-three percent indicated that they wished they had been more involved.

Men who were more involved rated their sexual satisfaction higher than did less involved men. Men who were not involved demonstrated a greater degree of emotional disruption than men who were involved in decision making. However, the investigators suggest that it is more important to ascertain the couple's normative pattern of decision making, than to impose intensive involvement on all husbands.

Valanis and Rumpler (1985) reviewed literature to examine the factors which influenced women in their breast cancer treatment decisions. Families and spouses were viewed as having a significant influence on the women's treatment decisions. The authors suggest that excluding a spouse from treatment decision making has the potential for creating friction in the couple's relationship. Valanis and Rumpler maintain that spousal involvement in treatment decisions provides support for the woman when making decisions, and is crucial for post-surgical sexual adjustment.

A qualitative study by Hilton (1994) examined family decision making processes in relation to early stage breast cancer treatment. Forty-one of the fifty-five families interviewed included spouses as family members. Family decision making patterns were similar to those described earlier by Pierce (1993) in her study of women with breast cancer. The four major patterns found were: deference to physician, minimal exploration, joint engagement, and extensive deliberative examination.

Deferrers showed negligible involvement in the decision making process and deferred to the physician for decision making. Spouses were either not involved or also deferred to the physician. These families sought minimal information and some considered information to be threatening. Deferrer families were passive in their prediagnosis decision making and had private decision areas (certain decisions are the sole responsibility of the family member directly affected by the decision). Deferrer families were generally older and had lower levels of education than the families in the other patterns. Deferrers were generally satisfied with the health care team.

Minimal explorers were also quite passive, being minimally involved in treatment decisions. These families were satisfied with minimal information and generally followed the physician's recommendation. Prediagnosis decision making patterns were generally passive, but less so than deferrers. Like deferrers, these families were generally older and had less education than families who showed more active participation. Minimal explorers were usually satisfied with the health care team.

In joint engagement, families engaged in moderate joint decision making. They often followed the physician's recommendation but only after they weighed the alternatives. Joint engagers moderately searched for information, sought opinions of other family members, and sometimes sought a second medical opinion. Information was viewed as helpful because it gave them a sense of control. Prediagnosis decision making patterns were mixed, but generally active and involved other family members. Joint engagers were younger and better educated than respondents who fit the previous two patterns. Satisfaction with the health care team varied among these families.

Families who were categorized as extensive, deliberate examiners were actively involved in decision making. They tended to question the physician's recommendation. They undertook extensive information searches, sought the opinions of other family members and friends, and often sought second medical opinions. Technical information was viewed as critical to decision making because it provided a sense of control. Prediagnosis decision making patterns were generally active and rational, and involved other family members. Like joint engagers, these families were younger and better educated than deferrers and minimal explorers. The families in this category were frequently dissatisfied with the health care team.

Approximately half of the families participated to some degree in the decision making process. Couples were usually congruent in their participation, both either participating actively or passively. Prediagnosis decision making patterns were maintained in the cancer experience. "...Similarity of views and the presence of private decision areas often determined the amount of information shared by the partner" (p.14). Treatment decisions were usually joint, involving the spouse or whole family. Hilton suggests that health care providers should assess the importance of spousal/family involvement for decision making and support previous decision making patterns.

In conclusion, spouses are often involved in breast cancer treatment decisions; spousal involvement is beneficial for both the patient and spouse; prediagnosis couple decision making patterns influence breast cancer treatment decisions and as such should be supported by health care professionals. Assessing each partners' preferred role in treatment decision making is the initial step to facilitating couples' previous decision making patterns.

Summary

This chapter has outlined the rationale for this study. Literature related to breast cancer treatment choices, spouse/family responses to illness, significance of information for family/spouse, and decision making has been reviewed. The literature indicates that a diagnosis of breast cancer creates physical, psychological, and social distress for both the woman and her husband.

Husbands of women with breast cancer report that the diagnostic period is most stressful, due to lack of information, and the expectation of making treatment decisions while coping with the emotional turmoil of the diagnosis. Empirical research reports that husbands influence breast cancer treatment decisions and are often involved in treatment decision making. In addition, couples' prediagnosis decision making patterns are often maintained during breast cancer decision making. However, husbands are not always formally acknowledged by health care professionals as having a role in decision making, and as such are not always included in patient-physician treatment discussions. Lack of inclusion in treatment discussions limits husbands' ability to obtain desired information; may prevent husbands from developing rapport with, and seeking support from health care providers; may make husbands feel peripheral to the treatment process; and may hinder their ability to assist their wives in treatment decision making.

Husbands of women with breast cancer have been shown to have some of the same disease/treatment information needs as do their wives. However, husbands also have information needs related to emotional support for and interaction with their wives. Literature indicates that information assists husbands of women with breast cancer to cope with the stress of the cancer experience; prepares them for their supportive role; and information facilitates husbands'involvement in treatment decisions.

The literature suggests that patients with cancer may gain a sense of control over their illness experience by acquiring information and participating in treatment decision making. Participation in treatment decision making has been shown to have a positive effect on psychological outcomes for both women with breast cancer and their husbands. However, empirical research indicates that there is individual variation in patients' desire for information and their preferred roles in decision making. Therefore, the best clinical approach is individulized assessment of information needs and decisional role preference. To date, there has been no research that examines husbands' preferred roles in breast cancer decision making, and no research that examines the relationships between husbands' information needs and their preferred roles in breast cancer treatment decision making.

Knowledge of husbands' information needs may assist health care professionals to address their information needs. Addressing husbands' information needs may enhance their ability to cope with the breast cancer experience, and may enhance their ability to assist their wives with treatment decision making. Knowledge of husbands preferred roles in breast cancer treatment decisions may encourage health care professionals to include husbands in treatment decision making to their desired extent and may facilitate previous couple decision making patterns.

CHAPTER IV

METHODOLOGY

Introduction

A descriptive survey of husbands of women with breast cancer was undertaken to: describe the information needs of husbands; and to modify, refine and test a tool to measure husbands' preferred roles in their wives' surgical treatment decision making. The Control Preferences Scale (CPS) (Degner, Sloan & Venkatesh, 1997) previously used with women with breast cancer, was modified, tested, and used with husbands of women who had recently undergone surgery for breast cancer. The goal of methodological research is "to develop an effective, serviceable and trustworthy instrument that can be used by other researchers and to evaluate his or her success in accomplishing this goal" (Polit & Hungler, 1991, p.216).

A methodological study was chosen because the CPS had not been previously tested with husbands of women with breast cancer. Modification and testing of the tool occurred during the pilot phase of the project. In the second phase of the study, a descriptive design was used. A descriptive design was chosen as it met the following criteria, as outlined by Brink and Wood (1989).

1) The variables exist in the population, and are single variables amenable to description.

2) There is little or no literature that describes the variables in the population.

3) Previous research provides the rationale for the present study (p.126).

This chapter will include a description of the instruments, methodology, data analysis, data collection method, the setting, sample, and approaches to protect human subjects.

Instrumentation

The research data was obtained using the following three instruments: Control Preferences Scale - Husbands, Family Inventory of Needs - Husbands, and a Sociodemographic Questionnaire.

A - Control Preferences Scale

The Control Preferences Scale (Degner, Sloan, & Venkatesh, 1997) was modified for use with husbands of women had recently undergone surgery for breast cancer. The CPS consists of five cards containing statements that describe five potential roles in decision making that a patient could assume when interacting with the physician about treatment decision making (Appendix B). The role preference statements range from the patient keeping control (active) through the patient sharing control with the physician (collaborative) to the patient giving away control to the physician (passive). The CPS-Husbands role preference statements range from husband and wife keeping control (active) through shared control with the physician (collaborative) to giving away control to the physician (passive). As previously mentioned, the CPS is easy to administer and has proven to be a reliable and valid measure of preferred roles in health care decision making (Degner, Sloan & Venkatesh, 1997). The procedure for administration of the CPS is described under the Pilot Study.

B - Family Inventory of Needs - Husbands

The Family Inventory of Needs - Husbands (FIN-H) was developed by Kilpatrick (1995) to identify the information needs of husbands of women newly diagnosed with breast cancer (Appendix C). Kilpatrick found the FIN-H to be clear, content valid and simple to administer. Internal consistency reliability as measured by Cronbach's alpha coefficient was .91 at time 1 (initial interview) and .93 at time 2 (24 hours later) (Kilpatrick, 1995). Kilpatrick's factor analysis suggested that the FIN-H is a multidimensional scale with five subscales (Appendix D). The FIN-H consists of thirty items addressing husbands' concerns and need for information. The tool assesses the degree of importance of the thirty items and the extent to which husbands perceive that their identified needs are met.

Each participant was asked to read each need statement and rank the importance of each statement by placing a number from one to five in the first column (one being not important and five being extremely important). After ranking the degree of importance of the need statement, participants were asked to place a check mark in either the second, third or fourth column indicating whether the need had been met, partly met or unmet.

C - Sociodemographic Questionnaire

The literature suggested that age (Blanchard et al., 1988; Cassileth et al., 1980; Degner & Sloan, 1992; Hilton, 1994; Strull, Lo & Charles, 1984) and educational level (Degner & Sloan, 1992; Hack et al., 1994; Hilton, 1994; Strull et al., 1984) influenced preference for control over treatment decisions. Kilpatrick (1995) found that husbands' age, education, and occupation and their wives' stage of disease, type of surgery, and number of surgeries influenced either the number of identified needs, the type of identified needs or the number of unmet needs. Therefore, participants were asked for data pertaining to these preference for control and information variables (Appendix M).

Pilot Study: Phase I : Sample, Method, and Analysis

The CPS (Degner,Sloan, & Venkatesh, 1997) was modified to index the husband's preferred role in treatment decisions (Appendix E). A pilot study was used to establish the reliability and validity of this modified tool.

A pilot study is used to pretest the methodology, instruments, directions, and data recording forms (Brink & Wood, 1989). A small sample of the defined study population is used as subjects for the pilot study (Brink & Wood, 1989). Six husbands of women with breast cancer were recruited from the Breast Cancer Action support group to act as pilot test participants. The panel was asked to assess the modified role statements for clarity, and consistency. Following an explanation of the pilot study, husbands were provided with a written disclaimer (Appendix P) and an explanation of the clarity and apparent internal consistency measures (Appendix Q & R). Husbands were then asked to complete the CPS-H with the following direction: "How would you have preferred to participate with your wife and the doctor with respect to your wife's surgical treatment decision making ?"

Imle and Atwood's (1988) method for assessing a tool's clarity and apparent internal consistency was used to pilot test the modified CPS. Imle and Atwood used the term apparent internal consistency to refer to the judgement made by content experts that the items reviewed represent the same construct. Imle and Atwood suggest that an item should be retained if agreement among raters is equal or greater than 70%.

The Control Preferences Scale (CPS) is based on the hypothesis that individuals have systematic preferences about keeping (active), sharing (collaborative) or giving away (passive) control over health care decision making (Degner, Sloan & Venkatesh, 1997) (Appendix F). The modified scale was analysed in accordance with unfolding theory as described by Degner, Sloan, and Venkatesh . The premise of unfolding theory is that each individual has a specific position on a hypothetical psychological continuum called an "ideal point" (Degner, Sloan & Venkatesh, 1997) (Appendix G). The ideal point (I scale) can be determined by presenting successive paired comparisons of stimuli falling on the continuum. The individual's successive choices on either side of the ideal point becomes meshed into a simple order and represents the rank order preference (Degner, 1984).

According to Degner, Sloan, and Venkatesh, three different research procedures have been used for administration of the CPS. The authors state that the "fixed order presentation " is useful since subjects can locate their ideal point in general terms (active, collaborative, passive) in their paired comparisons and the order effects are held constant across all subjects. The revised CPS consists of five cards, each describing a role (active, collaborative, passive) that the husband could assume in breast cancer decision making. Each card is labeled by a letter (A,B,C,D,E). The order of the cards in fixed presentation is as follows: B,D,C,A,E -beginning with the first two cards: B and D. Husbands were asked to select the preferred card. The preferred card was placed on top of the nonpreferred card. The next card (C) was compared to the preferred card . If the husband still preferred the previous card over the new one, the previous card was flipped over and the new card was compared to the next one in the stack. If the husband preferred the new card, the new card was placed between the two cards in the new stack, if the previous second card was preferred, the new one was placed last in the new stack. This process continued until the husband's entire preference was unfolded into his rank order preference.

There are 120 different ordered permutations for any five point hypothetical scale/metric, but there are only eleven valid ordered permutations (Degner, Sloan & Venkatesh, 1997) (Appendix H). Determining the proportion of the preference orders obtained that fall on the hypothesized dimension provides evidence about whether or not the revised stimuli form a unidimensional scale. If 50% plus one of the pretest subjects preference orders fall on the metric (valid permutations), then the revised scale is justified (Degner, Sloan & Venkatesh).

Phase II : Population, Sample and Setting

The population for this study was all married and common-law husbands living with women who had recently undergone surgery for breast cancer and were residing in the province of Manitoba. A consecutive sample of seventy husbands (over 18 years of age and able to read and write English) of women who had recently undergone surgery for breast cancer was used for the second phase of the study. Following approval from the facilities involved, the sample was recruited from five Winnipeg hospitals (Grace General Hospital, Health Sciences Centre, Misericordia General Hospital, St. Boniface General Hospital, and Victoria General Hospital).

The number of women diagnosed with breast cancer and treated at a health care facility in Manitoba has steadily increased from 712 in 1992 to 761 in1994, and 1996's estimate of new cases is 760 (Canadian Cancer Statistics, 1996; Manitoba Cancer and Research Foundation Statistics, 1992, 1994). In 1995, approximately 67 % of all breast cancer surgeries occurred in the five previously mentioned urban recruitment facilities (Manitoba Cancer and Research Foundation Statistics, 1995). Approximately 62% of women who are diagnosed with breast cancer live in urban Manitoba (Manitoba Cancer and Research Foundation Statistics, 1995). Approximately 45% of all Manitoban women diagnosed with breast cancer (rural and urban) are married or living with common- law husbands (Manitoba Cancer and Treatment Foundation Statistics, 1995). Using the aforementioned estimations, there will be approximately 342 Manitoban women diagnosed with breast cancer who are married or living with a common-law husband in 1996. A sample size of 70 will represent approximately 20% of Manitoban men who are married or living common-law with women who have been diagnosed with breast cancer.

Therefore recruitment of 70 participants from five settings was feasible. A sample size of 70 was sufficient to test the instruments and generate hypothesis related to information needs and decision making preferences of husbands of women who have recently undergone surgery for breast cancer.

Phase II: Data Collection

The researcher contacted each of the five facilities several times per week to assess the number of potential participants undergoing breast cancer surgery. Following surgical intervention for breast cancer, head nurses, charge nurses, or nurses assigned to the patient asked women (whose husbands met the eligibility criteria) for permission to have their names submitted to the researcher. The researcher then approached the woman to explain the study, prior to discussing the study with her husband. The woman was asked to provide written consent to contact her husband and access her medical record. The woman was also asked for assistance for contact arrangements with her husband. The medical record was reviewed post discharge for information related to type of surgery, stage of disease and prognostic indicators.

The researcher contacted the husband in person or by phone to explain the study; formally invite him to participate in the study; and to determine a time and place for data collection. Following explanation of the study and disclaimer, the husband was asked to complete the sociodemograhic questionnaire and the FIN-H Scale. The Control Preferences Scale- Husbands (CPS-H) was then administered as outlined in the pilot study. Once the CPS-H preference order was obtained, husbands were asked to pick the one card that was closest to the role they had actually assumed in their wives' surgical treatment decision making.

If the wife was present, the husband was given the option of remaining in or leaving the room while the instruments were being completed. In the few cases where the husband asked his wife for input for completion of the instruments, the couple was reminded that there were no right or wrong answers and that this study was eliciting the husband's opinion. The length of time spent with each participant ranged from 20 minutes to 2 hours. This time included an explanation of the study, the disclaimer, and the data collection tools; answering questions related to the tools as participants completed the tools; and listening to questions, concerns, and diagnostic history from both the husband and wife.

Participant accrual began October 22, 1996, and continued until July 2, 1997.

Phase II : Data Analysis

Quantitative methods of data analysis were used in this study. Descriptive statistics were used to summarize the sample according to sociodemographic variables; to describe the mean, standard deviation, and frequency of the items on the needs scale; and to describe the frequency of the categories of decisional role preference (active, collaborative, passive). Parametric testing was used to determine how the independent variables (e.g., age, education, stage of disease, category of decisional role preference) affected the dependent variables (number of needs sum score of needs, and extent to which needs were met). The FIN-H was assessed for internal consistency reliability using Cronbach's alpha coefficient. The reliability and validity of the CPS-H were analysed by unfolding theory.

The following research questions were addressed in this study:

1) In the pilot study, to what extent does the CPS-H demonstrate clarity, apparent internal consistency, and unidimensionality?

The expert panel of judges assessed the role statements for clarity and apparent internal consistency. The unidimensionality of the CPS-H was analysed according to unfolding theory.

2) What are husbands' preferred roles for participation in treatment decisions when their wives have recently undergone surgery for breast cancer?

Husbands' decisional preferences were analysed in accordance with unfolding theory. Rank order preferences were "unfolded" to obtain the scale position of the role statements. The role preference orders are called individual scales (I). The unfolded scale is called a joint scale (J) because it represents both the individual and the role statements. "The object is to search for the J scale that best represents the I scales in a unidimensional space" (Degner & Russell, 1988, p.371). The combination of five decisional roles and their midpoints generates an ordinal score ranging from 1-11 (Degner & Sloan, 1992). The lower the score, the greater the preference for control over decision making. Husbands' scores were used to classify their decisional role preferences as: active, collaborative, or passive. Discrepancies between preferred and actual roles were used to calculate a discrepancy score for each husband.

The distribution of husbands' role preference scores according to husbands' demographic variables (i.e., age, education) and their wives' disease/treatment variables (i.e., stage of disease, type of surgery) were compared using the Fisher's Exact Test

3) What is the internal consistency of the Family Inventory of Needs- Husbands (FIN-H) Scale?

The internal consistency of the FIN-H was assessed using Cronbach's alpha coefficient. The criterion level for the coefficient alpha was .80 and above, as suggested by Nunnally (1978). Nunnally also recommended that 50% of the inter-item correlations within the scales should be between .30 and .70, with item- to- total correlations between .40 and .70.

4) What are the priority information needs of husbands of women who have recently undergone surgery for breast cancer?

Husband's overall information needs were ranked according to means to determine their priority information needs. The highest and lowest ranked needs were identified and presented in table format.

5) To what extent have the information needs been met?

Mean number of needs, mean number of unmet needs and percentage of unmet needs were illustrated in tables. Pearson's correlation was also used to examine the relationship between subscales (total needs, sum score, and number of unmet needs).

6) Do husband's information needs differ according to demographic and disease related variables?

Husbands' information needs were ranked in order of importance by means, according to subjects' demographic variables (i.e., age, education) and their wives' disease/treatment variables (i.e., stage of disease, type of surgery) and variations in data collection (i.e. postoperative day of data collection, and who was present at data collection). The importance of husbands' information needs by means, according to demographic and disease/treatment variables were compared to determine if there are differences in their priority needs. The t-test statistic and ANOVA were used to determine differences between the independent variable subdivisions and the dependent variables.

7) What is the relationship between husbands' desire for information and their preferences for participation in decision making?

Husbands' priority information needs, their number of identified needs, the sum scores of their identified needs, and their number of unmet needs were compared to their decisional role preferences (active, collaborative, passive) and presented in table format. Husbands' role preference categories were included as independent variables in the ANOVA analyses outlined under research question #6.

Ethical Considerations

This research proposal was submitted to the Faculty of Nursing Ethical Review Committee, University of Manitoba, Winnipeg, Manitoba in September, 1996 for approval prior to data collection. Verbal and written explanations of the study and expectations of the participants were given to all women and their husbands. Women and their husbands were informed that participation was voluntary and that they may withdraw at any time. Assurance was provided that non-participation would not influence care.

A written consent for participation in the study and permission to access medical information was obtained from the women. Copies of signed consents were and are currently being stored in a locked drawer, accessible only to the researcher. Women and their husbands were assured of confidentiality of information. The women's medical information, the sociodemographic and FIN-H questionnaires, and the CPS data were identified by a code number, not by name. Women and their husbands were assured that their names would not appear in any written document.

Only the researcher and thesis advisor had access to any identifying data. Data will be stored in a locked drawer for at least seven years. The data will not be used beyond this study. A copy of the patient consent form, the husband disclaimer form, the patient chart data form and the data collection instruments were submitted to the Faculty of Nursing Ethical Review Committee and hospital access committees for approval in September, 1996.

A breast cancer diagnosis creates stress for both the woman and her family. A woman's hospitalization and surgical intervention compounds the stress engendered by a breast cancer diagnosis. Therefore, the researcher initially approached the woman so she could decide whether the intent of the study or her husband's time involvement would create additional stress.

It was anticipated that participation in the study may create tension for the husbands, if they have not been able to actualize their preferred role in treatment decision making. If tension was expressed or observed, the researcher encouraged the participant to verbalize their concerns, and asked the participant if he wished to be referred to a resource for further discussion of his concerns.

It was also anticipated that husbands who participated may also desire information related to their identification of unmet needs. Husbands were provided with a written list of informational resources (Appendix S) and a booklet entitled "Sharing: A Family's Guide to Breast Cancer". Participants were also given the opportunity to receive a written summary of the study results.

Summary

This chapter has described the methods that were used to conduct a study of husbands' preferences for participation in surgical treatment decisions and their need for information when their wives have recently undergone surgery for breast cancer.

CHAPTER V

RESULTS

Introduction

This study was comprised of two phases. Phase I involved the modification and pilot testing of the CPS-H. The information needs and decision making preferences of husbands of women who had recently undergone surgery for breast cancer were examined in phase II.

