

**SYMPTOM DISTRESS, FUNCTIONAL ABILITY, FAMILY FUNCTION AND  
DECISION MAKING PREFERENCES  
IN CANCER PATIENTS AND THEIR FAMILIES**

**BY**

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

**MASTER OF NURSING**

**Faculty of Nursing  
University of Manitoba  
Winnipeg, Manitoba**

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**Symptom Distress, Functional Ability, Family Function and Decision Making Preferences  
in Cancer Patients and their Families**

**BY**

**Margaret Anne Lysack Kvern**

**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**

The literature on measures of family decision making preferences, and on the decision making roles patients and their family members prefer to take, is sparse. No work has been done to examine the variables which may affect these role preferences.

The purposes of this research were to modify Degner et al.'s (1997b) Control Preferences Scale (CPS) for use with cancer patients and their family members, to describe patient and family member decision making preferences, and to identify differences in preferred decision making roles by selected variables.

Using a descriptive correlational design, 61 cancer patient and family member pairs were interviewed twice, 24 hours apart. The CPS was modified to elicit decision making preferences of patients in relation to their family members.

Psychometric testing demonstrated that the modified instrument, the Control Preferences Scale - Family (CPS-F), is both unidimensional and reliable. Using this instrument, patients chose highly active decisional roles in relation to their family member. Congruent with this, family members chose passive decisional roles. Family members, however, were prepared to engage in more active roles when they perceived their patient family member as deteriorating cognitively and/or physically.

Although higher levels of education were found to be associated with more active decision making preferences for patients in this study, more research is necessary to determine the relationship between demographic variables and family decision making preferences.

One of the most striking findings of this study was the movement toward more

passive decision making roles by both patients and family members when symptom distress increased.

Implications for nursing practice and research are presented, based on the study results.

## ACKNOWLEDGEMENTS

Many people contributed to the completion of this thesis. It is with appreciation for their support that I make these acknowledgements.

First, to my thesis committee who guided me through the research process. To Dr. Linda Kristjanson, for her generosity with time, her encouragement, and her thoughtful approach to research. Her constructive feedback and questions were appreciated. To Dr. Lesley Degner, for her enthusiasm for nursing research which propelled me through this research project. To Dr. Michael Harlos, for his perspective on the clinical realities that all of our research participants face and his insight into how research findings can be used at the bedside.

Second, to the individuals who assisted with recruitment of study participants at the various sites. Thank you for your willingness to assist me in your already busy work lives.

Special appreciation goes to the patients and family members who participated in this research project. Despite physical and emotional stress, these people were willing to participate in a project they knew would possibly benefit others, but not necessarily themselves. For their selflessness, I thank them.

To my friends, classmates and colleagues, who supported me by listening and by being gracious about my “disappearances” to work on this thesis.

To my parents and siblings, where not too many family dinners are complete without pulling out at least one reference book to check the facts. This environment of desiring to understand our world, and to use that knowledge to improve things for others, has been a constant for which I am very grateful.

To my husband, Brent, who has lived through the “master’s years”, supporting and encouraging me all along the way. For his unflagging enthusiasm and willingness to hear about the high points and the lows, I am indebted.

Lastly, to the National Cancer Institute of Canada whose studentship allowed me to pursue my graduate studies full time and to the Health Sciences Centre Nursing Education Fund for its bursary award.

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**SYMPTOM DISTRESS, FUNCTIONAL ABILITY, FAMILY FUNCTION AND  
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**CHAPTER 1**

**STATEMENT OF THE PROBLEM**

Current predictions are that 129,300 Canadians will be diagnosed with cancer in 1999. More than half of these new cases will be prostate, breast, lung, or colorectal cancer (National Cancer Institute of Canada, 1999). This diagnostic period is stressful and emotional, and compounded by expectations that treatment decisions must be made (Hilton, 1994; Northouse, 1984). The entire family unit, not only the person diagnosed, is affected by this shattering news (Blustein, 1993; Cooper, 1984; Erstling, 1985; Hardwig, 1990; Hilton, 1994; Northouse, 1984). The individual with cancer, and often the family, must quickly make decisions about treatment.

Over the past 30 years there has been a trend away from paternalism and movement toward consumerism within the health care system (Blustein, 1993; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Haug & Lavin, 1981; Levy, 1986; Morra 1985). One way this is evident is that some patients prefer and take a more active role in decisions regarding their treatment (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Cassileth et al., 1980; Degner & Russell, 1988; Hack, Degner, & Dyck, 1994; Strull, Lo, & Charles, 1984; Ward, Heidrich, & Wolberg, 1989). Consumerism, in the form of active participation in one's own health care, fits with the tenet of Western biomedical ethics which gives primacy to the individual and to the right of self-determination (Beauchamp & Childress, 1983). These foundations have influenced beliefs about how patients and physicians should relate to each other (Muller & Desmond, 1992).

Patients however do not function, or make decisions, in a vacuum. They are affected by

a host of variables including severity of symptom distress experienced (Sims, Boland, & O'Neill, 1992), functional ability (Blanchard et al., 1988; Ende, Kazis, Ash, & Moskowitz, 1989), and their families (Ebell, Smith, Seifert, & Polsinelli, 1990; Erstling, 1985; Hilton, 1994; Northouse, 1984; Scanzoni & Szincovacz, 1980).

Symptom distress has been identified as a factor in decision making. Sims et al. (1992), using grounded theory to guide data collection and analysis, found families took on a greater role in decision making when the patient's symptoms worsened. This change occurred despite families' strong desires to maintain previous decision making roles. This initial finding of no change in family members' preferred decisional role, despite a change in actual role because of the patients' worsening symptoms, warrants further study to either support or refute family members' decision making preferences in relation to changes in symptom distress.

Functional ability also plays a part in decision making. Both Blanchard et al.'s (1988) study of 89 oncology in-patients and Ende et al.'s (1989) study of 312 randomly selected ambulatory primary care patients found an association between poor functional status and an increased preference to defer decision making to their physician. These studies examined the relationship between functional status and individual decision making preferences. Understanding decision making preferences of family members in relation to functional status will permit nurses and other health care professionals to support patients and families through their decision making.

Family members encounter changes during a cancer illness in the family, including initial feelings of exclusion, and ongoing emotional, communication, and role adjustment difficulties (Hilton, 1984). These changes affect family function. Erstling (1985) stresses the importance of understanding and managing these feelings. In the midst of family members

dealing with their own issues, they are valued for their input in decision making involving the patient's care. Ebell et al. (1990) indicates that spouses, children and physicians are identified by outpatients at a family practice centre as the three equally preferred groups of people with whom to discuss "do not resuscitate" orders. Hilton (1994) describes four patterns of family decision making processes, ranging from passive (family not involved or defers to physician) to active (generally family quite involved) stances. These decision making patterns are characterized by family responses to the nature and perception of the situation; patient, couple, and family factors; physician factors; and satisfaction with the health care team and system. Given the findings of disrupted family function and patients' desires for their families' input in decision making, a clearer understanding of the relationship between the level of family function and decision making preferences is necessary.

Some studies indicate positive outcomes for individuals