The results of phase I and phase II of this study are reported in this chapter. This chapter describes the sociodemographic characteristics of the sample, and the findings related to each of the research questions.

Phase I: Pilot Study Data Analysis

As described in the previous chapter, six husbands of women who were members of the Breast Cancer Action support group participated in the pilot test of the CPS-H. Participants were first asked to rate the clarity of the modified CPS statements (Appendix Q). All six members of the panel agreed that the modified role statements were clear, and none of the participants provided any comments with respect to the clarity of the statements.

With respect to the apparent internal consistency measure (Appendix R), all six participants agreed that the modified role statements described a variation of the same message. Five of the six participants agreed that each of the modified role statements described a single message. The cumulative responses for clarity and apparent internal consistency met Imle and Atwood's (1988) criteria for percent agreement (equal or greater to 70%) for items' clarity and apparent internal consistency.

To determine whether the CPS-H revised role statements formed a unidimensional scale, husbands were asked to complete the CPS-H. Husbands were asked to complete the scale with the following direction: " How would you have preferred to participate with your wife and the physician with respect to your wife's surgical treatment decision?"

The CPS-H was administered in the "fixed order", as described in the previous chapter. The results indicated that five of the six participant's preference orders were valid permutations. The valid preference orders observed in the pilot test were as follows: ABCDE (2), BACDE (2), BCADE (I). Degner, Sloan and Venkatesh (1997) stated that if 50% plus one of the pretest subjects preference orders are valid permutations, then the revised scale is justified. The results of the pilot test indicate the CPS-H forms a unidimensional scale.

Summary

Results of the pilot test indicated that the previously determined criteria for clarity, apparent internal consistency, and unidimensionality of the CPS-H were met.

Phase II- Data Analysis

Demographic Statistics

Data Collection Circumstances

From October 22, 1996 to July 2, 1997, a total of 70 husbands of women recently diagnosed with breast cancer agreed to participate in the study. All participants were husbands of women who had undergone surgery for breast cancer within the previous 33 days. Ninety- six percent of data collection occurred within 14 days of surgery. Variation in time of data collection occurred for a variety of reasons. Several women who had undergone lumpectomy were discharged within twenty-four hours and were approached for permission to release their names to the researcher just prior to discharge. The researcher did not contact these women until they had a few days to adjust to being at home. Husbands contacted in person at the hospital or by phone determined the most convenient date and time for data collection. Data collection that occurred beyond 14 days was due to cancellation of rural appointments due to inclement winter weather conditions. Table 4 illustrates the frequency and percent of participants according to three collapsed categories of post-operative day of data collection.

Table 4: Frequency and Percent Distribution of Sample According to Postoperative Day of Data Collection (n = 70)

Day following surgery	Frequency	Percent
Day 1	26	37.1 %
Day 2-7	26	37.1 %
Day 8-33	18	25.7 %

Participants were recruited from five Winnipeg Hospitals: Grace General Hospital, Health Sciences Centre, Misericordia General Hospital, St. Boniface General Hospital, and Victoria General Hospital. The variation in the numbers of participants from the five facilities outlined in Table 5 can be attributed to the following factors. The timing of initial access to each facility varied due to each institution's administrative time constraints. Participant recruitment began at: the Grace General Hospital and the Victoria General Hospital in late October, 1996; St. Boniface General Hospital and Health Sciences Centre in the middle of November, 1996; and at the Misericordia General Hospital in the middle of December, 1996. Elective surgery was canceled at the Misericordia General Hospital, St. Boniface General Hospital and the Health Sciences Centre from one to three weeks due to the flooding of the Red River. The low number of participants from the Health Sciences Centre can be partially explained by the researcher's difficulty in the monitoring of potential participants. Although the researcher had recruitment arrangements with the three units that usually cared for women with breast surgery, breast surgery patients were assigned to a unit on a postoperative basis. If all three units were full, postoperative breast surgery patients were assigned to a variety of other surgical units. In addition, the Health Sciences Centre appeared to have a larger proportion of patients who did not meet the eligibility requirements. Table 5 outlines the frequency and percent of participants from the various facilities.

Table 5: Frequency and Percent Distribution of Sample According to Hospital (n =70)

Hospital	Frequency	Percent
Grace	21	30.0 %
Victoria	15	21.4 %
St. Boniface	14	20.0 %
Misericordia	13	18.6 %
Health Sciences Centre	7	10.0 %

Demographic Characteristics of Participants

The following table (Table 6) demonstrates the demographic characteristics of the husbands. Twenty-two husbands (31%) were 50 years of age or younger, 26 husbands (37%) were between fifty-one and sixty-four years of age, and twenty-two husbands (31%) were sixty-five years and older. The mean age of husbands was 58 years. Forty-one participants (59%) had a high school diploma or post secondary education, and 29 participants (41%) did not have a high school diploma.

Participants' occupations were classified as retired, professional, labourer and other. The majority of husbands in the "other" category were self-employed or worked in sales. Forty- one percent of the sample was retired. Seventy-one percent of participants lived in the city of Winnipeg. The majority of participants (57%) were of British or European descent and 89% of the participants identified English as the language they spoke at home. Several participants who were born in Canada questioned the need for identification of ethnic background. Four participants identified their ethnic background as "other" and wrote "Canadian". Participants who spoke a language other than English, or spoke English and another language at home were placed in the "other" category.

Table 6: Frequency and Percent Distribution of Husbands according to Demographic Variables (n=70)

Characteristic	Frequency	Percent
Age		
37- 50	22	31.4 %
51 - 64	26	37.1 %
65 -84	22	31.4 %
Education Level		
Less than high school	29	41.4 %
Graduated high school	17	24.3 %
Greater than high school	24	34.3 %
Occupation		
Retired	29	41.4 %
Professional	10	12.9 %
Labourer	18	21.4 %
Other	13	24.3 %
Ethnic Group		
European	18	25.7 %
British Isles	22	31.4 %
French	9	12.9 %
Aboriginal	3	4.3 %
Asian	2	2.9 %
Other (includes Canadian)	16	22.9 %
Language		
English	62	88.6 %
Other	8	11.4 %
Residence		
Urban	50	71.4 %
Rural	20	28.6 %

Demographic Characteristics of the Women

The following table (Table 7) outlines the demographic characteristics of the women. Twenty-four women were fifty years and younger (34.3%), twenty-six women were between the ages of fifty-one and sixty-two (37.1%), and twenty women were between the ages of sixty-three and eighty-two (28.6%). The mean age of the women was fifty-six years. Fifty-nine women had undergone their first surgery for breast cancer. Ten women were experiencing their second surgery for breast cancer, and one woman had a prophylactic mastectomy following a previous surgery for breast cancer. Forty-five women (64.3%) underwent mastectomy, versus twenty-five women (35.7%) who underwent lumpectomy.

Chart information with respect to each women's primary tumor was reviewed and categorized according to the TNM staging criteria (Waltman, 1994). TNM staging criteria included the following: tumour size, lymph node involvement, and presence of metastasis. Women were categorized by clinical stage of disease (Stage 0,1,2,3,4) according to TNM clinical staging for breast cancer (Waltman, 1994). One woman was categorized as Stage 0, thirty-five women (50%) as Stage 1, twenty-eight women (40%) as Stage 2, and six women (8.6%) as Stage 3.

Table 7: Frequency and Percent Distribution of Women According to Demographic and Disease Related Variables (n=70)

Characteristic	Frequency	Percent
Age		
35-50	24	34.3 %
51-62	26	37.1 %
63-82	20	28.6 %
Number of surgery		
First surgery	59	84.3 %
Second surgery	10	14.3 %
Second for prophylaxis	1	1.4 %
Type of surgery		
Lumpectomy	25	35.7 %
Mastectomy	45	64.3 %
Clinical Disease Stage		
Stage 0	1	1.4 %
Stage 1	35	50.0 %
Stage 2	28	40.0 %
Stage 3	6	8.6 %
Stage 4	0	

Instrument Administration Variables

Information related to administration of the research instruments was also collected. This included: location of data collection, who was present at data collection, and the time required for administration of the instruments and discussion. Data collection occurred in hospital (n =37), at the participant's home (n =32) or the participant's place of employment (n =1). In the majority of cases (63%) wives were present when their husbands completed the data collection tools. In four of these cases, data collection occurred in the presence of the wife and a son or daughter. The length of time spent with participants ranged from 20 minutes to 2 hours (included explanation of data collection tools, completion of data collection tools, the time spent answering questions and concerns expressed by both the husband and wife, and listening to the couples' experiences since diagnosis).

The exact time spent with respect to explanation of the data collection tools and completion of the data collection was difficult to measure, as at times instrument completion was interspersed with discussion of the participant's experiences. The approximate time for explanation and completion of the data collection tools ranged from 15 to 40 minutes. The length of time spent with participants was generally longer if the wife was present at data collection and when data collection occurred at the participant's home. However, even if the wife was not present during completion of the data collection tools, the majority of wives engaged the researcher and their husband in an experiential discussion following completion of the data collection tools.

Table 8: Frequency and Percent Distribution According to Instrument Administration Variables (n = 70)

Characteristic	Frequency	Percent
Location		
Hospital	37	52.9 %
Husband's Residence	32	45.7 %
Husband's Work	1	1.4 %
Individuals Present		
Husband only	26	37.1 %
Husband and Wife	40	57.1 %
Husband / Wife and Son/Daughter	4	5.7 %
Length of Time		
0 - 35 minutes	12	17.1 %
36 - 40 minutes	19	27.1 %
41 - 50 minutes	15	21.4 %
60 - 75 minutes	11	15.7 %
76 - 120 minutes	13	18.6 %

Non- Participants

Four women who agreed to meet with the researcher declined to participate in the study. Three of these women declined to participate because they felt the intent of the study would upset their husbands, and one woman declined because she did not want the researcher to have access to her chart. Three other women stated that they would agree to participate in the study if their husbands agreed to participate. However, these women did not want the researcher to contact their husbands, preferring to have their husbands contact the researcher if the husband was interested in the study.

Five husbands of women who had provided written consent to contact their husbands and access their medical record declined to participate in the study. Two women contacted the researcher by phone to indicate that their husbands were “not interested “ in participating. One husband stated he was “not interested” after the study was explained to him over the phone. One husband of a woman who preferred to have her husband contact the researcher if he was interested in participating, did not contact the researcher. The only husband to refuse to participate following an in-person explanation of the study stated that he did not like questionnaires.

Table 9 illustrates the demographic and disease related variables of women whose husbands declined to participate, but who had provided a written consent to access their medical charts. Two women were less than forty-five years of age, two women were less than sixty years of age, and one woman was less than sixty-five years of age. All of the five women had undergone their first surgery for breast cancer. Three women had undergone a mastectomy, one woman a bilateral mastectomy, and one woman had undergone a lumpectomy. Two women were classified as Stage 1 disease and three women were classified as Stage 2 disease. Three women resided in a rural area, and two women resided in an urban area.

The demographic and disease related variables of women whose husbands declined to participate in the study was fairly similar to the demographic and disease related variables of women whose husbands agreed to participate in the study. However, there was a higher proportion of women who had undergone their first surgery and who resided in the rural area in the non-participant group than in the participant group.

Table 9: Frequency and Percent of Demographic and Disease Related Variables of Women Whose Husbands Declined to Participate (n=5)

Characteristic	Frequency	Percent
Hospital		
St. Boniface	2	40%
Grace	2	40%
Victoria	1	20%
Age		
35 -50	2	40%
51 -62	2	40%
63 -82	1	20%
Residence		
Urban	2	40%
Rural	3	60%
Number of surgeries		
First	5	100%
Second	0	
Type of surgery		
Mastectomy	4	80%
Lumpectomy	1	20%
Stage of disease		
Stage 1	2	40%
Stage 2	3	60%

Husbands' Preferred Roles for Participation in Decision Making

Decisional preferences were analyzed according to unfolding theory. Unfolding theory is based on the theory of preferential choice. Individual preference orders are "unfolded" to ascertain whether they are consistent with the existence of the underlying psychological dimension, providing a direct test of the hypothesis that husbands had systematic preferences about the degree of control they wanted in their wives' surgical treatment decision making, ranging from no control to complete control (Degner et. al., 1997). Preference orders fell on the dimension if they were in a sequence that captured the hypothetical rank order of the decisional roles and the midpoints between them (Degner et al.,1997). For example, the husband who had the most extreme desire to keep control would have arranged the role statements in Appendix E in the order ABCDE, and would have received an ordinal score of 1, indicating that he wanted the highest degree of control in decision making. The person with the next most extreme score would have the preference order BACDE, having crossed the midpoint between A and B, and would have an ordinal score of 2; and so on using the model as described by Coombs (1976). The combination of 5 decisional roles and their midpoints produces a dimension with 11 possible valid preference orders, thus generating the ordinal score range from 1 to 11

The preference orders of 49/70 of the husbands (70%) unfolded onto the psychological dimension about keeping, sharing, or giving away control over decision making to the physician. Valid preference orders observed in this sample were as follows: ABCDE (4.3%), BACDE (10%), BCADE (5.7%), BCDAE (4.3%), CBDAE (14.3%), CDBAE (15.7%), CDBEA (7.1%), CDEBA (4.3%), DECBA (1.4%), and EDCBA (2.9%). Coombs (1976) set the criterion for accepting the dimensionality of any scale at 50% plus 1 of observed valid preference orders. The criterion was met in this sample, with 70% of preference orders falling directly on the dimension.

The majority of husbands (54.3%) preferred a collaborative treatment decision making role with their wife and the physician in their wives' surgical treatment decision making, 27.1% preferred an active role, and 18.6% preferred a passive role. Husband's actual treatment decision making role was determined by the husband indicating which of the five decisional role statements was closest to the husband's actual role in their wife's surgical treatment decision making. Twenty-seven husbands (38.6%) indicated that they had assumed an active treatment decision making role with their wife during their wives' surgical treatment decision making, 28.6% a collaborative role, and 32.9% a passive role. Tables 10 and 11 indicate the frequency and percent of husbands' preferred roles and actual roles in their wives' surgical treatment decision making according to the first card selected.

Table 10: Husbands' Preferred Role According to First Card Selected (n=70)

Preferred Role		Frequency	Percent
Active:	Card A	4	5.7 %
	Card B	15	21.4 %
Collaborative:	Card C	38	54.3 %
Passive:	Card D	6	8.6 %
	Card E	7	10.0 %

Table11: Husbands' Actual Role According to First Card Selected (n=70)

Actual Role		Frequency	Percent
Active:	Card A	3	4.3 %
	Card B	24	34.3 %
Collaborative:	Card C	20	28.6 %
Passive:	Card D	16	22.9 %
	Card E	7	10.0 %

Discrepancies between preferred and actual roles were used to calculate a discrepancy score for each husband. The husband's first choice from the card sort procedure was subtracted from his actual role, yielding a score that could range from 0 (no discrepancy) to 4 (4 steps of discrepancy). The greatest discrepancy occurred if the husband wanted the most active role (A) and believed he had actually played the most passive role (E), or vice-versa.

Fifty percent (50%) of the husbands achieved their preferred roles in their wives' surgical treatment decision making. Fifteen husbands (21.4%) believed they had assumed more control in decision making than they had desired. Twenty husbands (28.6%) believed they had achieved less control in decision making than they had wanted. Agreement between preferred and actual role was most evident for husbands who preferred an active decision making role. There was a large discrepancy between preferred and actual role for husbands who preferred a collaborative decision making role Sixteen of the thirty-eight (42%) husbands who preferred a collaborative role actually assumed a passive role. The largest discrepancy (54%) between actual and preferred role, occurred when husbands preferred a passive role but had actually assumed a collaborative or active decision making role. Table 12 indicates the discrepancy between husbands' preferred decision making category and husbands' actual decision making category.

Table 12: Preferred Decision Making Category Versus Actual Decision Making Category

		Actual Role	
Preferred Role	Active (27)	Collaborative (20)	Passive (23)
Active (19)	**15**	3	1
Collaborative (38)	8	**14**	16
Passive (13)	4	3	**6**
	Received more control than desired		Received less control than desired

Bold numbers = congruent roles

Decisional Role Preference According to Demographic and Disease Related Variables

Comparison of decisional role preferences according to sociodemographic and disease/treatment variables using Fisher's Exact Test indicated that demographic and disease related variables were not significantly related to decision making preferences of the husbands in this study. As indicated by Table 13, the overall preference for a collaborative role in decision making is seen in all the subdivisions of the major variables, with the exception of a minimal difference in two of the subdivisions (professional, and British Isles). Four of the ten husbands in the "professional" occupational category preferred a passive role, in comparison to the three husbands in this category who preferred a collaborative role. Ten of the twenty-two husbands who identified their ethnic origin as "British Isles" preferred an active role in comparison to the three husbands who preferred a collaborative role.

Table 13: Husbands' Preferred Decision Making Roles According to Demographic and Disease Related Variables

Characteristic	Active	Collaborative	Passive
All Husbands	19	38	13
Age			
37- 50	5	13	4
51- 64	6	16	4
65- 84	8	9	5
Education			
< high school	8	15	6
High school diploma	4	11	2
> high school	7	12	5
Occupation			
Retired	8	17	4
Professional	3	3	4
Labourer	3	13	2
Other	5	5	3
Language			
English	16	33	13
Other	3	5	0
Ethnic Group			
European	4	12	2
British Isles	10	8	4
French	3	3	3
Aboriginal	0	3	0
Asian	0	2	0
Other	2	10	4
Residence			
Urban	14	26	10
Rural	5	12	3
# of Surgeries			
First surgery	16	32	11
Second surgery	3	6	2
Type of Surgery			
Lumpectomy	7	14	4
Mastectomy	12	24	9
Stage of disease			
Stage 0-1	12	15	9
Stage 2	6	19	3
Stage 3	1	4	1

Reliability and Validity of the FIN-H

Internal Consistency of the FIN-H

Internal consistency was assessed using Cronbach's alpha coefficient. Nunnally (1978) suggested that a scale demonstrates internal consistency reliability when values equal to or above .80 are obtained. Nunnally also suggested that 50 % of inter-item correlations within scales should range from .30 to .70, with item to total correlations ranging from .40 to .70. Items greater than .70 suggest redundancy of information, and items less than .40 do not significantly contribute to the scale. Internal consistency of the FIN-H as measured by Cronbach's standardized alpha coefficient was .95. Therefore, the standardized alpha coefficient satisfies the above criterion for internal consistency reliability.

The inter-item and item to total correlations are as follows. The item means ranged from 3.33 to 4.87 with a standard deviation ranging from .38 to 1.5. All items on the scale demonstrated an alpha of .91 or greater, with 23 of the 30 items (77%) achieving item to total correlations between .40 and .70. Six items (5, 24, 11, 6, 22, and 23) achieved item to total correlations of .71, .71, .75, .76, .80, and .81 respectively. Item 20 obtained a low item to total correlation (.26).

The majority of items (24 / 30) achieved greater than 50% of inter-item correlations between .30 and .70. Items 18, 19, 20, 28, 29, and 30 did not meet the preset inter-item correlation criteria. However, the majority of items (80%) did correlate with one another.

Internal Validity Estimates

Factor analysis of the FIN-H scale by Kilpatrick (1995) revealed five subscales (Appendix D). Factor analyses using principle axis factoring with promax rotation were conducted with this study's data to assess the internal construct validity of the scale, and to compare to the factor structures reported by Kilpatrick. Criteria for factor analysis estimates of construct validity were factor loadings of at least .40.

Squared multiple correlation coefficients were used as initial communality estimates. Examination of the scree plot (plot of the variance accounted for by each extracted factor), suggested that between 4 and 6 factors were responsible for the underlying pattern of correlations found within the 30 items. Examination of the eigenvalues revealed five factors greater than 1.0. The five factors accounted for 79 percent of the total item variance.

The promax rotational method was used to determine the final item factor loadings. Item factor loadings ranged from .40 to .91. All item factor loadings met the preset criteria of .40. Need # 20 "be told about people who could help with problems" loaded at .40. Need #18 " help with my wife's care while in hospital " loaded as .43 on Factor 1, but demonstrated a minimal difference (.09) in factor loadings on three factors (1, 2, and 5).

Rotated factor solutions were qualitatively analysed for clinically meaningful interpretations. The analysis illustrated in Table 14 reveals five factors containing three to nine items on each factor. The five factors were examined to determine the following labels: 1) Initial disease/treatment communication with health professionals 2) Emotional and physical care needs 3) Family relationship issues 4) Ongoing communication with health professionals 5) Husband and wife interpersonal communication.

Table 14: Factor Analysis of the FIN-H

Description of Needs in each Factor with the Factor Loadings for each Need		
Factor 1:	**Initial Disease/Treatment Communication with Health Professionals**	
Need # 22	-know specific facts concerning my wife's treatment	.87
Need # 5	-know exactly what is being done for my wife	.81
Need # 1	-have my questions answered honestly	.76
Need # 21	-know specific facts concerning my wife's disease	.76
Need # 2	-know specific facts concerning my wife's future	.70
Need # 7	-have explanations given in terms that are understandable	.65
Need # 17	-feel included by health professionals	.50
Need # 18	-help with my wife's care while she is in hospital	.43
Factor 2:	**Emotional and Physical Care Needs**	
Need # 9	-feel there is hope	.91
Need # 10	-be assured that the best possible care is being given to my wife	.87
Need # 3	-feel that the health professionals care about my wife	.78
Need # 23	-know what side effects are caused by the treatment	.77
Need # 24	-know how to provide physical care to my wife	.71
Need # 11	-know what symptoms are caused by the illness	.69
Need # 25	-know how to provide emotional support to my wife	.64
Need # 16	-have information about what to do for my wife at home	.56
Need # 13	-know the probable outcome of my wife's illness	.48
Factor 3:	**Family Relationship Issues**	
Need # 28	-know how to approach changes related to sexuality	.80
Need # 29	-know how to touch my wife	.76
Need # 30	-know what to expect of my wife's energies	.64
Need # 19	-have someone be concerned about my health	.56
Need # 26	-know what to say to the children	.44
Need # 20	-be told about people who could help with problems (financial, household)	.40
Factor 4:	**Ongoing Communication with Health Professionals**	
Need # 8	-be told about changes in treatment plans while they are being made	.83
Need # 15	-know the names of the health professionals involved in my wife's care	.81
Need # 12	-know when to expect symptoms to occur	.71
Need # 4	-be informed of changes in my wife's condition	.65
Factor 5:	**Husband and Wife Interpersonal Communication**	
Need # 6	-know what treatments my wife is receiving	.82
Need # 14	-know why things are done for my wife	.74
Need # 27	-know how to talk to my wife about the disease/illness	.60

Ranking of Needs According to Means:

Assessment of the FIN-H demonstrated item means that ranged from between 3.33 to 4.87 with standard deviations ranging between .38 and 1.50. The five top ranked needs in descending order of importance were: 1) feel there is hope 2) be assured that the best possible care is being given to my wife 3) know what side effects are caused by the treatment 4) know the probable outcome of my wife's illness 5) know how to provide emotional support to my wife.

The five needs ranked as least important were: 1) be told about people who could help with problems (financial, household) 2) have someone be concerned with my health 3) know how to approach changes related to sexuality 4) know what to say to the children 5) know how to touch my wife. The means and standard deviations of the highest and lowest ranked needs are illustrated in Table 15

Table 15: Highest and Lowest Ranked Needs According to Means (n=70)

Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
- feel there is hope	4.87	.38	- help with problems	3.33	1.48
- best care for wife	4.87	.38	- concerned my health	3.40	1.50
- side effects of treatment	4.81	.43	- changes sexuality	3.88	1.29
- outcome of illness	4.78	.53	- what say to children	4.10	1.30
- provide emotional support	4.76	.49	- how to touch	4.10	1.23

Ranking of Needs According to Means by Demographic, Disease, and Instrument Related Variables:

The following tables (Table 16 to 23) illustrate the highest and lowest ranked needs by the following demographic, disease, and instrument related variables: age, education, occupation, residence, number and type of surgery, stage of disease, who was present at data collection, and the postoperative day of data collection. Husbands in all categories ranked the needs "have someone be concerned with my health" and "be told about people who could help with problems" as two of their lowest priority needs. Husbands in all categories except husbands who resided in a rural area, listed "know how to approach changes related to sexuality" as one of their lowest ranked needs. The two other lowest ranked needs varied among categories but were one of the following needs: "know what to say to children", "help with my wife's care while in hospital", know how to touch my wife", and "feel included by health professionals" (the last need only indicated by husbands who had a high school diploma).

Husbands in all categories were able to identify five needs that were of low priority (according to means). However, husbands in several categories prioritized six to eleven needs as high priority needs, on the basis of needs with the same mean and standard deviation.

Husbands in all categories ranked the need "feel there is hope" as one of their top priority needs. Husbands in all categories except husbands who were placed in the "other" occupational category listed "be assured that the best possible care is being given to my wife" as one of their priority needs. Husbands in all categories except husbands whose wives had stage three disease listed "know what side effects are caused by the treatment" as one of the top priority needs.

Table 16 indicates that husbands in all three age categories listed "feel there is hope", "be assured that the best possible care is being given to my wife", and " know what side effects are caused by treatment" as priority needs. Husbands less than fifty years of age also listed "know specific facts concerning my wife's future" and "know how to provide emotional support to my wife" in the five top priority needs. Husbands less than fifty years reported higher means for their highest ranked needs than did husbands in other age categories Husbands 51-64 years of age listed "know the probable outcome of my wife's illness" and "know exactly what is being done for my wife" as their fourth and fifth highest ranked needs. Husbands 65-84 years of age listed seven (mean and standard deviation the same for four needs) priority needs. In addition to the needs listed as common by husbands in all age groups, husbands over the age of sixty-five listed four priority needs related either to initial or ongoing communication with health care professionals or to physical and emotional care needs.

Table 16: Highest and Lowest Ranked Needs According to Means by Age

Category	Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
Age 37- 50						
	-feel there is hope	4.95	.21	-concerned my health	3.13	1.48
	-best care for wife	4.95	.21	-help with problems	3.68	1.25
	-side effects of Rx	4.86	.35	-changes sexuality	3.77	1.20
	-provide emotional support	4.86	.35	-how to touch	4.04	1.33
	-specific facts future	4.82	.50	-help with care in hospital	4.04	1.09
Age 51-64						
	-feel there is hope	4.85	.46	-help with problems	3.26	1.51
	-best care for wife	4.85	.46	-concerned my health	3.46	1.50
	-side effects of Rx	4.85	.46	-what say to children	3.88	1.39
	-probable outcome	4.81	.49	-changes sexuality	4.00	1.33
	-exactly what being done	4.81	.49	-how to touch	4.35	1.01
Age 65-84						
	-feel there is hope	4.81	.39	-help with problems	3.04	1.65
	-best care for wife	4.81	.39	-concerned my health	3.59	1.53
	-outcome of illness	4.81	.39	-changes sexuality	3.86	1.39
	-side effects of Rx	4.73	.45	-how to touch	3.86	1.35
	- condition changes - symptoms caused by illness -specific facts Rx	4.73	.46	-what say to children	4.04	1.36

Husbands in all three educational categories listed three of the same needs as priority needs (hope, best care for wife, and side effects of treatment). Husbands with less than a high school education were the only educational category to list "have explanations given in terms that are understandable" listed as a priority need. Husbands who had a high school diploma listed "know how to provide emotional support to my wife" and "feel that health care professionals care about my wife" as priority needs. Husbands with greater than a high school education listed needs related to husband and wife interpersonal communication (know what treatments my wife is receiving and know why things are done for my wife) as priority information needs. Husbands with greater than a high school education did not list "know the probable outcome of my wife's illness" as a priority need, whereas husbands in the other two educational categories had listed this need as a priority. Husbands who had more than a high school education reported higher means for their priority needs than did husbands in the other educational categories

Table 17: Highest and Lowest Ranked Needs According to Means by Education

Category	Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
< High school						
	-outcome of illness	4.93	.26	-help with problems	3.10	1.61
	-feel there is hope	4.90	.31	-concerned my health	3.48	1.55
	-best care for wife	4.83	.38	-what say to children	4.03	1.27
	-side effects of Rx	4.83	.38	-changes sexuality	4.10	1.26
	-condition changes -understandable terms	4.76	.44	-how to touch	4.17	1.20
High school						
	-feel there is hope	4.76	.56	-help with problems	3.18	1.60
	-best care for wife	4.76	.56	-concerned my health	3.24	1.71
	-feel health professionals care	4.64	.61	-changes sexuality	3.59	1.46
	-changes in Rx -side effects Rx	4.59	.62	-what say to children	3.70	1.45
	-outcome of illness -provide emotional support	4.59	.62	-feel included by health professionals	3.94	1.20
> High school						
	-best care for wife	5.00	0	-concerned my health	3.42	1.32
	-side effects Rx	4.96	.20	-help with problems	3.70	1.20
	-specific facts Rx	4.96	.20	-changes sexuality	3.83	1.20
	-what Rx wife receiving	4.96	.20	-how to touch	4.08	1.32
	-feel there is hope - why things are done	4.92	.28	-help with care in hospital	4.12	1.07

Table 18 shows that husbands in all occupational categories listed more than five needs as priority needs, on the basis of similar means and standard deviations. Husbands who were retired listed six priority needs, four of which were related to emotional and physical care needs and two needs which were related to either initial or ongoing communication with health professionals. Husbands categorized as professionals listed ten priority needs (4 with a mean of 5, and 6 with a mean of 4.9). The priority needs of husbands in the professional category were related to the following categories of needs: four emotional and physical care needs, two initial disease and treatment communication needs, two ongoing communication needs, and two husband and wife interpersonal communication needs.

Husbands categorized as labourers, listed seven priority needs, all of which were related to emotional and physical care needs. Husbands in the "other" category listed eight priority needs. Four needs were related to initial disease and treatment communication with health professionals, three needs related to physical and emotional care, and one need related to husband and wife interpersonal communication.

Husbands who were categorized as labourers and professionals listed "know how to provide emotional support to my wife" as a priority need, whereas, husbands in the retired and other categories did not list this need as a priority. Husbands categorized as professionals were the only husbands who did not list "know the probable outcome of my wife's illness " as a priority. Husbands in the professional category reported higher means for the highest ranked needs than did husbands in the other occupational categories.

Table 18: Highest and Lowest Ranked Needs According to Means by Occupation

Category	Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
Retired						
	-feel there is hope	4.79	.49	-help with problems	2.93	1.56
	-best possible care	4.79	.49	-concerned my health	3.48	1.48
	-outcome of illness	4.76	.51	-what say to children	3.90	1.47
	-condition changes	4.72	.52	-changes sexuality	3.93	1.41
	-specific facts Rx -side effects of Rx	4.69	.54	-how to touch	4.03	1.30
Professional						
	-what Rx receiving	5	0	-concerned my health	3.40	1.26
	-best possible care	5	0	-help with problems	3.80	1.23
	-side effects of Rx	5	0	-what say to children	4.00	1.70
	-provide emotional support	5	0	-help with care in hospital	4.10	.99
	-specific facts future -condition changes -exactly what done -feel there is hope -why things done -specific facts Rx	4.90	.32	-changes sexuality	4.10	.87
Labourer						
	-feel there is hope	4.94	.23	-concerned my health	3.50	1.58
	-best possible care	4.94	.23	-changes sexuality	3.55	1.38
	-outcome of illness	4.89	.32	-help with problems	3.83	1.29
	-side effects Rx	4.83	.38	-how to touch	3.83	1.42
	- professionals care -symptoms of illness -provide emotional support	4.72	.46	-help care in hospital	4.05	1.30
Other						
	-outcome of illness	5.00	0	-concerned my health	3.08	1.70
	-feel there is hope	4.92	.28	-help with problems	3.15	1.57
	-side effects of Rx	4.92	.28	-changes sexuality	4.08	1.19
	-specific facts future	4.92	.28	-what say to children	4.30	0.85
	-exactly what done -what Rx receiving -understandable terms -specific facts disease	4.92	.28	-how to touch	4.38	1.04

Husbands who resided in the city of Winnipeg listed priority needs that were the same as listed by the total sample. Husbands who lived in a rural area listed six needs as priority needs (three needs with the same mean and standard deviation). Four of the rural residents' needs were the same as listed by the urban residents. Rural residents ranked "be informed of changes in my wife's condition" and "have explanations given in terms that are understandable" as additional priority needs, but did not include "know how to provide emotional support to my wife" as had the urban residents.

Table 19: Highest and Lowest Ranked Needs According to Means by Residence

Category	Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
Urban						
	-best care for wife	4.88	.39	-help with problems	3.46	1.43
	-feel there is hope	4.86	.40	-concerned my health	3.62	1.41
	-side effects of Rx	4.84	.42	-changes sexuality	3.86	1.30
	-provide emotional support	4.80	.50	-what say to children	4.18	1.30
	-outcome of illness	4.78	.58	-how to touch	4.18	1.11
Rural						
	-feel there is hope	4.90	.31	-concerned my health	2.85	1.60
	-best care for wife	4.85	.37	-help with problems	3.00	1.59
	-outcome of illness	4.80	.41	-help with care in hospital	3.85	1.39
	-side effects of Rx -condition changes -terms understandable	4.75	.44	-what say to children	3.90	1.29
	-what to do at home	4.75	.55	-how to touch	3.90	1.48

Table 20 indicates that husbands whose wives had undergone their first breast surgery and husbands whose wives had undergone a second breast surgery listed four of the same needs as priorities. The four identical needs were related to emotional and physical care needs. Husbands whose wives had undergone surgery for the first time listed six priority needs, with the remaining two needs related to ongoing communication with health professionals. Husbands of women who had undergone a second breast surgery listed eleven priority need, each need with a mean of 5. Husbands of women who had their second breast surgery, listed an additional three needs related to emotional and physical care, three needs related to initial disease and treatment communication with health professionals, and one need related to husband and wife interpersonal communication.

Table 20 shows that husbands whose wives had undergone a lumpectomy and husbands whose wives had undergone a mastectomy listed four of the same priority needs which were related to emotional and physical care. Husbands whose wives had undergone a lumpectomy listed six priority needs, two of which differed from husbands whose wives had undergone mastectomy. Husbands of women who had undergone a lumpectomy listed the following additional needs: "know how to provide emotional support to my wife", and "feel that the health professionals care about my wife". Whereas, husbands of women who had undergone a mastectomy listed "be informed of changes in my wife's condition" as a priority need. Husbands whose wives had undergone a mastectomy reported slightly higher means for their highest and lowest priority needs than did husbands whose wives had undergone a lumpectomy.

Table 20: Highest and Lowest Ranked Needs According to Means by Number and Type of Surgery

Category	Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
1st surgery						
	-feel there is hope	4.85	.41	-help with problems	3.35	1.42
	-best possible care	4.85	.41	-concerned my health	3.37	1.48
	-side effects of Rx	4.78	.46	-changes sexuality	3.83	1.33
	-outcome of illness	4.74	.58	-what say to children	4.05	1.30
	-condition changes -changes in Rx	4.71	.49	-help with care in hospital	4.10	1.20
2nd surgery						
includes one woman						
with current surgery	-feel there is hope	5.00	0	-help with problems	3.18	1.83
for prophlyaxis	-best possible care	5.00	0	-concerned my health	3.54	1.63
	-outcome of illness	5.00	0	-how to touch	4.09	1.44
	-side effects of Rx	5.00	0	-changes sexuality	4.18	1.08
	-provide emotional support -exactly what done -what Rx receiving -understandable terms -what to do at home -specific facts Rx -how provide physical care	5.00	0	-what say to children	4.36	1.29
Lumpectomy						
	-feel there is hope	4.84	.37	-help with problems	3.00	1.53
	-best possible care	4.84	.37	-concerned my health	3.24	1.48
	-side effects of Rx	4.76	.43	-what say to children	3.96	1.31
	-outcome of illness	4.72	.46	-changes sexuality	3.96	1.24
	-provide emotional support -feel professionals care	4.72	.46	-help with care in hospital	4.04	1.24
Mastectomy						
	-feel there is hope	4.88	.38	-concerned my health	3.49	1.52
	-best possible care	4.88	.38	-help with problems	3.51	1.44
	-side effects of Rx	4.84	.42	-changes sexuality	3.84	1.33
	-condition changes	4.82	.44	-how to touch	4.11	1.31
	-outcome of illness	4.82	.57	-what say to children	4.18	1.30

Husbands of women whose clinical stage of disease was 0-1, and 2 identified four of the same priority needs, all of which were related to emotional and physical care needs. Husbands of women whose clinical stage of disease was stage three, listed two priority needs (feel there is hope and assured of best possible care for wife) that were the same as husbands of women classified as stage zero to one and stage two. Husbands of women classified as stage three disease also identified the following as priority needs: feel health professionals care about wife, be informed of changes in wife's condition and, know what symptoms are caused by the illness. Husbands of women who were classified as stage two, listed seven priority needs, whereas husbands of women whose clinical disease stage was 0-1 or 3 listed five priority needs. Husbands of women classified as stage zero to one and stage three had slightly higher means for their highest ranked needs than did husbands whose wives were classified as stage two disease. Husband whose wives were classified as stage zero to one had higher means for their lowest ranked needs than did husbands of women who were classified as stage two or three.

Table 21: Highest and Lowest Ranked Needs According to Means by Disease Stage

Category	Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
Stage 0 & 1						
	-feel there is hope	4.92	.28	-help with problems	3.42	1.63
	-best possible care	4.92	.28	-concerned my health	3.80	1.33
	-side effects of Rx	4.92	.28	-what say to children	4.22	1.24
	-outcome of illness	4.86	.35	-changes sexuality	4.22	1.07
	-what Rx receiving	4.86	.35	-how to touch	4.36	0.99
Stage 2						
	-feel there is hope	4.78	.50	-concerned my health	2.96	1.57
	-best possible care	4.78	.50	-help with problems	3.32	1.28
	-provide emotional support	4.78	.50	-changes sexuality	3.53	1.43
	-outcome of illness	4.75	.52	-how to touch	3.78	1.37
	-side effects of Rx -specific facts Rx -changes in Rx plans	4.71	.53	-what say to children	4.03	1.29
Stage 3						
	-feel there is hope	5.00	0	-help with problems	2.83	1.60
	-best possible care	5.00	0	-concerned my health	3.00	1.67
	-feel professionals care	4.83	.41	-help with care in hospital	3.50	1.64
	-condition changes	4.83	.41	-changes sexuality	3.50	1.51
	-symptoms of illness	4.83	.41	what say to children	3.67	1.75

Table 22 indicates that husbands in the three categories of postoperative day of data collection listed three of the same needs as priority needs (hope, best care for wife, and side effects of treatment). When data collection occurred on the first postoperative day or 8 days postoperative and beyond, husbands listed "know the probable outcome of my wife's illness" as a priority need. Husbands who completed the FIN-H on the first postoperative day also listed "know specific facts concerning my wife's future" as a priority need. Husbands who completed the FIN-H from 2-7 days postoperatively included the following as priority needs: "have information about what to do for my wife at home" and "know how to talk to my wife about the disease/illness". When data collection occurred from 8-33 days postoperatively, husbands listed "know how to provide emotional support to my wife" as a priority need. When data collection occurred from 2-7 days postoperatively, husbands reported slightly higher means for priority needs than did husbands who completed the FIN-H on the first postoperative day and on postoperative days 8-33.

Table 22: Highest and Lowest Ranked Needs by Means According to Post-operative Day of Data Collection

Category	Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
Day 1						
	-feel there is hope	4.85	.46	-concerned my health	3.00	1.47
	-best care for wife	4.85	.46	-help with problems	3.11	1.48
	-outcome of illness	4.81	.49	-changes sexuality	3.69	1.29
	-side effects of Rx	4.81	.49	-how to touch	3.85	1.43
	-specific facts future	4.76	.51	-what say to children	3.88	1.45
Day 2-7						
	-feel there is hope	4.96	.20	-help with problems	3.23	1.66
	-best care for wife	4.92	.27	-concerned my health	3.88	1.47
	-what to do at home	4.92	.27	-changes sexuality	4.23	1.24
	-talk about disease	4.92	.27	-help with care in hospital	4.27	1.11
	-side effects of Rx	4.88	.32	-what say to children	4.54	1.03
Day 8- 33						
	-outcome of illness	4.89	.32	-concerned my health	3.28	1.45
	-best care for wife	4.83	.38	-changes sexuality	3.67	1.34
	-feel there is hope	4.78	.43	-how to touch	3.78	1.31
	-side effects Rx	4.72	.46	-what say to children	3.78	1.30
	-provide emotional support	4.72	.46	-help with problems	3.78	1.16

Table 23 indicates that when completion of the FIN-H occurred with only the husband present or when the wife and children were also present, husbands listed three of the same priority needs (all related to physical and emotional care needs). When husbands were alone during completion of the FIN-H, they identified an additional two priority needs related to emotional and physical care needs, and one priority need related to initial disease and treatment communication with health professionals (feel professionals care, what to do at home, and explanations in understandable terms). When completion of the FIN-H occurred in the presence of the wife and children, husbands listed the following as additional priority needs: probable outcome of illness and be informed of changes in wife's condition. Husbands who completed the FIN-H when they were alone reported higher means for both their highest and lowest ranked needs than did husbands who completed the FIN-H in the presence of their wife and children.

Table 23: Highest and Lowest Ranked Needs by Means According to Individuals Present at Data Collection

Category	Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
Husband only						
	-feel there is hope	4.96	.20	-help with problems	3.46	1.45
	-what to do at home	4.96	.20	-concerned my health	3.65	1.41
	-side effects of Rx	4.96	.20	-changes sexuality	4.00	1.39
	-best possible care	4.92	.27	-what say to children	4.31	1.12
	-health professionals care -understandable terms	4.92	.27	-how to touch	4.38	1.17
Husband/ Wife & Child						
	-best possible care	4.84	.43	-concerned my health	3.25	1.50
	-feel there is hope	4.82	.45	-help with problems	3.25	1.50
	-outcome of illness	4.77	.48	-changes sexuality	3.81	1.24
	-side effects of Rx	4.73	.50	-how to touch	3.93	1.25
	-changes in condition	4.73	.50	-what say to children	3.98	1.39

As previously mentioned, there was minimal variation among the demographic, disease, and instrument related categories with respect to the identification of husbands lowest ranked needs. The majority of husbands in all the categories identified three of the same highest ranked needs. Husbands who were classified as being professionals and husbands of women who had undergone their second surgery listed the greatest number of priority needs (10 and 11 respectively).

Number of Needs, Sum Score of Needs and Extent to Which Needs are Met

The theoretical range for the sum score of items on the scale was 30-150. The mean sum score for this sample was 135.43 (s.d. = 13.25) with a range of 87-150. The theoretical range for the number of needs that were "somewhat important " to "extremely important" was 0 - 30. The mean total number of needs for this sample was 29.36 (s.d.= 1.19) with a range of 24 - 30.

Number of needs reported as compared to number of needs unmet were pro-rated out of a possible 30 needs. The extent to which each need was met was ranked as follows: 0 (not applicable), 1 (not met), 2 (partly met), or 3 (met). If the importance of a need was ranked as a 2 or higher, husbands were asked to what degree they believed the need had been met at this point in time. The mean prorated number of unmet needs for this sample was 6.53 (s.d. = 6.28) with a range of 0 - 20.4. According to Table 24, husbands reported that two of their priority information (feel there is hope and assured of best possible care needs) were extremely close to being met, and their other three priority needs (side effects of treatment, probable outcome of illness, and how to provide emotional support) were partly met.

Table 24: Sample Means and Standard Deviations According to Extent that Highest Ranked Needs were Met

Highest Ranked Needs	Means and Standard Deviations of Extent Met	
feel there is hope	2.63	.64
assured of best possible care for wife	2.66	.63
side effects caused by treatment	2.02	.88
probable outcome of wife's illness	2.10	.85
how to provide emotional support to wife	1.97	.87

There was a low moderate correlation between the prorated sum score of needs (.37, p = .0017) and the prorated total number of needs, indicating that husbands who indicated that they had more needs also rated their needs as more important. The prorated number of unmet needs was slightly negatively correlated (.26, p = .0310) with the prorated total number of needs, indicating husbands who indicated they had greater number of needs, also indicated a smaller number of unmet needs. Therefore, husbands' indication of their need for information was not necessarily indicative of a perceived lack of information, but rather an indication of information that is needed when their wives have recently undergone surgery for breast cancer.

Differences between the subdivisions of the demographic, disease, and instrument related variables with respect to the means of the dependent variables (sum score of needs, total number of needs, and number of unmet needs) were analyzed by the t-test for independent samples (two groups) or one-way ANOVA (three or more groups). Multiple comparison techniques (tukey and least squared differences) were used to evaluate independent subdivision variables that demonstrated a homogeneity of variance in the means of the dependent variables. The level of significance for mean scores of the dependent variables was Alpha = .05.

When husbands were alone with the researcher during completion of the FIN-H, they had a significantly higher (p = .012) sum score (139.96) than the sum score (132.75) of husbands who completed the FIN-H with the additional presence of their wife and/or child. Husbands of women with Stage 3 disease reported a significantly (p = .018) greater number of unmet needs (13.27) than the number of unmet needs reported by husbands of women with Stage 0-1 disease (5.55), and Stage 2 disease (6.35).

The following tables (Tables 25 to 27) illustrate the sum score of needs, the mean number of needs, and the mean number and percentage of unmet needs according to demographic, disease, and instrument variables. The range of mean number of needs reported according to husbands' demographic variables was 28.8 - 29.6, and the range of percentage of unmet needs was 14%- 29% . As previously indicated, husbands who resided in rural areas reported a smaller number of needs as important than husbands who resided in an urban area. However, husbands living in a rural area reported a greater percentage (10%) of unmet needs than reported by husbands in an urban area and the highest percentage (29%) of unmet needs with respect to other demographic variables. Husbands who were classified as professionals reported the lowest percentage (14%) of unmet need with respect to the other demographic variables.

Table 25: Mean: Sum Scores, Number of Needs, Number of Unmet Needs and Percentage of Unmet Needs According to Demographic Variables

Category	Sum Score	Mean # Needs	Mean # Unmet Needs	Percent Unmet	n
Age					
37-50	136.45	29.6	5.6	18.9 %	22
51-64	135.8	29.3	7	23.9 %	26
65-84	133.95	29.1	7	24%	22
Education					
< high school	136.38	29.4	7.3	24.8 %	29
High school diploma	128.41	28.8	6.9	23.9 %	17
> high school	139.25	29.7	5.4	18.2 %	24
Occupation					
Labourer	135.28	29.4	7.3	24.8 %	18
Other	138.7	29.5	6.4	21.7 %	13
Professional	138	29.7	4.1	13.8 %	10
Retired	133.17	29.1	6.9	23.7 %	29
Residence					
Rural	132.95	28.8	8.4	29.2 %	20
Urban	136.42	29.6	5.8	19.6 %	50

The range of mean number of needs according to disease related variables was 29-29.6, and the range of percentage of unmet needs was 17%- 46%. Although husbands of women with Stage 3 disease rated their identified needs lower as compared to all other disease related variables, they reported the greatest percentage of unmet needs. Husbands of women with stage 3 disease reported twice as many unmet needs than did husbands of women with Stage 0-1 or Stage 2 disease.

Table 26: Mean: Sum Scores, Number of Needs, Number of Unmet Needs and Percentage of Unmet Needs According to Disease Related Variables

Category	Sum Score	Mean # of Needs	Mean # of Unmet Needs	Percent Unmet	n
# of surgery					
1st	134.39	29.4	6.8	23.1 %	59
2nd	141	29.3	4.9	16.7 %	10
Type of Surgery					
Lumpectomy	133.24	29.4	6.2	21.1 %	25
Mastectomy	136.64	29.4	6.7	22.8 %	45
Clinical Stage					
Stage 0 & 1	139.14	29.6	5.5	18.6 %	36
Stage 2	132.11	29.1	6.3	21.6 %	28
Stage 3	128.67	29	13.3	45.9 %	6

According to Table 27, the range of mean number of needs according to instrument variables was 29.2-29.5, and the range of percentage of unmet needs was 19%- 26%. Although husbands rated their identified needs higher when data collection occurred between day 2 and day 7, husbands reported a greater number of unmet needs when data was collected on the first postoperative day.

Table 27: Mean: Sum Scores, Number of Needs, Number of Unmet Needs and Percentage of Unmet Needs According to Instrument Variables

Category	Sum Score	Mean # of Needs	Mean # of Unmet Needs	Percent Unmet	n
Present at data collection					
Husband only	139.96	29.5	6	20.3 %	26
Husband/other	132.75	29.2	6.8	23.2 %	44
Post-op day					
Day 1	134.04	29.2	7.5	25.7 %	26
Days 2-7	139.31	29.4	5.6	19%	26
Day 8+	131.83	29.5	6.4	21.7 %	18

Information Needs and Decisional Role Preference

Ranking of Needs According to Decisional Role Preference

Table 28 indicates that husbands who preferred a collaborative role in their wives' surgical treatment decision making listed five priority needs, whereas, husbands who preferred an active or passive role listed seven priority needs. Husbands in the three preferred decisional role categories identified two of the same priority needs (assured of best possible care and side effects caused by treatment). Husbands who preferred an active or collaborative role listed "feel there is hope" as a priority need. Husbands who preferred an active or passive role listed "know what treatments my wife is receiving" as a priority need. Husbands classified as preferring a collaborative role were the only husbands to identify "know the probable outcome of my wife's illness" and "know how to provide emotional support to my wife" as priority needs.

The priority needs of husbands who preferred a collaborative role were all related to physical and emotional care needs. Husbands who preferred an active role listed four priority needs related to emotional and physical care needs, two priority needs related to initial disease and treatment communication with health professionals, and one priority need related to husband and wife interpersonal communication. Husbands who preferred a passive role listed two priority needs related to emotional and physical care needs, two priority needs related to initial disease and treatment communication with health professionals, one related to ongoing communication with health professionals, and two priority needs related to husband and wife interpersonal communication. Husbands who preferred a passive role reported a higher mean for their highest ranked needs (seven needs with a mean of 5) and a higher mean for their lowest ranked needs, than husbands in the active and collaborative categories.

Table 28: Highest and Lowest Ranked Needs by Means According to Decisional Role Preference

Category	Highest Ranked Needs	Mean and Standard Deviation		Lowest Ranked Needs	Mean and Standard Deviation	
Active						
	-side effects of Rx	4.84	.37	-help with problems	3.58	1.50
	-what Rx -understandable terms	4.79	.42	-concerned my health	3.79	1.32
	-feel there is hope -best possible care	4.79	.42	-changes sexuality	3.95	1.08
	-what to do at home	4.79	.42	-how to touch	4.00	1.05
	-specific facts Rx	4.79	.42	-help with care	4.05	1.35
Collaborative						
	-feel there is hope	4.89	.39	-help with problems	3.05	1.45
	-best possible care	4.87	.41	-concerned my health	3.16	1.55
	-outcome of illness	4.84	.44	-changes sexuality	3.68	1.44
	-side effects of Rx	4.74	.50	-what say to children	3.82	1.49
	-provide emotional support	4.74	.50	-how to touch	3.95	1.39
Passive						
	-condition changes	5.00	0	-concerned my health	3.54	1.56
	-specific facts future	5.00	0	-help with problems	3.77	1.48
	-specific facts Rx -what Rx receiving	5.00	0	-help with care in hospital	4.38	1.19
	-best possible care -why things done	5.00	0	-changes sexuality	4.38	1.04
	-provide emotional support	5.00	0	-what say to children	4.54	0.78

<u>Sum Score of Needs, Number of Needs, and Extent to Which Needs are Met</u>

As indicated in Table 29, husbands in all three decision making categories reported a similar number of needs. However, there were differences between the categories with respect to the sum score of needs and percentage of unmet needs. Husbands who preferred a passive decision making role reported a significantly (p = .009) higher sum score (143.08) for identified needs than the sum scores reported by husbands who preferred a collaborative role (132.58). Husbands who preferred a passive decision making role reported the highest percentage of unmet needs (29%), as compared to the percentage of unmet needs reported by husbands who preferred an active role (18%) or a collaborative role (22%).

Table 29: Mean: Sum Scores, Number of Needs, Number of Unmet Needs, and Percentage of Unmet Needs According to Decisional Role Preference

Category	Sum Score	Mean # Needs	Mean # Unmet Needs	Percentage Unmet	n
Active	135.89	29.7	5.2	17.8 %	19
Collaborative	132.58	29	6.4	22.1 %	38
Passive	143.08	29.7	8.7	29.3 %	13

Summary

The results can be summarized as follows:

1. The CPS-H revised role statements formed a unidimensional scale.
2. The majority of husbands preferred a collaborative decision making role with their wives and the physician in their wives' surgical treatment decision making.
3. Fifty percent of the husbands achieved their preferred decision making roles.
4. Husbands' decisional role preferences were not associated with demographic or disease related variables.
5. The FIN-H was found to be internally consistent and 80% of the items correlated with one another.
6. Factor analysis results suggest that the FIN- H is a multidimensional scale with the following five subdimensions: 1) Initial disease/treatment communication with health professionals 2) Emotional and physical care needs 3) Family relationship issues 4) Ongoing communication with health professionals 5) Husband and wife interpersonal communication.
7. Husbands' highest ranked needs were related to emotional and physical care needs

Husbands' lowest ranked needs were related to family relationship issues.

8. There was minimal variation in husbands' highest and lowest ranked needs according to demographic, disease, instrument, and decision making role variables.
9. There was a low moderate correlation (.37, p = .0017) between the sum score of needs and the total number of needs.
10. There was a slight negative correlation (.26, p = .0310) between number of unmet needs and total number of needs.
11. Husbands of women with Stage 3 disease reported a statistically significant (p = .018) greater number of unmet needs than husbands of women with Stage 0-1 or Stage 2 disease.
12. A profile of husbands who were at greatest risk for not having their needs met were identified. Husbands who were older, had less education, lived in a rural area, were retired or worked as labourers, were married to women who had undergone their first surgery for breast cancer and /or had Stage 3 disease, and preferred a passive decision making role reported a greater percentage of unmet needs when compared to husbands within their respective variable categories.

CHAPTER VI

DISCUSSION

Introduction

The purposes of this study were to: (a) modify the Control Preferences Scale (Degner, Sloan, & Venkatesh, 1997) to index husbands' preferences for participation in their wives' surgical treatment decisions when their wives have recently undergone surgery for breast cancer, (b) assess the reliability and validity of the modified CPS scale (CPS-H), (c) describe husbands' role preferences for participation in their wives' surgical treatment decisions when their wives have recently undergone surgery for breast cancer, (d) describe information needs of husbands of women who have recently undergone surgery for breast cancer, utilizing Kilpatrick's (1995) FIN-H tool, and (e) examine the relationship between husbands' desire for information and their preferences for participation in their wives' surgical treatment decision making.

This study was guided Hanks' (1993) Structure of Knowledge Model of Family Decision Making. Hanks' framework recognizes the existence of multiple decision makers in family decision making, the variations in each family member's access to and informational requirements for decision making, and variations in each family member's decision making roles.

This chapter will begin with a discussion and interpretation of the study's findings in relation to specific research questions. Clinical implications with respect to the findings will then be presented. This chapter will conclude with a discussion of the study's results in relation to strengths and limitations, and implications for future nursing research.

Interpretation of the Findings According to Research Questions

Husbands' Preferred Roles of Participation

To date, there is minimal research that has quantitatively measured husbands' participation in their wives' surgical treatment decision making. Wellisch et al's (1978) study of factors related to husbands' adjustment post mastectomy did examine husbands' involvement in their wives' surgical treatment decision making. Wellisch et al., found that 56.6% of husbands viewed themselves as being involved to quite or a considerable extent", while 43.3% of husbands viewed themselves as being "only very little" or "not at all" in their wives' surgical treatment decision making. In retrospect, twenty-three percent of husbands in this study indicated that they wished that they had been more involved in their wives' surgical treatment decision making, and 3.3% of husbands wished they had been less involved in decision making. However, the measurement of husbands' participation in decision making was not evaluated in terms of preference for participation with wife and physician, but rather was based on a four point decision making involvement scale that ranged from "not at all" to "to a very considerable extent". Comparison of Wellisch et al's results is difficult due to the differences in measurement scales. However, both studies found that the majority of husbands preferred to have some degree of involvement in their wives' surgical treatment decision making.

Hilton's (1994) longitudinal qualitative study of family decision making processes about early stage breast cancer treatment found four major family decision making patterns: deference to physician, minimal exploration, joint engagement, and extensive deliberative examination. Deferrer and minimal explorer families deferred to the physician or were minimally involved in surgical treatment decision making. Joint engagement and deliberate examiner families engaged in moderate joint decision making or were actively involved in decision making. Hilton's study was not exclusive to spousal involvement in surgical treatment decision making, however, 74.5% of the families interviewed included spouses as family members. Hilton did not report the percentages of each pattern of family decision making, but did report that approximately half of the families participated to some degree in women's surgical treatment decision making.

Again, direct comparison to the current study is difficult due to the type of analysis and timing of data collection (prospective versus retrospective). However, this study found a greater percentage of husbands (67.2%) who participated to some degree in their wives' surgical treatment decision making than the percentage of husbands (approximately 50%) who participated to some degree in Hilton's study. In addition, the current study found that 28.6% of husbands would have preferred a greater degree of involvement in their wives' treatment decision making than they had achieved.

All three studies report that the majority of husbands prefer to be involved to some degree in their wives' surgical treatment decision making. Wellisch et al.'s (1978) findings were similar to the findings of this study if collaborative and active patterns of decision making can be equated to " quite" and " a very considerable degree of involvement". The higher percentage of husbands who felt they were involved in their wives' surgical treatment decision making in this study, as compared to Hilton's study may be explained by the different methodologies. In the current study, husbands indicated their degree of decision making participation by choosing a card that best expressed their actual experience. Whereas, Hilton assigned the degree of decision making involvement based on her observations.

Stetz's (1993) study of the experiences of patients with liver cancer and their spouses found that spouses were co-decision makers with respect to treatment decisions. Three studies related to reproductive issues (Bean & Egelhoff, 1984; Frank, 1989; Miller et al., 1991) found that couples were joint decision makers. Couples were influenced by their spouse's feelings and beliefs and acted as a unit in making decisions.

Davison et al. (1995) investigated the decision making process of men with prostate cancer and found that wives asked the physician more questions than did their husbands.

Although the majority of men preferred a passive role in treatment decision making, the researchers suggest that the husbands' passivity may have been because their wives assumed more of the decision making role on their husbands' behalf. Hilton (1994) found that when family members were involved in breast cancer treatment decisions, decision making was usually joint, involving the spouse or whole family. The families in Hilton's study varied in the amount of time and information needed to make a decision.

Husbands' Comments on Involvement in Decision Making

Although involvement or participation may have been defined and measured differently in all three studies, the studies concur that the majority of husbands want to included in their wives' surgical treatment decision making. This study quantitatively measured husband's preferred and actual participation roles with their wife and physician with respect to surgical treatment decision making. However, the majority of husbands also provided insight into how they viewed their involvement in decision making. Almost 70% of the husbands indicated that they had attended at least one of their wives' preoperative physician appointments. Several husbands stated that both husband and wife asked the physician questions. Some husbands stated they asked questions because their wives were too stressed to do so. A couple of husbands assisted their wives in preparing written lists of questions prior to physician appointments.

A few husbands initiated referrals for a second opinion. Some husbands initiated information searches through various community resources, the Internet, and/or friends and family. A few husbands assumed the responsibility for reading information, as their wives were having difficulty concentrating or coping with the information.

Husbands' major area of involvement in decision making was discussing surgical treatment options with their wives. Only a handful of husbands stated that they did not discuss treatment options with their wives. Husbands who indicated that they were not involved in discussion of treatment options made statements as follows: " It's her body, her decision" and "I trust her to make the right decision". Some husbands indicated that their adult children were also involved in the surgical treatment discussions. One of the younger husbands in the study stated that his wife's parents participated in treatment discussions. Several husbands indicated that while they were comfortable discussing the pros and cons of the surgical options with their wives, the final decision was up to wives. Husbands also indicated that they were involved in decision making by supporting their wife's choice of surgery, even when the surgical choice was not what the husband would have preferred.

Husbands varied in their perceptions of whether they believed they had enough time and information for decision making. Some husbands of women who had surgical intervention within a week of a definitive diagnosis believed a week was insufficient to assimilate information, whereas, other husbands were pleased with the rapidity of surgical intervention. Some couples exerted greater control over the decision making time period by seeking additional information resources and second medical opinions. However, once the decision was made most husbands desired a limited time period for surgical intervention. Waiting increased anxiety, and questioning of their surgical decision. One husband stated "waiting is very difficult, each day you feel worse".

Husbands' insights and concerns about how they participated with their wives in surgical treatment making is supported by Hanks' (1993) family decision making model and also by previously mentioned empirical research. Hanks contends that family decision making includes multiple decision makers who interact to create a shared decision making process. Individual family members may assume different roles in the decision making process and vary in the amount of decisional responsibility assumed for specific decisions. Individual family members also vary in the amount of time and amount of information needed to make a decision. Variations in individual member's learning and decision making styles influence the family's decision making processes.

Comparison of Findings with Decisional Preferences of Oncology Patients

The majority of decision making research is exclusive to the patient's preference for control over treatment decisions or families' involvement in treatment decisions when the patient is unable to participate in decision making. However, the current study's finding of husbands' strong preferences for some degree of participation in their wives' treatment decision making is similar to findings of several studies that have examined oncology patients' decisional role preferences (Blanchard et al., 1988; Cassileth et al., 1980; Degner et al.,1997; Degner & Russell, 1988; Hack et., 1994; Pierce, 1993). With the exception of Hack et al. (1994), recent studies that have used Degner and Sloan's (1992) CPS for measurement of decisional role preferences of women with breast cancer report a higher percentage of preference for a passive role, than reported by the husbands of women with breast cancer in the current study (Beaver et al., 1996; Bilodeau & Degner,1996; Degner et al., 1997). Table 31 indicates the percentage of decisional role categories found in studies that utilized Degner and Sloan's CPS to examine women's breast cancer decisional role preferences.

Table 30: Decisional Role Preferences of Husbands of Women with Breast Cancer versus Decisional Role Preferences of Women with Breast Cancer

Study	Active	Collaborative	Passive
Current study (husbands)	27%	54%	19%
Hack et al., (1994)	23%	57%	20%
Bilodeau & Degner, (1996)	20%	37%	43%
Beaver et al., (1996)	20%	28%	52%
Degner et al., (1997)	22%	44%	34%

The higher percentage of preference for a passive role in treatment decision making indicated by women with breast cancer as compared to the husbands of women with breast cancer in this study, may be explained by the personal threat imposed by a cancer diagnosis. Degner and Sloan (1992) compared the role preferences of newly diagnosed cancer patients with members of the general public with respect to cancer treatment decision making. Fifty- nine percent of patients in the study preferred a passive role in decision making, in contrast to 64% of the general public's preference for an active role in cancer treatment decision making. The researchers suggest that a life threatening illness influences decision making and may lead to a less active role in decision making. In Beaver et al's. (1996) study, 46% of women with benign breast disease chose a collaborative decision making role in contrast to the percentage of women (28%) with a breast cancer diagnosis who chose a collaborative decision making role.

Although husbands of women with breast cancer can not be equated with members of the general public or women with benign breast disease, the absence of threat to one's own body may allow for a more active role in decision making. Husbands may also feel they need to advocate for their wives, and as such prefer a higher degree of participation with the physician in treatment decision making. However, husbands' actual role in decision making was often less participatory than they would have preferred.

Actual Versus Preferred Role

Two recent breast cancer studies have examined the discrepancies between women's actual and preferred roles in breast cancer treatment decision making, and similar to the current study report a preference for more participation than actually achieved (Bilodeau & Degner, 1996; Degner et al.,1997). Degner et al. (1997) suggested that the discrepancy between actual and preferred roles may be related to women feeling that they really do not have a choice in the face of a life threatening illness. Similarly, husbands of women with breast cancer may moderate their preferred level of participation in light of the magnitude of the decision and the unpredictability of decision outcomes. The finding that over half (54%) of the husbands who preferred a passive role but actually assumed a more active role is interesting. As previously mentioned, perhaps these husbands assumed a more active role than desired because they were assuming an advocacy role on behalf of their wives. Alternatively, husbands may have believed that a more active role is an expectation of their gender.

Decisional Role Preference According to Demographic and Disease Related Variables

Demographic and disease related variables were not associated with husbands' preferences for participation in their wives' surgical treatment decision making. The strong preference for a collaborative decision making role was seen in the majority of all the subdivisions of the variable categories.

Education and age have been found to be the most predictive sociodemographic variables related to preference for control for women with breast cancer. Women with higher education levels preferred a more active role in decision making than women with lower educational levels (Beaver et al., 1996; Degner et al., 1997; Hack et al., 1994). Younger women preferred a more active role in breast cancer decision making than women who were older (Beaver et al., 1996; Bilodeau & Degner, 1996; Degner et al.,1997; Pierce, 1993). However, as previously stated the educational level and age of the husbands in this study did not demonstrate a relationship to preference for decisional role. Perhaps demographic variables are not predictive of decisional role preference when decision making is on behalf on another and/or when there is an absence of personal bodily threat.

An interesting finding in this study is the preferred role preferences of husbands classified as professionals. Although there were only ten husbands in this occupational category, four of the ten "professional" husbands preferred a passive role in their wives' treatment decision making. Based on the assumption that a professional occupation would require a higher level of education and the empirical findings of decision making research, it was anticipated that a lower percentage of "professional" husbands would have preferred a passive role. The greater percentage of preference for a passive role expressed by "professional" husbands may possibly be explained by an assumption that "like attracts": i.e. wives of husbands in this occupational category would also be professionally employed and/or have a high level of education.

The literature suggests that women with higher educational levels generally exert a greater degree of control over breast cancer decision making. If husbands felt that their wives were actively assuming decisional responsibility for treatment decision making, they may have believed that participation on their part was unwarranted. Alternatively, husbands' belief's in their own expertise as professionals may have lead them to believe that the physician was best suited to determine the treatment decision.

Information Needs of Husbands

Highest Ranked Needs

Husbands in this study indicated that their highest ranked information needs were related to emotional and physical care needs. Three of the highest ranked needs (feel there is hope, assured of the best possible care for my wife, and know the probable outcome of my wife's illness) may be viewed as information that helps a husband cope with the helplessness, anxiety and uncertainty engendered by a cancer diagnosis. Husbands also wanted information related to the side effects of treatment and wanted to know how to provide emotional support to their wives. Knowledge of treatment side effects may be related to feelings of uncertainty, but may also be related to husbands' concerns for their wives' physical well being. Husbands' need to know how to provide emotional support to their wives may reflect their need for assistance in supporting their wives through the cancer experience.

Husbands' Comments about Highest Ranked Needs

During the post instrument completion discussions, 15/70 husbands specifically stated that their greatest concern was for their wife's health and welfare. One husband stated that he felt emotional care/bedside manner was as important as physical care. Husbands often commented on their perceptions of the physician's interpersonal and communication skills and whether or not the physician portrayed a caring attitude. Husbands also commented on their perceptions of the care and caring attitude of nurses. Husbands who commented either had a very positive or very negative experience with physician or nursing care practices. Although husbands did not rank " to feel health professionals care about my wife" as a priority need, researcher observations and husbands' comments indicate that health professionals' attitudes are extremely important to husbands of women who had recently undergone surgery for breast cancer. Perhaps being assured of the best possible care was interpreted as both physical and emotional care needs.

Physicians' preoperative attitudes and interpersonal skills appeared to be more important than postoperative physician and nursing care aspects. However, having an opportunity to speak to the surgeon following surgery was also viewed as important to many of the husbands in the study. Again, husbands who commented about this aspect of physician care either had a negative or positive experience. One husband who was upset that the physician had not spoke to him after surgery stated "I know he can't tell me much, but he could at least tell me how she was after surgery". When husbands did have an opportunity to speak to the physician after the surgery, they were most appreciative and expressed a greater confidence towards physician care. With respect to nursing care, husbands appeared to evaluate nursing care by: inclusion of husbands in explanations about care procedures, information sharing, caring attitude towards wife, and discharge care instructions. Husbands' anxiety and helplessness may be lessened if they feel that health care providers are providing appropriate care to their wives, and care about their wives' or the couple's welfare.

In relation to the needs: to feel there is hope, know the probable outcome of my wife's illness, and know the side effects of treatment, one husband expressed these needs most aptly "I think the worst, so I need to know everything or be reassured". Another husband stated "I need an idea of what is going to happen, what to expect". Several husbands reported the anxiety they experienced waiting for pathology results. These statements reflect the uncertainty that husbands experience when their wives are diagnosed with breast cancer.

Empirical Support of Priority Needs Findings

Although there is limited research related to the information needs of husbands of women with breast cancer, literature related to family and spousal information needs of oncology patients support some of the empirical and observational findings of this study. Literature suggests that husbands are the frequently the major source of emotional support when their wives are diagnosed with a life threatening illness (Baider & Kaplan De-Nour, 1988; Chaitchik, et al., 1992; Hannum et al., 1991). Northouse and Swain (1987) found that concerns expressed by husbands of women during the early stages of illness were related to emotional issues. As such, husbands require information that will allow them to cope with their emotions and information that will assist them in the emotional support of their wives.

Oberst and James (1985) reported that the primary concern of spouses of patients post surgical intervention for bowel and genitourinary cancer was the patients' health. Kristjanson (1989) reported that the major concern of families of oncology patients in the acute phase of illness was to receive information related to the patient's care. Northouse (1989) reported that the major concern of husbands of women who had undergone mastectomies was survival of the disease. Another concern identified by husbands was their wives' ability to cope with the emotional ramifications of the illness and the loss of a breast. Husbands found the diagnostic period most stressful due to feelings of uncertainty and indecisiveness about treatment options, anxiety about the unknown, and frustrations with waiting for diagnostic tests or results. Husbands' postoperative anxiety was related to the uncertainty of the extent of the breast cancer. Hilton's (1993) qualitative study of families of patients with breast cancer, similarly reports on the high degree of uncertainty experienced by family members in the diagnostic period and the postoperative anxiety related to whether the surgery "got it all".

Tringali (1986) found that family members of oncology patients ranked the following needs as one of the top 12/53 information needs: #3 feel there is hope, #5 assured of best possible care, #7 treatment symptoms, and #12 probable outcome of illness. Tringali 's publication of findings did not list all 53 need statements, therefore it is uncertain if the need "know how to provide emotional support to my wife" was one of the need statements or if it was not ranked as a high priority need. Wright and Dyck (1984) report that two of the four primary concerns of family members of hospitalized oncology patients were: "fear of the future" and "waiting". These two concerns were most acute just prior to and after diagnosis. Waiting for treatment and diagnostic results lead to feelings of anger and frustration.

Replication Comparison

The FIN-H was developed by Kilpatrick and Kristjanson and used by Kilpatrick (1995) to describe the information needs of husbands of women who had recently undergone surgery for breast cancer. Kilpatrick had husbands complete the FIN-H twice, the first time in the presence of the researcher and then within 24 hours of initial instrument completion (husbands mailed in the second completed questionnaire). Sixty-two percent of the husbands in the study did the initial completion of the FIN-H one to three days post surgical intervention. The husbands in Kilpatrick's study identified the following five priority information needs at **Time 1:** 1) to have my questions answered honestly 2) to be assured that the best possible care is being given to my wife 3) know the probable outcome of my wife's illness 4) to know specific facts concerning my wife's future 5) to be informed of changes in my wife's condition. **Time 2:** 1) to know specific facts concerning my wife's future 2) to be assured that the best possible care is being given to my wife 3) to feel that health professionals care about my wife 4) to be informed of changes in my wife's condition 5) to have my questions answered honestly.

Fifty percent of the husbands in the current study completed the FIN-H from the first to third postoperative day of their wives' surgery. Only two of the priority needs identified by the husbands in Kilpartrick's study at time one (probable outcome, and best possible care), and one of the priority needs at time two (best possible care) were identical to the priority needs identified by husbands in the current study. Kilpatrick classified the priority needs of husbands in her study as needs related to immediate care needs and communication with health professionals. Husbands in Kilpatrick's study appeared to have a greater number of needs related to communication with health professionals than husbands in the current study. However, knowing specific facts about my wife's future may be viewed as similar to knowing the probable outcome of the illness.

Priority needs similar to those reported by Kilpatrick were reported by Hilton (1993), Tringali (1986), and Wright and Dyck (1984). Family members of oncology patients (Tringali, 1986) ranked similar information needs as follows: #1 questions answered honestly, #2 informed of changes in condition, and #4 feel personnel care. Wright and Dyck (1984) found that family members of oncology patients rated "to be kept informed of condition", "to be informed of an changes", and "acceptance, support, and comfort from nursing staff" as their first, third, and sixth priority needs. Hilton (1993) reported that families of women with breast cancer found that lack of general breast cancer knowledge and lack of specific facts related to their own situations was an information issue, particularly for families in the diagnostic phase of illness.

Husbands in Kilpatrick's study and husbands in the current study did prioritize needs related to the immediate care needs. However, husbands in the current study did not identify needs related to communication with health professionals as had been identified by the husbands in Kilpatrick's study. The differences in needs related to communication with health professionals identified by husbands in Kilpatrick's study and the previously mentioned empirical studies may be explained by the following reasons. During the time frame between the studies, there has been an increase in the media's dissemination of general knowledge about breast cancer. In addition, women's advocacy groups have put increased pressure on health professionals with respect to communication of disease and treatment information.

Fifty percent of the current study's data collection occurred after the third postoperative day. Husbands' emotional care needs may take precedence over health professional communication issues once their wives have initially recovered from surgery, and the couple is at home waiting for pathology results. Although husbands did prioritize "know what side effects are caused by treatment", this need may also be reflective of the timing of data collection. Husbands whose wives had undergone a lumpectomy were probably worried about their wives' future radiation treatments. Husbands of women who had undergone a mastectomy may have anticipated the need for adjuvant treatment in the absence of the pathology report, or may have been informed of the probable need for adjuvant treatment.

According to Hanks'(1993) model of family decision making, communication with health professionals and the receipt of factual information is essential to arriving at a decision. Postsurgical information needs may shift from information needed to make a surgical decision, to information that facilitates living with the surgical decision, coping with the illness, and information required to make additional treatment decisions.

The lack of identification of communication needs with health professionals, may also be reflective of the majority of husbands' experiences with health professionals. As previously mentioned, approximately 70% of the husbands in the current study accompanied their wives to at least one preoperative physician appointment. Approximately half of the husbands who accompanied their wives to appointments indicated that they felt included by the physician in treatment discussions. Several husbands asked questions during the treatment discussions and some came armed with a list of written questions. Some of the husbands who initiated a second opinion did so because they did not feel included in treatment discussions, and/or disliked the physician's interpersonal and communication skills.

Lowest Ranked Needs

Intimacy issues (how to approach changes related to sexuality and how to touch my wife), disruption to family role functioning (be told about people who could help with problems: financial and household), personal well- being (have someone be concerned with my health), and communication with children (what to say to children) were ranked by this sample as the lowest priority needs. Husbands frequently commented that they were not concerned about themselves, only about their wives. However, husbands appeared to be pleased with the researcher's questioning about their well-being. One husband stated "You are the first one to inquire about how I'm doing". A few husbands did express concerns about their personal well being, but indicated that they were trying to suppress their personal feelings. Comments like: " I don't want to burden my wife with my concerns" and " I need to be up for my wife, but I'm a basket case", reflect husbands' subjugation of their feelings.

With respect to intimacy issues (how to approach changes to sexuality and how to touch wife), several husbands made comments when they were ranking the importance of the two need statements related to these issues. Many husbands indicated that while intimacy issues were important, they did not take precedence over cognitive and emotional care information needs. Several husbands indicated that intimacy needs were an interpersonal issue between husband and wife and did not want, or expect an external source of information on how to deal with intimacy issues. Older participants often laughed when they came to the intimacy questions, stating that their marital relationships were not based on intimacy issues. However, a few of the younger husbands whose wives had undergone a mastectomy did express fears related to intimacy issues by the following comments: I used to always like to pinch her boobs, now I'm afraid to touch her ..... I'm afraid of hurting her or being rejected "and " my wife's breasts have always been important to my sexual satisfaction, how can I hide my feelings".

Disruption to family roles (help with financial and household problems) were rarely commented on by husbands in this study. However, a few husbands did comment on the strain that their wife's illness did impose on normal family functioning as demonstrated in the following comments: "My wife is the focal point of this household", and "I'm having difficulty balancing support of my wife with caring for my children and doing my job".

Communication with children (what to say to children) was not rated as a priority need by the majority of participants, however, the mean age of husbands in this sample was fifty- eight years. However, several husbands stated that adult children were involved in treatment decision making and others stated that daughters had either accompanied their mothers to physician appointments with or without the presence of the husband. Several husbands also indicated that adult daughters had initiated information searches and were used as a source of information. As indicated in the next section, husbands under fifty years of age did not list " knowing what to say to children" as one of their lowest priority needs.

Therefore, the low ranking of the need to communicate with children is probably reflective of the older age of the children of the majority of participants.

Empirical Support of Lowest Needs Findings

The majority of literature related to the needs of family members of oncology patients focuses on priority needs, rather than non-priority needs. However, a few investigators have reported similar findings with respect to needs that are viewed as a lower priority. Husbands in Kilpatrick's (1995) study reported the same five lowest ranked needs as did husbands in the current study. Three studies related to the needs of families of oncology patients found that financial and household problems were considered low priority needs

(Tringali, 1986; Wright & Dyck, 1984; Wingate & Lackey, 1989). Husbands in Northouse's (1989) study of couples post mastectomy reported that sexual and marital ramifications of surgery were insignificant compared to their concerns about their wives' survival. Lifestyle concerns and concerns related to children were less of a concern to the husbands than they were to the wives in Northouse's study.

Husbands in the current study ranked "to have someone be concerned with my health" as a low priority at this point in time. However, literature indicates that spouses of oncology patients do experience physical and psychosocial distress throughout the cancer experience. Spouses of patients with bowel and genitourinary cancer reported a higher incidence of anxiety and depression than reported by the patients at 10, 30, and 60 days postdischarge (Oberst & James,1985). By 30-60 days postdischarge, spouses had an increase in physical symptoms (indigestion, vague diffuse pain), and reported anger and frustration at the lack of support they received from health professionals. Husbands may rank the need for concern about personal health higher once they have recovered from the initial shock of the diagnosis and surgical intervention.

Information Needs According to Demographic, Disease and Instrument Variables

Ranking of Needs

There was minimal variation among the demographic, disease, and instrument related variables with respect to husbands' lowest ranked information needs. Husbands in all categories were able to identify five low priority needs. The vast majority of needs ranked as low priority were related to family relationship issues. Husbands in several of the independent variable subdivisions identified 6-11 needs as high priority information needs. However, the vast majority of the highest ranked needs according to all the independent variables were related to physical and emotional care needs.

Husbands in the professional occupational category and husbands of women who had undergone their second surgery listed the greatest number of priority needs (10 and 11 respectively) and the highest means for their priority needs. These findings may be related to the small number of husbands in both of these categories (10 professionals, and 11 second surgery). However, there were only 6 husbands of women who had Stage 3 disease and there was not the same increased number of priority needs and there was only a minimal difference in the means reported for priority means between husbands of women with Stage 0-1 disease and husbands of women with Stage 3 disease.

The higher means reported by the youngest husbands (<50), and their need to know specific facts about the future and know what to say to children is not surprising given their families' place in the lifespan. Husbands over the age of 65 listed a greater number of priority needs than husbands in the other age categories, and indicated more needs related to disease, treatment, and condition communication with health professionals. Perhaps older husbands have greater concerns regarding their wives' physical ability to cope with the disease and treatment and/or had been less proactive in information seeking than husbands who were younger.

Husbands with greater than a high school education prioritized more needs related to treatment specific needs than did the other educational categories and were the only educational category to prioritize needs related to husband and wife communication. Perhaps a greater degree of formal education assists husbands to concentrate on information related to specific points in the cancer experience and the decisions to be made according to the phase of illness. Husbands with greater than a high school education may have assigned a higher priority to information needs that would assist them to deal with adjuvant decision making and support of their wives in the post surgical phase of their illness.

"Professional" husbands listed the greatest number of priority needs in the occupational subdivisions and also prioritized a couple of needs in all of the needs classifications except for needs related to family relationship issues. Perhaps husbands who are professionally employed are adept at dealing with large amounts of information and require more information to provide a global understanding of a topic than husbands who are not professionally employed. Like husbands who had a greater than high school education, husbands classified as professionals indicated three needs related to treatment specifics.

The differences in the priority needs identified by rural and urban residents may be explained as follows. Rural husbands' need to have explanations given in tems that are understandable may be related to the average level of education of the rural participants (55% had less than a high school education). Rural participants may have had a greater need for information about changes in their wives' condition and what to do for their wives at home, as their access to physician (surgeon and oncologist) and nursing support is limited as compared to urban participants.

Husbands of women who had undergone their second breast surgery were the only husbands to list "know how to provide physical care to my wife" as a priority need. The greater number of priority needs and the higher means for priority needs reported by husbands whose wives had undergone their second breast surgery may be related to the increased anxiety caused by the need for a second surgery. The high number of physical and emotional care needs and the need to know how to provide physical care may be related to husbands' previous experience with their wives' post surgical needs.

The single difference in the prioritization of needs reported by husbands of women who had a lumpectomy (emotional support) to husbands of women who had a mastectomy (changes in condition) may be explained as follows. Perhaps husbands of women who had a mastectomy had already been dealing with the emotional ramifications of surgery in their surgical treatment decision making and were now more concerned about potential changes in their wives' condition. The slightly higher means for the highest and lowest priority needs reported by husbands of women who had a mastectomy as compared to husbands of women who had a lumpectomy may be related to the extent of surgery and the longer period of recovery from surgery.

The startling difference in the prioritization of needs among the husbands of women with varying stages of disease was that husbands of women with Stage 3 disease did not list any needs related to treatment. Perhaps husbands of women with Stage 3 disease had anticipated the need for further treatment and had already sought information related to adjuvant treatment. Alternatively, husbands may have been aware of a poorer prognosis for their wives, so were most concerned with information that assisted them to cope with emotional and physical care needs.

The slight changes reported in the priority information needs in relation to the day of data collection suggests that husbands' priority needs may change according to the phase of the cancer experience. The differences in the highest and lowest ranked means according to who was present at data collection suggests that husbands may feel more vulnerable when they were alone and thus rate their information needs as more important.

Number of Needs, Sum Score of Needs, and Extent to Which Needs are Met

Some of the study's independent variables were statistically significant when compared to husbands' sum score of needs, and the extent to which identified needs had been met. Statistically significant and clinically significant findings are presented in the following paragraphs.

Although there were no significant differences in the number of unmet needs according to educational level, there was a trend for the number of unmet needs to increase as level of education decreased. Husbands with greater than a high school education may have more of their needs met for the following reasons: post-secondary education may enhance husbands' comprehension of information, their information seeking and clarification skills, and may minimize feelings of knowledge and educational inequality between the husband and health care professionals.

With respect to occupational categories, husbands who were retired or classified as labourers reported the greatest percentage of unmet needs, whereas husbands who were classified as professionals reported the lowest percentage of unmet needs. The same explanation that accounted for the differences in unmet needs according to educational level can be used for the reported differences among occupational categories, if one accepts the following assumption. Husbands who were classified as labourers and the majority of husbands who had reached the age of retirement probably had less formal education than husbands who were currently employed as professionals.

Although husbands who resided in urban areas reported a greater number of needs than did rural residents, rural residents reported a greater percentage of unmet needs than did urban residents. The difference in unmet needs can be partially explained by differential access to information in the urban and rural settings. An additional explanation may be the educational level of the rural participants. The majority (80%) of husbands who resided in a rural area had not gone beyond a high school education, and 55% of rural residents had less than a high school education.

The only statistically significant finding related to disease variables was the difference in unmet needs according to stage of disease. The elevated percentage of unmet needs reported by husbands of women with Stage 3 disease may be related to the receipt of presurgical diagnostic information. All of the women who had Stage 3 disease had undergone mastectomies, and all of their husbands stated that a mastectomy had been strongly recommended by the physician. Two of the six husbands whose wives had Stage 3 disease indicated that they had been told of the possibility of advanced disease. Husbands' anxiety may have limited their comprehension and retention of information and may have precluded information seeking if they had been told that their wives had diagnostic indications of more advanced disease, or if they had assumed so on the basis of the recommendation for a mastectomy. Alternatively, the amount of information presented by the physician may be related to the physician's perceived need for surgical decision making. Physicians may provide more information when a woman has a choice of surgery.

The higher percentage of unmet needs reported by husbands of women who had undergone their first surgery for breast cancer compared to husbands of women who had a second surgery may be related to knowledge gained from the previous surgical experience. However, husbands of women who had undergone their second surgery for breast cancer rated their identified needs higher than did husbands of women who had their first surgery for breast cancer. Perhaps, the anxiety related to the need for a second increases husbands' perceptions of the importance of specific information.

The significantly higher sum score of needs reported by husbands who completed the FIN-H with only the researcher present, as compared to husbands who completed the FIN-H with the additional presence of their wives or children may be explained by the following reasons. Husbands may have felt more vulnerable when they were alone. Alternatively, husbands who chose to complete the FIN-H in the absence of their wives may have been needier and wanted to be able alone so they could express their concerns more freely.

Replication Comparison

Husbands in Kilpatrick's (1995) study reported higher percentages of unmet needs for all of the demographic and disease related variables, with the exception of the number of surgeries, than reported by husbands in this study. The mean percentage of unmet needs in Kilpatrick's study according to demographic and disease related variables was 39% with a range of 21% - 54%. The mean of percentage of unmet needs for demographic and disease related variables in the current study was 23% with a range of 14% - 46%.

Both studies reported similar trends with respect to differences in unmet needs within the variable subdivisions, except for clinical stage of disease. Husbands who were older, had less education, lived in a rural area, were retired or worked as labourers, and were married to women who had undergone their first surgery for breast cancer, reported a greater percentage of unmet needs when compared to husbands within their respective variable category. However, Kilpatrick found greater discrepancies within the subdivisions of the demographic and disease related variables than was demonstrated in this study.

Kilpatrick did not report the number of unmet needs in relation to clinical stage of disease. However, the findings of this study indicated that husbands of women with Stage 3 disease had a significantly greater number of unmet needs when compared to husbands of women with Stage 0-1, and Stage 2 disease and the highest percentage of unmet needs when compared to all other independent variables.

A comparison of the percentage of husbands within each of the demographic and disease variables that related to the number of reported unmet needs was done to ascertain if the reported differences in the studies could be accounted for by sample differences. The mean age of husbands in both samples was 58 years. In both studies, the majority of men were retired, lived in an urban area, and were married to women who had undergone their first surgery for breast cancer.

Kilpatrick's sample was also comprised of a slightly higher percentage of husbands who were classified as labourers (26%) as compared to the percentage of husbands (21%) classified as labourers in the current study. The percentage of husbands represented in the less than high school and greater than high school educational subdivisions was essentially transposed in the two studies. In Kilpatrick's sample, 33% of husbands had less than a high school education and 41% had greater than a high school education. In the current study, 41% of the husbands had less than a high school education and 34% had greater than a high school education. On the basis of the aforementioned comparisons, the decrease in the percentage of reported unmet needs in this sample can not be accounted for by demographic and disease related variable differences between the samples.

Possible explanations for the decreased percentage of unmet needs are as follows. Health care professionals may have become more attuned to the information needs of families who are experiencing a breast cancer diagnosis. The public's general knowledge about breast cancer and breast cancer information resources has increased due to the increase in mass media education in the time frame between the two studies. The increase in general knowledge about breast cancer may have allowed families to be more open about a breast cancer diagnosis. This increased openness may have facilitated information sharing within the family and facilitated the receipt of information from family and friends.

The aforementioned possible explanations were supported by information provided by some of the couples in this study. A large percentage of participants in this study had received written resource materials at their initial visit with the surgeons. Some of the resource material had been earmarked or highlighted to facilitate reading of the most pertinent information. Several of the participants had a surgeon who spent a considerable length of time with the couple at their initial appointment. Husbands who received information from this particular surgeon, consistently praised the surgeon's interpersonal and communication skills. This surgeon's receptionist was also praised for her sensitivity and promptness in addressing telephone relayed questions and concerns. Husbands stated they immediately felt at ease, felt included in the treatment discussions, and were encouraged to ask questions. Husbands whose wives were attended by this surgeon consistently indicated that they had the majority of their information needs met.

Several husbands whose wives were attended by other surgeons stated that they felt they had adequate access to information. Husbands varied in their perceived need for oral versus written information, and also varied in how they preferred to access information.

Some husbands were content to rely on information sharing from their wives. Other husbands were actively involved in information seeking. Several husbands indicated that they read more of the informational resources than their wives did. Other husbands accessed information through the Internet, and a few had received information from the Hope Breast Cancer Information and Resource Centre. As previously mentioned, a few husbands initiated referrals for second opinions and prepared written lists of questions for their wives' physician appointments. Other husbands stated that they selectively read information, either because of a perceived need for information related to a specific area or on the recommendation of their wives.

Several husbands indicated that they had received information from family and friends. Adult daughters appeared to be most involved in information seeking. A number of husbands indicated that they had family and/or friends who had previously been diagnosed with breast cancer. One husband noted that after his wife had shared her breast cancer diagnosis with her co-workers, she received several phone calls from women who had not previously shared their own breast cancer diagnosis. As this husband so aptly stated "women with breast cancer seemed to appear out of the woodwork" after my wife's diagnosis.

However, there were several husbands who stated that they had not received adequate information and were not aware of informational resources. Only a handful of husbands related their lack of information to their wives' reluctance to share information. However, some husbands believed that their wives may have been selective in their information sharing, as reflected in the following statement. "She tells me what she feels I need to know, not what I may want to know". Another husband felt he should have received information that was specific to the husband.

The majority of husbands who felt that they had inadequate information did not have written resource material and/or had not received any information from family and friends. Husbands who had relied on the verbal explanations provided at the time of diagnosis indicated that they either could not recall all information or had been too overwhelmed to process the information. Some husbands were reluctant to seek clarification of information when it was presented, and others stated that they did not know what questions to ask. A few husbands stated that they wished that the information presented at the physician appointment had been written, so it could have been reviewed at home.

Some husbands stated that they could have been given all the information in the world, but were too immobilized by the breast cancer diagnosis to process the information. Some husbands would not read available information, others stop reading because it increased their anxiety and a few husbands stated that they initially denied the seriousness of the diagnosis.

The previously mentioned researcher observations and husbands' comments suggest that the following factors may limit husbands' ability to have their information needs met: a lack of written resources, limited information sharing between the couple, limited information sharing from family and friends, and a limited ability for information seeking due to emotional trauma.

The individual variations reported by husbands with respect to the amount and type of information they desired is supported by Hanks' (1993) Structure of Knowledge Model of Family Decision Making. Hanks' model notes that individuals and individual family members vary in their informational requirements. Hanks' model also acknowledges the effect that contextual variables can have on the receipt of information. When husbands felt at ease and included by health professionals, and when they were accorded a significant amount of time for treatment discussions, they felt comfortable in asking questions and expressed satisfaction with the information they received.

Needs According to Decisional Role Preference

The hypothesis that husbands who preferred an active role in their wives' surgical treatment decision making would have a greater need for information (on the basis of number of needs and means of priority needs) than husbands who preferred a collaborative or passive decision making role was not supported. Husbands in all three preferred decision making categories reported a similar number of information needs. However, there were differences between the categories with respect to the sum score (degree of importance of identified needs) and percentage of unmet needs.

Empirical Support of Needs According to Decisional Role Findings

Research that has examined the relationship between patient's preferences for control over treatment decisions and patient's desire for information report inconsistent findings. Cassileth et al. (1980) and Hack et al. (1994) suggested that the desire for information and the desire for decisional control are correlated: a greater desire for control indicating a greater desire for information. Other researchers found no correlation between information seeking and decision making preferences (Blanchard et al., 1988; Ende et al., 1989; Sutherland et al., 1989).

Although comparison of this study's findings is difficult due to differences in the information measures utilized, the current findings do not support either of the aforementioned research findings. Husbands who preferred a passive role rated their identified needs higher than husbands in both the active and collaborative decision making categories. In addition, husbands who preferred a passive decision making role indicated that they had a higher percentage of unmet needs than reported by husbands who preferred a collaborative or active decision making role. Perhaps husbands who preferred a passive decision making role were also passive in their information seeking prior to their wives' surgical intervention for breast cancer. This explanation would account for the higher ratings of their identified needs and the greater percentage of unmet needs as compared to husbands who preferred active or collaborative decision making roles.

Recent studies that have used the CPS for measuring preferences for decisional control and used the same nine categories of information needs reported different findings with respect to the relationship between decisional and informational preferences (Davison, et al. 1995; Degner et al., 1997). Davison et al.'s study of men with prostrate cancer found that men who desired a collaborative role and men who wanted the physician to make the decision after seriously considering their opinion wanted more information about the likelihood of cure than did men in all other decision making categories. Whereas, Degner et al.'s study of women with breast cancer found that information about likelihood of cure was more important to women who preferred an active decision making role than women in the other decision making categories.

Again, comparison with the current study's findings is difficult due to different information measurement tools. However, comparison can be made if "facts about my wife's future" and "probable outcome of disease" are equated with "likelihood of cure". The current study's findings are closer to the findings of Davison et al.(1995). Husbands who preferred a collaborative role listed " know the probable outcome of my wife's illness" as a priority need, and husbands who preferred a passive role listed "specific facts concerning my wife's future" as a priority need. Husbands who preferred a passive role rated their need to know about their wives' prognosis higher than husbands who preferred a collaborative role. Husbands who preferred an active role did indicate that they needed to feel there was hope but did not indicate a need for more specific information related to their wives' prognosis. The same possible explanation for differences with respect to the degree of importance of information can be used for differences related to the type of information sought by husbands in the various decisional role categories.

Husbands who preferred a passive role indicated a higher number of needs related to communication with health professionals and a greater number of needs related to husband and wife interpersonal communication than did husbands in the other two decision making categories. Husbands in the passive category also indicated less needs related to physical and emotional needs than did husbands in the active and collaborative categories.

On the assumption that husbands who preferred a passive role in decision making were also passive in their information seeking and/or sharing with their wives, they would have a greater need for information related to communication about their wives' disease and treatment. Husbands who preferred an active role in decision making may have previously sought information with respect to their wives' prognosis and were now interested in information that assisted them to cope with the current situation and information needed to make future decisions.

ANOVA Results

The only clinically and statistically significant result of the ANOVA analysis was related to the greater number unmet needs reported by husbands of women with Stage 3 disease. Therefore, individual assessment of information needs remains the best clinical approach to determining the information needs of husbands of women who have undergone surgery for breast cancer. However, presurgical indicators of advanced disease may warrant increased diligence on the behalf of health care professionals to continually assess the information needs of husbands of women who are potentially or actually diagnosed with advanced disease.

Methodological Issues

Control Preferences Scale

The Control Preferences Scale for Husbands (CPS-H) was pilot tested for clarity, internal consistency, and for the validity (responses that indicate an understanding of the hypothesized dimension) of the revised role statements with a panel of six husbands whose wives had previously undergone surgery for breast cancer. The results of the pilot study indicated that the revised role statements were clear and internally consistent, with 83% of the pilot subjects' preference orders falling directly on the hypothesized psychological dimension of control. Phase two results supported the unidimensionality of the revised scale, with 70% of the participants indicating that they had systematic preferences about the degree of control they desired about their wives' surgical treatment decision making.

CPS-H Administration Observations

The CPS-H was administered to both the pilot and study participants in a fixed order to ensure that order effects were kept constant across all participants. The majority of participants did not have difficulty with completion of the CPS-H. However, the majority of the participants did read each card a couple of times prior to choosing between the two alternative choices. Some husbands struggled with their choices and sought clarification of their perceived meaning of the role statements. Husbands had less difficulty in choosing between two cards when either card A (wife and I make final decision) or card E (leave all decisions to doctor) was presented, than they did with choices between the other three cards. A few husbands questioned the subtle differences between card B (wife and I make the decision after considering doctor's opinion) and card C (doctor, wife and I share responsibility for deciding). A few husbands believed that there should have been a card that only included their wives and the doctor in the decision making process.

The majority of husbands did not have difficulty in picking the one card that they believed was closest to their actual role in decision making. This may have been due to their increased familiarity with the role statements, or the differences in certainty with respect to retrospective preference and actual behaviour.

Although not quantitatively measured, completion of the CPS-H at the husband's home appeared to invoke less questioning from the husbands with respect to the meaning of the role statements than when husbands completed the CPS-H at the hospital. This observation may be due to environmental differences or differences related to timing of the data collection. The limited space, the inherent noises in a hospital environment, and the anxiety related to hospitalization of their wives, may have limited husbands' comprehension and concentration abilities.

Although the information needs tool generally took longer to complete than the CPS-H, husbands appeared to have to put more effort into completing the CPS-H than the FIN-H. Perhaps, husbands were tired from completing the FIN-H, or had difficulty switching to examination of another concept.

Family Inventory of Needs: Reliability

The internal consistency of the FIN-H, as measured by Cronbach's standardized alpha coefficient was .95. Kilpatrick (1995) reported similar internal consistency reliability in her study at both Time 1(.91) and Time 2 (.93). The internal consistency reliability, inter-item and item to total correlations scored well above the preset criteria for this study.

Only two items achieved item to total correlations at .80 or greater, suggesting that there is minimal redundancy in the scale. One item (be told about people who could help with problems) obtained a slightly low item to total correlation (.26). Since this is the only item on the scale that directly asks about the need for "hands on" external resources, it may not be parallel to the other items that focus on emotional and cognitive needs.

Eighty percent of the items correlated well with one another. The few items that did not meet the preset inter-item criteria were items that were consistently ranked as a low priority. Five of the six items were related to family relationship issues, and the other item was "help with my wife's care while in hospital".

Items that were found to score above the preset criteria for item to total correlations in this study were not reported as such by Kilpatrick. The only item to total correlation that was similar to Kilpatrick's findings was for item 20 (help with problems). Kilpatrick reported a lower percentage (57%) of items that correlated well with one another, but similarly found five of the same items with low inter-item correlations

Removal of items on the basis of the correlational results of two studies would be premature. Although the need related to "help with problems" scored below the preset criteria for item to total correlations in this study and at time 1 in Kilpatrick's study, in both studies this item scored above .25. Therefore, this item should be monitored in subsequent studies. However, knowledge of a husband's need for external resources may be important regardless of whether it is a parallel item.

The finding that the majority of the items that did not meet the preset criteria for inter-item correlation were related to family relationship issues, suggests that the scale is multidimensional in nature. Although the factor analysis presented in the next section suggests that there are five subdimensions, the other four dimensions appear to be more parallel to one another. This is not surprising, as the other four dimensions are directly related to communication about their wives' disease/treatment or their wives' care needs rather than the impact of disease on the family as a unit.

Family Inventory of Needs: Validity

Internal construct validity of the FIN-H was assessed using factor analyses techniques. Factor analysis suggested that there may be five subsimensions to the FIN-H. Items that loaded on factor one appeared to be related to information and concerns that would assist the husband with initial disease and treatment communication with health professionals (i.e. facts about treatment, disease, and future, honest answers, and understandable explanations). Factor four also dealt with communication with health professionals, but contained items that had more relevance to ongoing communication issues and/or communication issues related to future treatment (i..e. changes in treatment and condition). Items that loaded on factor five also dealt with communication, but appeared to be related to information that would assist husbands in communicating with their wives about the disease and treatment (i.e. how to talk to wife about illness, why things are done, and what treatments wife receiving).

Factor two contained items that appeared to be related to information that would assist the husband with the emotional and physical ramifications of the diagnosis and the surgical intervention (i.e. assured best care, feel there is hope, what to do at home, and how to provide physical care). All of the five top priority needs identified by the sample were related to items in this factor. Factor three contained items that appeared to be related to information and /or concerns related to potential disruptions to family relationships or role functioning (i.e. intimacy issues, wife's energy, personal health, and communication with children). The five lowest priority needs listed by the sample were items related to factor three.

Item #20 " help with problems" obtained the lowest factor loading (.40). Item #18, "help with my wife's care while in hospital" demonstrated a minimal difference in factor loadings on three of the factors, with the highest loading (.43) just above the preset criterion. However, both of these items obtained factor loadings greater than .50 in Kilpatrick's factor analysis.

Although Kilpatrick identified the same number of factors in her study, the number of items per factor and the specific items per factor were not identical. The greatest degree of similarity occurred with the items that related to family relationship issues and as such were assigned identical labels. Although factor labeling is directed by the items that have the highest loadings on each factor, labeling also includes a subjective interpretation by the researcher (Hair, Anderson, & Tatham, 1987). However, both of the factor analysis results suggest that the FIN-H is a multidimensional scale, with five subdimensions.

Zellers and Carmine (1980) (as quoted by Brink & Woods, 1989) state that construct validity is never confirmed, but is supported from the results of multiple studies. Construct validity requires a pattern of consistent findings involving multiple studies across time performed by different researchers (Brink & Wood, 1989). Therefore, additional testing of the FIN-H would need to be undertaken to support the relationships among the items.

FIN-H Administration Observations

The majority of the husbands did not have difficulty with completion of the FIN-H, once the instructions for instrument completion were clear. Husbands were given verbal instructions and an example by the researcher, and then asked to read the instruction on their own. A few husbands did require repeated clarifications for the difference between ranking the need statements and scoring the need as to extent the need had been met. Several husbands did ask for clarification of the meaning of specific items. The two items related to symptoms (what symptoms caused by illness and when to expect symptoms to occur) were the most frequent items to require clarification. Perhaps husbands were unfamiliar with the term symptoms. Alternatively, husbands may have related symptoms to their wives' pre-diagnostic state, as reflected by one husband's statement "my wife didn't have any symptoms, she had a mammogram". Husbands who asked for clarification of the meaning of an item often required clarification of more than one item.

Only six husbands indicated additional information needs that had not been addressed by the FIN-H. However, several husbands indicated that they were unable to honestly answer the need for additional information at this point in time. The additional information needs indicated are as follows: guidance through the health care system (two participants), risk factors, "acceptance of guilt if I can't cope", and wife's postoperative activity limitations (two participants).

Several husbands indicated that they were reluctant to indicate that some of the need statements had not been met. As previously mentioned, several husbands indicated that they did not expect or want external sources of information about need statements related to intimacy issues. Reluctance was sometimes expressed about need statements that could be viewed as future rather than present information needs (i.e. treatment). Husbands explained their reluctance by the following rationale. Some husbands believed that although certain need statements had not been met at this point in time, they were confident that this information would be provided at future physician appointments. Husbands that provided this explanation seemed to believe that they did not have a current need for this information. Other husbands seemed to be hesitant to indicate that they had not been provided specific information, as if they did not want to blame anyone for their lack of information. Husbands would state that they may have received the information but had been too upset at the time to process the information. Other husbands indicated that they had been given so much information at one time that they were unable to remember what they had been told.

The rationale presented by some of the husbands suggests that husbands' recall of information may be limited by anxiety, and the amount or salience of presented information. In addition, husbands may prefer to obtain information specific to their current situation. Husbands' information needs may be better met by assessment of their information needs throughout the cancer experience, and by repeat of salient information at specific points in their wives' cancer experience.

Clinical Implications

Information Needs

Results of this study have implications for health professionals that interact with husbands of women with breast cancer. Physicians and nurses that interact with husbands of women with breast cancer must be aware of information needs that are specific to husbands, rather than to the couple as a unit. Recent studies that have examined the priority information needs of women diagnosed with breast cancer similarly found that women like their husbands prioritized information about the likelihood of cure or probable outcome of illness (Bilodeau & Degner; 1996; Degner et al., 1997; Luker et al., 1995). However, husbands of women who have recently undergone surgery for breast cancer have indicated that their priority information needs are also related to additional aspects of emotional care needs and also include assurance about physical care needs.

Health professionals' attitudes, and interpersonal and communication skills were viewed as a contributing factor towards having emotional care needs met. Health professionals may facilitate meeting husbands' needs and concerns by the following behaviours: demonstrating a caring attitude towards both the woman and the couple, taking time to inquire about individual concerns, including husbands in explanations about care procedures, and providing husbands with written discharge instructions that includes both physical care information and return appointments.

Husbands in this study have indicated that an opportunity to speak with the surgeon in the immediate postoperative period is a source of emotional support. Nurses can facilitate this need through appropriate preoperative communication. Physicians need to be aware of a husband's desire to speak with the physician, and the husband must be aware of where and when they are to be available to meet with the physician.

The booklet, "Sharing: A Family's Guide to Breast Cancer" contains information that would assist a husband to understand common husband and wife emotional reactions to diagnosis and surgical intervention. This booklet also contains information that is specific to general emotional experiences of various family members of a women who has breast cancer. Provision of this booklet to husbands and /or other family members prior to discharge could facilitate the emotional recovery of all family members. In addition, a list of informational and support resources similar to the one provided in this study could routinely be provided to husbands when their wives are discharged.

One of the priority needs identified by husbands in this study was information about the side effects of treatment. Observational findings of this study indicate that husbands may desire to receive information and/or can better process information that is directly related to their current situation. Husbands of women who have undergone lumpectomy could routinely be provided with written information about radiation treatment as part of the discharge instructions. Although the need for adjuvant therapy postmastectomy is never a certainty, husbands of women who have undergone mastectomy could be asked if they would desire information about possible adjuvant therapy. However, nursing would have to stress that the need for adjuvant therapy cannot be certain in the immediate postoperative period.

Husbands in this study have also indicated that they wanted information that would facilitate their understanding of their wives' disease and treatment and facilitate their communication with health professionals. Observational findings indicate that retention of information is facilitated by the receipt of written information. The majority of this information is required prior to surgical intervention. Nursing can facilitate receipt of preoperative written information through the following advocacy measures.

Breast cancer resource centres and breast cancer advocacy groups could be asked to compile and disseminate written informational resources that would be best suited to be available in the various areas (general practitioners' offices, x-ray clinics, same day surgery biopsy units, and surgeons' offices) that women with breast cancer attend during the diagnostic phase of their illness. Nurses who work in x-ray clinics and care for women who are undergoing biopsies for breast cancer could be asked to provide women and their husbands with written information about disease and treatment. Physicians could be made aware of the need to provide written informational resources specific to both the woman and her husband through the communication channels of the Manitoba Medical Association.

As noted by Kilpatrick (1995) and observed in some of the couples in this study, there is a group of women who choose not to share information with their husbands or selectively share information with their husbands. One may argue that it is a woman's right to maintain control of information. However, an alternative argument can be presented on behalf of the husband that is trying to cope with his wife's diagnosis and surgery with a lack of information. Empirical literature indicates that information assists family members to cope with the anxiety and stress of the cancer experience (Adams, 1991; Gotay, 1984; Meissner et al., 1990; Northouse & Northouse, 1987; Northouse, 1989; Wingate & Lackey, 1989; Wright & Dyck, 1984). Providing information to husbands may or may not improve husband and wife communication about disease and treatment, but does have the potential to assist the husband in coping with his anxiety and uncertainty and with his emotional support of his wife.

Observational findings of this study suggest that women are concerned about the impact that their diagnosis and surgical intervention has on their husbands. Several women indicated that they felt that their husbands lacked the same type of informational and emotional support that they had personally received. Some women agreed to participate in the study as they felt that their husbands would benefit from the acknowledgment of their personal needs. Other women indicated that they hoped that their husbands would be better able to share their needs and concerns with someone who was not emotionally involved with the family.

The majority of the priority needs indicated by the husbands in this study were needs that could not necessarily be met by information sharing from their wives. Health professionals are best suited to meet the following priority needs listed by the husbands in this study: feel there is hope, be assured of best possible care, know the probable outcome of illness, and how to provide emotional support to my wife. Therefore, health professionals while treating the family as a unit, must also recognize that husbands of women who have recently undergone surgery for breast cancer have informational and support needs that are specific to the husband.

Decision Making Preferences

The findings related to husbands' preferred and actual roles in their wives' surgical decision making has implications for health care professionals that interact with husbands of women who are making breast cancer treatment decisions.

One could argue that the high percentage of husbands who did not achieve their preferred role was due to the limitations imposed by the degree of their wives' decisional control, rather than the degree of control exerted by the physician. However, the decision making role statements were specific to husband and wife involvement with the physician, rather than to the degree of decisional responsibility between husband and wife. In addition, during post instrument completion discussions, the majority of women indicated that they wanted and needed their husbands to be involved in treatment decision making. Only a handful of husbands indicated that their wives had either excluded them from attendance at treatment discussion physician appointments, or chose not to involve them in treatment decision making.

The strong preference for some degree of involvement in their wives' surgical treatment decision making reported by husbands in this study suggests: health professionals should continue to encourage husbands to attend treatment discussion physician appointments; and health professionals should assess husbands' desired level of involvement and facilitate participation to the degree that they desire. Because nurses are rarely present during surgical treatment discussions, nursing may not be able to directly facilitate the previous suggestions with respect to surgical treatment decisions. However, nurses who interact with breast cancer families in the diagnostic phase can encourage couple attendance at physician appointments.

Although the decision making findings are specific to surgical treatment decision making, it seems probable that husbands would prefer a similar role with respect to adjuvant treatment decision making. Nurses who work in oncology clinics are in a prime position to both assess and promote husbands' preferred level of participation in their wives' adjuvant treatment decision making. Neufeld, Degner, and Dick (1993) designed and implemented an intervention strategy to provide decisional support to women who were diagnosed with breast or gynecological cancer. A similar intervention strategy could be utilized for husbands of women with breast cancer.

Strengths and Limitations

Brink and Wood (1989) note that the value of a descriptive study is related to the reliability and validity of the measurements being used. The FIN-H was previously used by Kilpatrick (1995) and was found to be both valid and reliable. The reliability and construct validity of the FIN-H were supported by the results of this study. The CPS-H was a modification of Degner and Sloan's (1992) CPS that had been found to reliable and valid in several large samples of oncology patients. The CPS-H was piloted tested for reliability and validity prior to data collection. The results of the pilot and the study indicated that the CPS-H's modified role statements supported the existence of the psychological dimension of systematic preferences about treatment decision making.

However, a number of limitations of this study have been identified. The mean sum score of needs for this sample was 135 (s.d. 13.25) with a range of 87-150, indicating that participants used an abbreviated upper range of the FIN-H. Therefore, the scale may not be sensitive to mid and lower needs. Alternatively, all of the scale items may be viewed as important to husbands of women with breast cancer. In addition, husbands may have been limited in their ability to distinguish the degree of importance of scale items due to the anxiety and stress of their wives' diagnosis and surgical intervention.

The mean number of unmet needs reported by this sample may have been biased by the reluctance expressed by some of the husbands to indicate that certain needs were not met. The researcher was able to clarify that the instrument was not being used to evaluate the actions of specific health professionals with husbands who expressed reluctance to indicate that their needs were unmet. However, it is uncertain if the researcher's clarifications of the instrument's intent moderated the participant's reluctance to indicate that specific needs were not met at this point in time.

Results of the factor analysis should be viewed with caution for the following reasons. Hazard Munro, Visintainer, and Batten Page (1986) recommend a ratio of at least five subjects per variable for generalization from the sample to the population. The sample size of this study does not meet this criterion. In addition, construct validity requires a pattern of consistent findings involving numerous studies across time and performed by different researchers (Brink & Wood, 1989).

Some of the participants in this study did ask for clarification of some of the need and role preference statements. Although, the researcher attempted to provide clarification of questions in an objective manner, the rephrasing of the statements may have inherently reflected the researcher's interpretation of the statements.

Husbands who completed the FIN-H when they were alone with the researcher, rated their identified needs significantly higher than when completion of the FIN-H occurred with the additional presence of their wives or children. Possible explanations for this occurrence have been previously provided. However, the effect that the presence of significant others had on the husband's determination of his preferred decision making role is uncertain.

Additional limitations with respect to husbands' completion of the CPS-H are as follows. Observational findings indicated that husbands' ability to concentrate and comprehend the CPS-H may have been influenced by prior completion of the FIN-H. In addition, observational findings indicated that husbands appeared to have less difficulty with completion of the CPS-H when data collection occurred at their homes. The lack of environmental distractions, and the time lapse since surgical intervention may have allowed husbands to better comprehend the CPS-H when they were interviewed at home. Perhaps the CPS-H should have been administered prior to the FIN-H, or administered in a secluded environment and at a time further away from surgical intervention.

The researcher encouraged husbands to discuss their concerns and attempted to obtain similar information from all husbands related to their information needs and their participation in their wives' surgical treatment decision making. However, the observational findings of this study would have been strengthened by the use of a qualitative interview format and qualitative analysis.

Although the sample was recruited from three urban community hospitals and two urban tertiary hospitals and included both urban and rural residents, the use of a non-probability sampling technique limits the generalizability of the findings. However, the results of this study should provide health professionals with a better understanding of the type of information that husbands desire when their wives have recently undergone breast surgery; and should encourage individual assessment of both the husband's need for information and his desired level of participation in his wife's treatment decision making.

Recommendations for Future Research

Recommendations for future research are suggested on the basis of the findings of this study. The first recommendation is to replicate the use of the CPS-H with a larger sample to determine if the preferred surgical treatment decision making trends are consistent with this study's findings. The CPS-H could also be used to identify husbands' preferences for participation in their wives' adjuvant treatment decisions to determine if husbands' adjuvant treatment role preferences are similar to their surgical treatment role preferences. Future decision making research could evaluate breast cancer couples' treatment decision making preferences by: comparing the woman and her husband's preferred roles in breast cancer treatment decision making to determine if their preferred roles are congruent; or by identifying the couple's preferred decision making role as a unit.

Future longitudinal research with the FIN-H is needed to investigate if husbands' information needs differ according to the phase of the breast cancer experience. Husbands' information needs could be assessed at diagnosis, during their wives' hospitalization, and at three months post discharge. Future research could compare the information needs of women with breast cancer to the information needs of husbands of women with breast cancer to determine informational differences and similarities when a couple faces a breast cancer diagnosis.

Future studies are needed to identify the type of interventions that would best meet the information needs of husbands of women with breast cancer. The current decision making intervention research that is being conducted with women with breast cancer could be replicated with husbands of women with breast cancer.

Finally, this study could be replicated with husbands of women with other types of cancer to determine if husbands' information needs and their preferences for participation in their wives' treatment decision making are reflective of a cancer diagnosis or are specific to a breast cancer diagnosis.

Conclusions

The aim of this study was to describe the information needs and treatment decision making preferences of husbands of women who had recently undergone surgery for breast cancer. The results of this study indicate that husbands of women who have recently undergone surgery for breast cancer prioritized information that would help them cope with the helplessness, anxiety, and uncertainty engendered by a breast cancer diagnosis and facilitate their emotional support of their wives. However, the mean total number of needs (29/30) that was reported by this sample as having some importance indicates that husbands also desire information that will: provide them with knowledge about the disease and treatment; facilitate their communication with health professionals; allow them to communicate with their wives about disease and treatment; and assist them with to cope with disruptions to family life.

This study has identified a profile of husbands who are at greater risk of not having their identified information needs met (husbands who are older, have a low level of formal education, are retired or labourers, live in a rural area, are married to women who have undergone their first surgery for breast cancer and/or have Stage 3 disease, and who prefer a passive role in their wives' surgical treatment decision making). However, given the ANOVA results of the demographic and disease related variables, individual assessment of husbands' information needs remains the best clinical approach to meeting the information needs of husbands of women who have recently undergone surgery for breast cancer.

The results of this study also indicate that husbands of women with breast cancer want to be involved to some degree with their wives and the physician in their wives' surgical treatment decisions. The observational findings of this study suggest that husbands are involved in breast cancer surgical decision making in a variety of ways. However, the lack of a relationship between demographic and disease related variables and the husbands' preferred treatment decision making role, suggests that individual assessment of the husbands' preferred decision making role is the best clinical approach to determining husbands' desired level of participation in their wives' surgical treatment decision making .

The empirical and observational findings of this study support previous empirical findings that suggest that a breast cancer diagnosis is a family issue rather than solely a patient issue. On a day to day basis, husbands of women who have recently undergone surgery for breast cancer are intimately involved with the emotional and physical ramifications of their wives' breast cancer diagnoses and their subsequent surgical interventions. Providing husbands with the information they desire and involving them to their desired extent in their wives' surgical treatment decision making may allow husbands to more effectively cope with their own needs and emotions, and subsequently facilitate husbands' emotional support of their wives and the families' ability to positively adapt to the ramifications of breast cancer.

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Appendix A

STRUCTURE OF KNOWLEDGE MODEL OF FAMILY DECISION MAKING

Individual Learning Styles ____________Family System
of
Inquiring

Individual Perception________________Family Structure
of
Decision
(Time, Information, Risk)

of Knowledge

Need for
Information

Use of Available
Information

Individual Roles in
Family Decision Making

Family Interaction

Collective Definition

Need for
Information

Use of Available
Information

Collective Action

Hanks (1993)

DEGNER AND SLOAN'S CONTROL PREFERENCES SCALE

ACTIVE ROLE

A. I prefer to make the decision about which treatment I will receive.

B. I prefer to make the final decision about my treatment after seriously considering my doctor's opinion.

COLLABORATIVE ROLE

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

PASSIVE ROLE

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

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

Appendix C

FAMILY NEEDS SCALE

Husbands

Instructions: The next set of questions are about the needs of family members of cancer patients. Please show how important the following needs are for you as a husband: **Not Important (1), Somewhat Important (2), Average Importance (3), Very Important (4), and Extremely Important (5).** If the need was important to you (2 or higher), check off in the column beside to show if the need has been met, partly met, or not met.

IF YOU RATED AN ITEM HIGHER THAN 1, CHECK IF MET, PARTLY MET, OR UNMET

I NEED TO:	RATINGS FROM 1-5	MET	PARTLY MET	UNMET
1. have my questions answered honestly	___	___	___	___
2. know specific facts concerning my wife's future	___	___	___	___
3. feel that the health professionals care about my wife	___	___	___	___
4. be informed of changes in my wife's condition	___	___	___	___
5. know exactly what is being done for my wife	___	___	___	___
6. know what treatments my wife is receiving	___	___	___	___
7. have explanations given in terms that are understandable	___	___	___	___
8. be told about changes in treatment plans while they are being made	___	___	___	___
9. feel there is hope	___	___	___	___
10. be assured that the best possible care is being given to my wife	___	___	___	___
11. know what symptoms are caused by the illness	___	___	___	___
12. know when to expect symptoms to occur	___	___	___	___
13. know the probable outcome of my wife's illness	___	___	___	___
14. know why things are done for my wife	___	___	___	___

IF YOU RATED AN ITEM HIGHER THAN 1, CHECK IF MET, PARTLY MET, OR UNMET

<u>I NEED TO:</u>	RATINGS FROM <u>1-5</u>	<u>MET</u>	PARTLY <u>MET</u>	<u>UNMET</u>
15. know the names of the health professionals involved in my wife's care	___	___	___	___
16. have information about what to do for my wife at home	___	___	___	___
17. feel included by health professionals	___	___	___	___
18. help with my wife's care while she is in hospital	___	___	___	___
19. have someone be concerned with my health	___	___	___	___
20. be told about people who could help with problems (i.e., financial, household)	___	___	___	___
21. know specific facts concerning my wife's disease	___	___	___	___
22. know specific facts concerning my wife's treatment	___	___	___	___
23. know what side effects are caused by the treatment	___	___	___	___
24. know how to provide physical care to my wife	___	___	___	___
25. know how to provide emotional support to my wife	___	___	___	___
26. know what to say to the children	___	___	___	___
27. know how to talk to my wife about the disease/illness	___	___	___	___
28. know how to approach changes related to sexuality	___	___	___	___
29. know how to touch my wife	___	___	___	___
30. know what to expect of my wife's energies	___	___	___	___
31. Are there any other information needs I may have missed?	___	___	___	___

Appendix D

Table 10: Factor Analysis of FIN-H

Need #	Factor 1 Pre and Post-op Care Needs	Loading
8	- be told about changes in treatment plans while they are being made	.77
5	- know exactly what is being done for my wife	.76
14	- know why things are done for my wife	.76
4	- be informed of changes in my wife's condition	.76
6	- know what treatments my wife is receiving	.74
11	- know what symptoms are caused by the illness	.59
13	- know the probable outcome of my wife's illness	.59
12	- know when to expect symptoms to occur	.57
15	- know the names of health professionals caring for my wife	.31
Need #	**Factor 2 Communication with Health Professionals**	**Loading**
1	- have my questions answered honestly	.89
10	- be assured that the best possible care is being given to my wife	.82
7	- have explanations given in terms that are understandable	.76
9	- feel there is hope	.75
3	- feel that the health professionals care about my wife	.73
17	- feel included by health professionals	.55
Need #	**Factor 3 Family Relationship Issues**	**Loading**
29	- know how to touch my wife	.90
28	- know how to approach changes related to sexuality	.86
30	- know what to expect of my wife's energies	.75
26	- know what to say to the children	.74
27	- know how to talk to my wife about her illness	.70
25	- know how to provide emotional support to my wife	.55
Need #	**Factor 4 Disease/Treatment Specifics**	**Loading**
22	- know specific facts concerning my wife's treatment	.83
23	- know what side effects are caused by treatment	.71
21	- know specific facts concerning my wife's disease	.61
16	- have information about what to do for my wife at home	.48
Need #	**Factor 5 Husbands' Practical Involvement**	**Loading**
18	- help with my wife's care while she is in hospital	.60
20	- be told about people who could help with problems (financial, household)	.54
2	- know specific facts concerning my wife's future	.53
19	- have someone be concerned with my health	.46
24	- know how to provide physical care to my wife	.40

MODIFIED ROLE PREFERENCE STATEMENTS

ACTIVE

A. I prefer that my wife and I make the final decision about which treatment my wife will receive.

B. I prefer that my wife and I make the final decision about my wife's treatment after seriously considering the doctor's opinion.

COLLABORATIVE

C. I prefer that the doctor, my wife, and I share the responsibility for deciding which treatment is best for my wife.

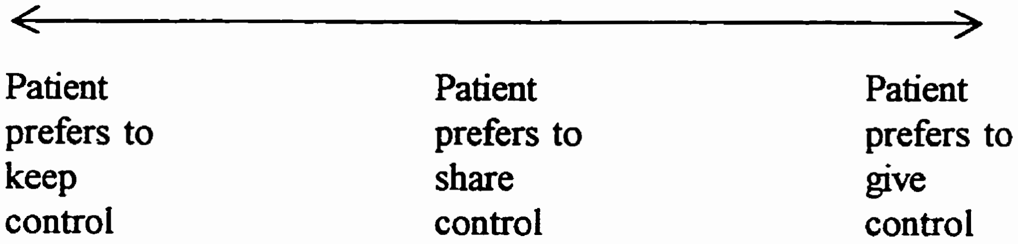
PASSIVE

D. I prefer that the doctor makes the final decision about which treatment will be used, but seriously considers my wife's and my opinion.

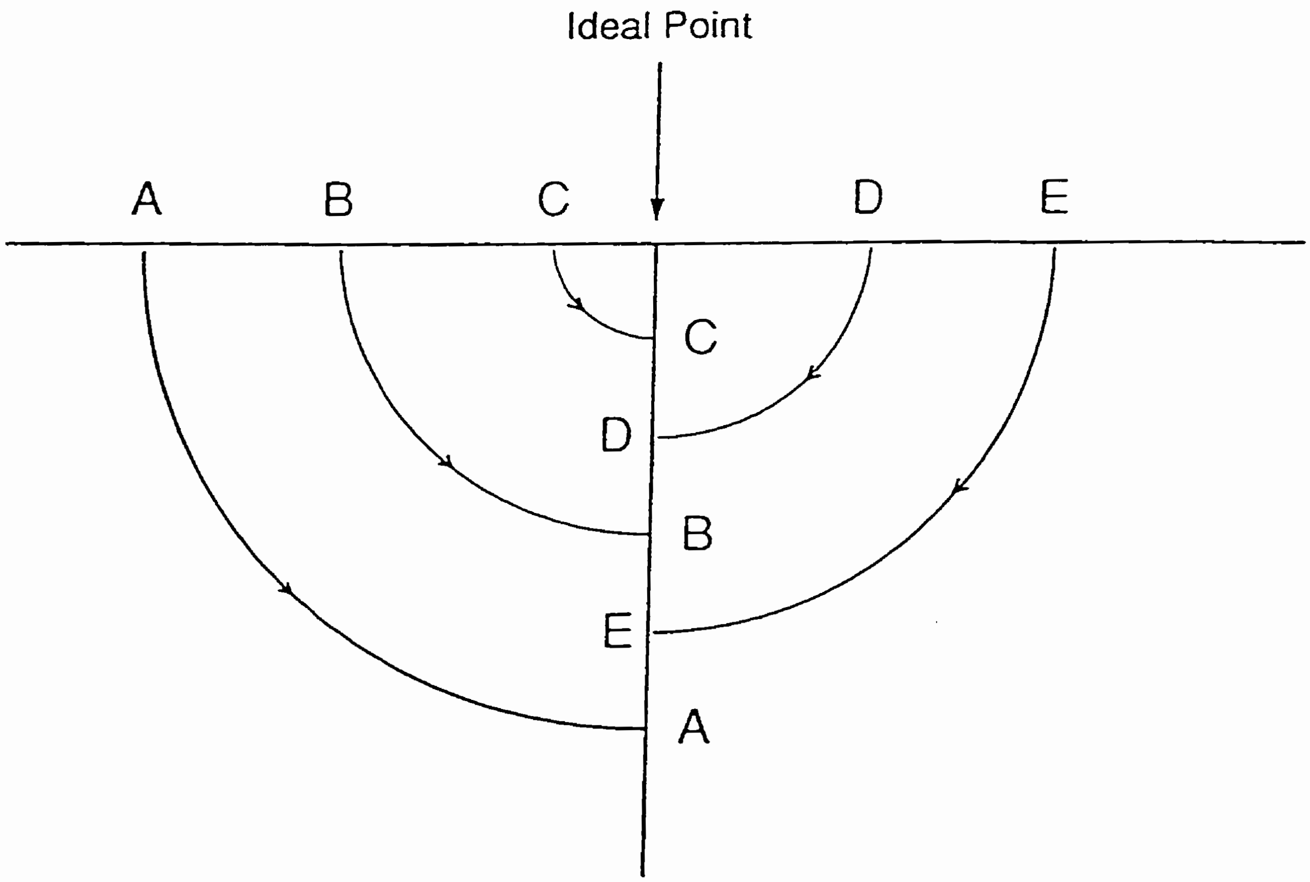
E. I prefer to leave all decisions regarding my wife's treatment to the doctor.

Appendix F

There exists a single psychological dimension such that

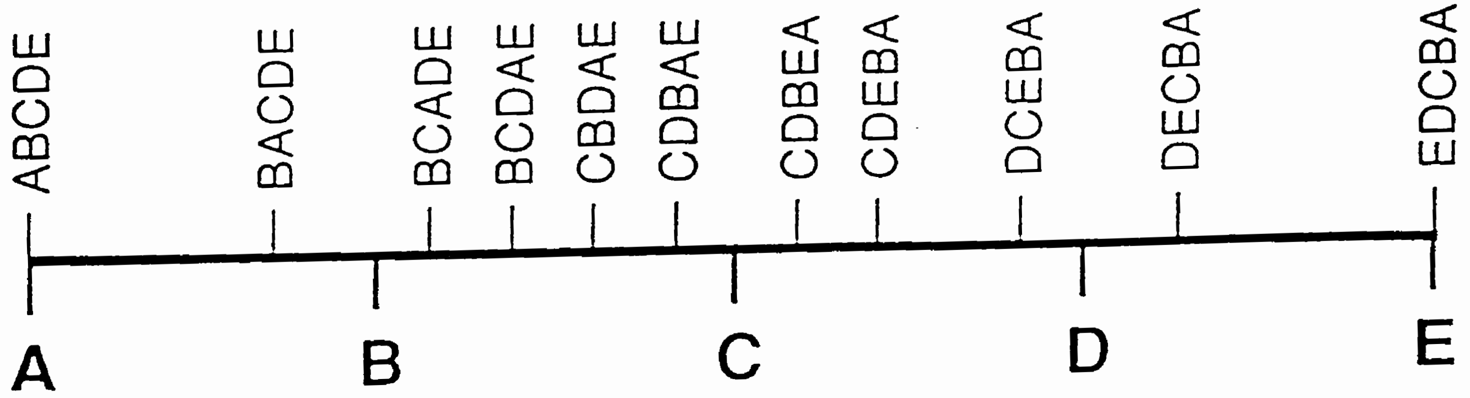


Hypothesis to test the dimensionality of the control preferences construct.



Ideal point CDBEA obtained by folding a J scale (after Coombs)

Appendix H



Valid Permutations for the ABCDE Scale

Request for Permission to Release Names

Brenda Dozenko is a registered nurse who has worked with patients with cancer and their families. She is doing a study about "Information Needs and Decision Making Preferences of Husbands of Women with Breast Cancer", as part of her Master of Nursing thesis.

Participation in the study would involve meeting with you and your husband to explain the study, and having your husband complete three questionnaires (about 20 minutes for all three items).

All information obtained is confidential. Participation is voluntary and whether or not you and your husband choose to take part will in no way effect the care you receive.

Would you be willing to speak with her so that she can explain the study, and you can decide whether or not you would like to take part?

(If agreeable, the name of the patient is given to the nurse researcher and the nurse thanks them).

(If the patient declines the nurse thanks them for their time).

Patient Consent Form

I invite you to take part in a study about the "Information Needs and Decision Making Preferences of **Husbands** of Women with Breast Cancer ". This study is being done to gain knowledge about the information needs and decision making preferences of **husbands** of women with breast cancer. The results of this study may help health care workers (like nurses) to better understand the kinds of information and decision making roles that husbands prefer when their wives have breast cancer. The costs to you involve the time you spend talking to me and the time involvement of your husband. You will receive answers to any questions you may have about this study at any time.

If you agree to take part in this study, you will be asked for your help in talking to your **husband** to arrange a meeting with the researcher (Brenda Dozenko) to complete an information sheet, an information needs questionnaire, and a decision making card sort. It will take about 20 minutes to complete all three items. The information sheet asks questions about your husband's age, education, type of work, and ethnic background. The information needs questionnaire is not a test of knowledge, but asks what types of information your **husband** would find helpful at this time. The card sort asks what kind of participation your **husband** would have preferred in your treatment decision making. When your husband has finished the study items, he will be given a booklet called "Sharing: A Family's Guide to Breast Cancer" and a list of resources that may help to answer his questions. With your permission, your chart will also be reviewed to obtain data about your type of disease and surgery.

To ensure your privacy, your chart data will be coded by a number, not by your name. To ensure privacy of your husband's answers, your husband will be asked not to write his name on any of the study items. Study items will coded by a number, not by name. Therefore, your name and your husband's name will not be listed in any report that may be written for this study. Study results will be presented in such a way that no single response can be identified. Only myself (Brenda Dozenko) and my thesis advisor (Dr. Linda Kristjanson) will have access to any identifying data. Your consent form and your husband's disclaimer form will be kept separate from the study item results. During and after the research: information sheets (chart and husband), questionnaires, card sort results, disclaimers, and consents will be stored in locked drawers and kept for seven years, and then destroyed.

Your participation in this study is voluntary, and whether or not you choose to take part will in no way have an effect on your care or treatment. If you decide to take part, you may choose to withdraw from the study at any time.

This study is being done as the basis for my thesis in the Master of Nursing Program, University of Manitoba. The Ethical Review Committee, Faculty of Nursing, University of Manitoba has approved this study.

If you choose to take part, thank you for your help. If you choose to withdraw, thank you for your time. Your signature below indicates only that you have given me permission to talk to your husband and access your chart for data about your type of disease and surgery. You will be given a copy of this form.

If you have any questions about this study, you can phone Brenda Dozenko at 832-4384 or Dr. Linda Kristjanson (thesis advisor) at the St. Boniface General Hospital Research Centre (235-3481). When the study is complete, a summary of the results can be obtained. If you wish to be mailed a copy of the results, please fill out the tear off sheet on the bottom of the page.

Brenda J. Dozenko, R.N., B.N.
Graduate Student
Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba

I agree to participate in the Information Needs and Decision Making Preferences Study, as described above.

Your signature ____________________________ Date ____________________

Interviewer signature ____________________________ Date ____________________

Thesis Committee:

Dr. Linda Kristjanson Associate Professor Faculty of Nursing University of Manitoba	Dr. Lesley Degner Professor Faculty of Nursing University of Manitoba	Dr. Clifford Yaffe Assistant Professor Faculty of Medicine Department of General Surgery University of Manitoba

----

Please send me a copy of the summary of the research report.

Send to:____Name

____Address

____Postal Code

Appendix K

PATIENT CHART DATA SHEET

I.D. #______________________________

HOSPITAL :____________________________

AGE LAST BIRTHDAY :_____________________

POSTAL CODE :____________________

TYPE OF SURGERY : Left Lumpectomy______
Right Lumpectomy______
Bilateral Lumpectomy______
Left Modified Radical Mastectomy_______
Right Modified Radical Mastectomy_______
Bilateral Mastectomy__________

DATE AT DIAGNOSIS :_______________________

PATHOLOGY STAGE AT DIAGNOSIS : Stage 0_____
Stage 1_____
Stage 2_____
Stage 3_____
Stage 4_____

EXTENT OF PRIMARY TUMOR : Cannot be assessed_______
No evidence of primary tumor_______
Tumor up to 2 cm._________
Tumor > 2 cm. and up to 5cm._______
Tumor > 5 cm._________
Tumor extension to chest wall or skin (Inflammatory carcinoma)_______
Tumor in situ_________

REGIONAL LYMPH NODES : Cannot be assessed________
Number of lymph nodes examined________
Number contain growth_________
Fixed to one another or to other structures_________

DISTANT METASTASIS: Cannot be assessed________
No distant metastsis________
Distant metastasis__________

ESTROGEN RECEPTOR________ PROGESTERONE RECEPTOR________

Disclaimer for Husbands

I invite you to take part in a study about the "Information Needs and Decision Making Preferences of Husbands of Women with Breast Cancer". This study is being done to gain knowledge about the information needs and treatment decision making preferences of husbands of women with breast cancer. The results of this study may help health care workers (like nurses) to better understand the kinds of information and decision making roles that husbands prefer when their wives have breast cancer. The costs to you involve the time it takes to complete three items. You will receive answers to any questions you may have about this study at any time.

If you agree to take part in this study, you will be asked to complete an information sheet, an information needs questionnaire and a decision making card sort. It will take about 20 minutes to complete all three items. The information sheet asks questions about your age, education, type of work, and ethnic background. The information needs questionnaire is designed to obtain your opinion about information needed as a result of your wife's recent diagnosis with breast cancer. This questionnaire is not a test of knowledge , but rather, asks what types of information about your wife's illness, you would find helpful at this time. The card sort asks about what kind of participation you would have preferred in your wife's treatment decision making.

The only known risk of taking part in this study is that it may make you feel uncomfortable either by thinking about your wife's illness and treatment, if you have not been able to get the information you want, or if you have not been able to take part in your wife's treatment decision making as you may have wished. If you wish to discuss your concerns with a member of the health care team, with your permission, I will help you to relay your concerns.

To ensure privacy of your answers, you will be asked not to write your name on any of the study items. Study items will be coded by a number not by your name. Therefore, your name and your wife's name will not be listed in any report that may be written for this study. Study results will be presented in such a way that no single response can be identified. Only myself (Brenda Dozenko) and my thesis advisor (Dr. Linda Kristjanson) will have access to any identifying data. Your disclaimer form and your wife's consent form will be kept separate from the study item results. During and after the research: information sheets (chart and husband), questionnaires, card sort results, disclaimers, and consents will be stored in locked drawers and kept for seven years, and then destroyed.

Your participation in this study is voluntary, and whether or not you choose to take part will in no way have an effect on your wife's care or treatment. If you decide to take part, you may choose to withdraw from the study at any time.

This study is being done as the basis for my thesis in the Master of Nursing Program, University of Manitoba. The Ethical Review Committee, Faculty of Nursing, University of Manitoba has approved this study.

By doing the three items, you will be agreeing to take part in this study. If you choose to take part, thank you for your help. If you choose to withdraw, thank you for your time. You will be given a copy of this form.

Appendix L

If you have any questions about this study, you may phone Brenda Dozenko at 832-4384 or Dr. Linda Kristjanson (thesis advisor) at the St. Boniface General Hospital Research Centre (235-3481). When the study is complete, a summary of the results can be obtained. If you wish to be mailed a copy of the results, please fill out the tear off sheet at the bottom of the page.

Brenda J. Dozenko, R.N., B.N.
Graduate Studies
Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba

Thesis Committee:

Dr. Linda Kristjanson
Associate Professor
Faculty of Nursing
University of Manitoba

Dr. Lesley Degner
Professor
Faculty of Nursing
University of Manitoba

Dr. Clifford Yaffe
Assistant Professor
Faculty of Medicine
Department of General Surgery
University of Manitoba

Please send me a copy of the summary of the research report

Send to:____Name

____Address

____Postal Code

INFORMATION SHEET FOR HUSBANDS

I. D. #______________________________

HOSPITAL :____________________________

AGE LAST BIRTHDAY :__________________

OCCUPATION :___________________________

EDUCATION: Less than high school_______

High school diploma_______

Greater than high school_____

POSTAL CODE:_________________

ETHNIC BACKGROUND:	European________	Aboriginal________
	British Isles_______	Asian__________
	French_________	Other__________

WHAT LANGUAGE DO YOU SPEAK AT HOME ?___________________

Appendix N

CPS DATA COLLECTION FORM

I. D. # ______________________________

CARD SORT ORDER ____

ORDINAL SCORE ____

ACTUAL ROLE______________________________________

Pilot Test Permission to Release Names

Brenda Dozenko is a registered nurse who has worked with patients with cancer and their families. She is doing a study about "Information Needs and Decision Making Preferences of Husbands of Women with Breast Cancer", as part of her Master of Nursing thesis. The tool used to describe decision making preferences was made for patients and has been used to describe the treatment decision making preferences of women with breast cancer. The tool has been changed to reflect the kind of involvement that husbands may prefer in their wives' breast cancer treatment decisions.

Participation in the pilot study would involve meeting with you in a group setting to complete three items that assess the changed tool. You will be asked to read five statements and comment on whether or not the statements are clear, and whether or not the statements describe a single message and a variation of the same message. You will also be asked to complete a card sort that asks about what kind of participation you would have preferred in your wife's treatment decision making. It will take about one hour to complete all parts of the pilot study.

All information obtained is confidential. Participation is voluntary and whether or not you choose to take part will in no way effect your or your wife's involvement in the support group.

Would you be willing to submit your name as a potential participant to the researcher (Brenda Dozenko).

Pilot Testing Disclaimer

I invite you to take part in a study titled "Information Needs and Decision Making Preferences of Husbands of Women with Breast Cancer". This study is being done to gain knowledge about the information needs and decision making preferences of husbands of women with breast cancer. I am doing this study as the basis for my thesis in the Master of Nursing Program, University of Manitoba. The Ethical Review Committee, Faculty of Nursing, University of Manitoba has approved this study.

The purpose of the pilot test is to evaluate a treatment decision making card sort. This card sort was made for patients and has been used to describe the types of participation in treatment decision making preferred by women with breast cancer. The card sort statements have been changed to describe types of participation in treatment decision making that may be preferred by husbands of women with breast cancer.

While your participation in this pilot testing may have minimal benefit to you, your comments will be useful to decide whether the card sort for husbands is clear. Your completion of the changed card sort will be useful to decide if the changed card sort is valid. The costs to you involve the time you take to complete the pilot test items and the time spent talking about your comments.

Participation in pilot testing will involve reading statements that describe five potential roles that you could assume in your wife's treatment decision making, and comment on: (1). whether or not the statements are clearly stated

(2). whether or not each statement describes a single message

(3). whether or not all of the statements describe the same message

You will also be asked to state the kind of participation you would have preferred in your wife's treatment decision making by doing the card sort. It will take about one hour to complete all aspects of the pilot test.

The only known risk of taking part in the pilot test is that it may make you uncomfortable either by thinking about your wife's illness and treatment, or if you were not able to take part in your wife's treatment decision making as you may have wished.

All information obtained is confidential. The forms used for testing and the card sort results will be coded by a number not by your name. Any information provided during the pilot test will be used only to test the changed card sort. Your name will not appear in any report that may be written for this study. Pilot study results will be presented in such a way that no single response can be identified. Only the researcher (Brenda Dozenko) and thesis advisor (Dr. Linda Kristjanson) will have access to any identifying information. The disclaimer will be kept separate from the pilot study results. During and after the research: the testing forms, card sort results and disclaimers will be stored in locked drawers, and kept for seven years and then destroyed.

Participation is voluntary and whether or not you choose to take part will in no way effect your or your wife's involvement in the support group. If you decide to take part, you may choose to withdraw at any time.

Appendix P

By doing the pilot test items, you will be agreeing to take part in the pilot testing. If you choose to take part, thank you for your help. If you choose to withdraw, thank you for your time. You will be given a copy of this form.

If you have any questions about this pilot testing , you may call Brenda Dozenko at 832-4384 or Dr. Linda Kristjanson (thesis advisor) at the St. Boniface General Hospital Research Centre (235-3481). When the study is complete, a summary of the results can be obtained. If you wish to be mailed a copy of the results, please fill out the tear off sheet on the bottom of the page.

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Please send a copy of the summary of the study results:

Send to :____Name

____Address

____Postal Code

CLARITY

Instructions:

This scale consists of five statements that describe roles that you could assume in your wife's treatment decision making. You are being asked to rate the statements on their clarity.

(a) Read each statement on the scale as you answer the question on the response sheet. Beside each statement on the response sheet circle C (clear) or U (unclear) to indicate whether the statement is clear to you.

(b) Write any comments in the space provided below each response.

(c) After you finish you may discuss your comments individually with the researcher.

Thank you for your assistance.

Role Statements:	Response:	
1. I prefer that my wife and I make the final decision about which treatment my wife will receive.	C	U

Comments ____

2. I prefer that my wife and I make the final decision about my wife's treatment after seriously considering the doctor's opinion.	C	U

Comments ____

3. I prefer that the doctor, my wife, and I share the responsibility for deciding which treatment is best for my wife.	C	U

Comments ____

4. I prefer that the doctor makes the final decision about which treatment will be used, but seriously considers my wife's and my opinion.	C	U

Comments ____

5. I prefer to leave all decisions regarding my wife's treatment to the doctor.	C	U

Comments ____

Appendix R

Apparent Internal Consistency

Instructions :

In this section, you are being asked to look at the role statements and decide if you think each statement describes a single message, and decide if you think each statement describes a variation of the same message.

Please read the entire set of role statements (listed below) first. After you finish reading the entire set of role statements, answer question (A) for each role statement. Then answer question (B). Answer each question by circling Y (yes) or N (no). Add any comments you want to explain your answers.

Thank you for your assistance.

ROLE STATEMENTS

1. I prefer that my wife and I make the final decision about which treatment my wife will receive.

2. I prefer that my wife and I make the final decision about my wife's treatment after seriously considering the doctor's opinion.

3. I prefer that the doctor, my wife, and I share the responsibility for deciding which treatment is best for my wife.

4. I prefer that the doctor makes the final decision about which treatment will be used, but seriously considers my wife's and my opinion.

5. I prefer to leave all decisions regarding my wife's treatment to the doctor.

A. Does each statement describe a single message ?

	Circle one		Comments
1.	Y	N	________________________________
2.	Y	N	________________________________
3.	Y	N	________________________________
4.	Y	N	________________________________
5.	Y	N	________________________________

B. Do all of the statements describe a variation of the same message ?

Y N ________________________________

RESOURCES FOR HUSBANDS OF WOMEN WITH BREAST CANCER

1. **Canadian Cancer Society : 774-7483**

a) Cancermount / Family Support- a peer support group designed to help people cope with a diagnosis of cancer. With the patient's permission, trained volunteers who have experienced cancer make one-to-one visits with patients with cancer.

b) Reach for Recovery - a peer support program which provides assistance to women with breast cancer. With the patient's permission, trained volunteers who have experienced breast cancer make one-to-one visits with women with breast cancer.

c) Taking Charge: Cancer Information and Support - an information and support group for people with cancer , their families, and friends.

2. **Breast Cancer Action Winnipeg: Alison 488-8443 or Barb 667-3626**

Established in 1991, by a group of women who have experienced breast cancer. They have small informal gatherings at the YM-YWCA downtown, to share with others the impact of living with breast cancer.

3. **Support Group for Couples Living with Breast Cancer: 235-3186 or 788-8165**

A joint program of the Dept. of Social Work, Misericordia General Hospital, and the Dept. of Psychosocial Oncology, Manitoba Cancer Treatment and Research Foundation.

4. **Kids Can Cope: 787-2109 or 235-3374**

An information and support group for children aged 5-18 who have a parent or close relative with cancer.

5. **Hospital Social Workers**

6. **Manitoba Cancer Treatment and Research Foundation**

Patient/Family Counseling **787-5159 or 235-3141**

7. **Information Available from Winnipeg Public Library**:

a) Murcia, Andy & Bob Stewart
Man to Man
616.99449 MUR

b) Hirshaut, Yashar & Peter I. Pressman
Breast Cancer: The Complete Guide
616.99449 HIR

c) Kahane, Deborah Hobler
No Less a Woman: Ten Women Shatter the Myths about Breast Cancer
362.196994 KAH

d) Kaye, Ronnie
Spinnig Straw into Gold: Your Emotional Recovery from Breast Cancer
616.99449 KAY

e) McGinn, Kerry Anne & Pamela J. Haylock
Women's Cancers: How to Prevent Them, How to Treat Them, How to Beat Them
616.994 MCGI

8. **Internet:**

A **Atlantic Canada's Breast Cancer Archive (ACBCA)**

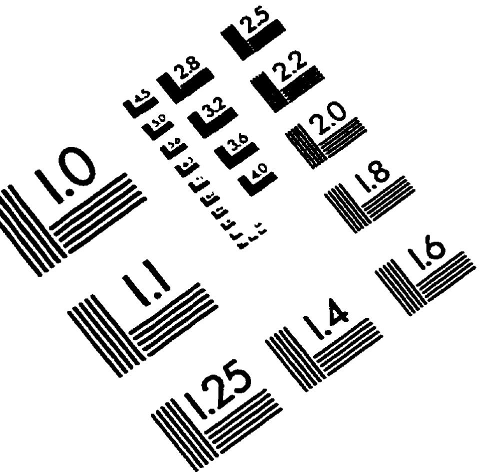
1. a) Using WWW browser, type in the following address: *http://www.mun.ca*
   b) Then select menu item *Research at Memorial University*, twice
   c) Then select *ACBCA*
2. a) Using an Internet text browser (gopher), select menu item #3- *MUN Campus Information*
   b) Select menu item #9- *Research at Memorial University*
   c) Select menu item #2- *ACBCA*

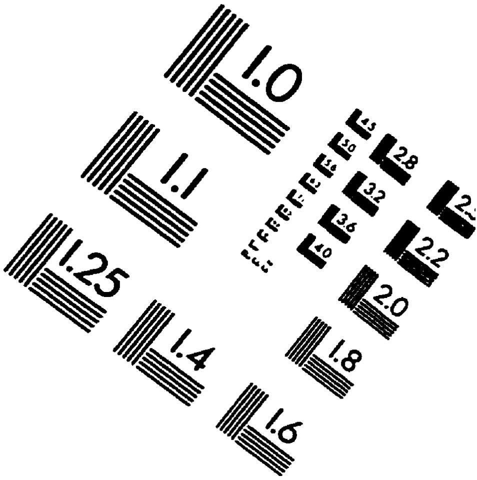
Contact: Dr. Jon Church (jchurch@morgan.ucs.mun.ca)

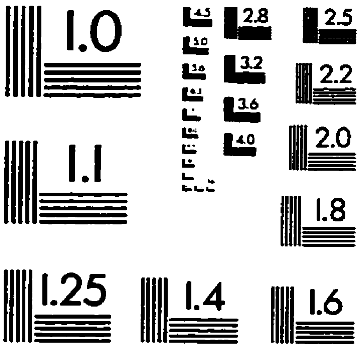
B. **Cancer Links:** A compilation of links to dozens of sources of cancer information

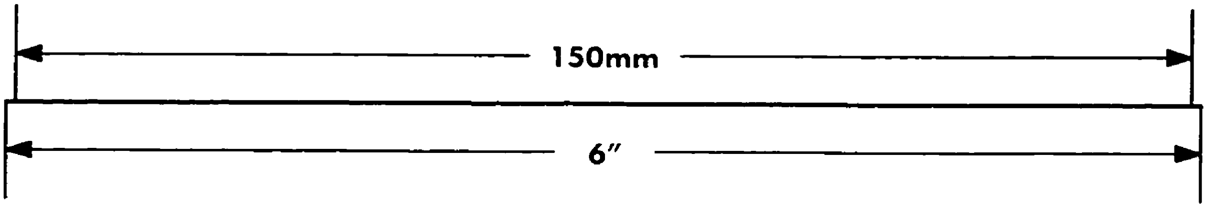
a) Using WWW browser, type in the following address:
http://dialin.ind.net/~rmarriag/rcancer.html#disease

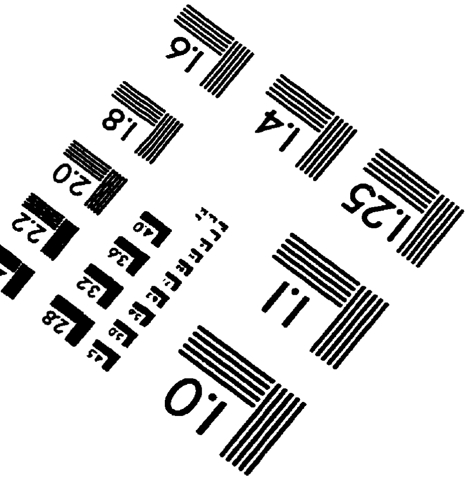
IMAGE EVALUATION
TEST TARGET (QA-3)

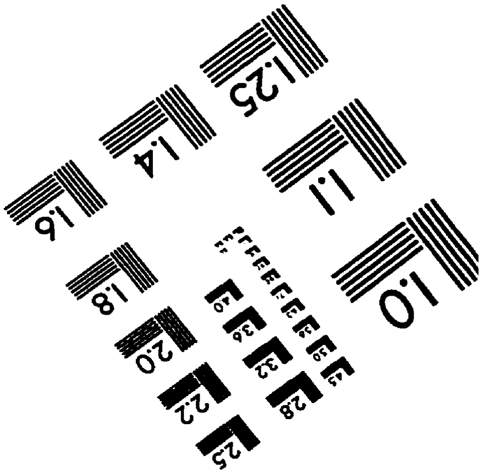












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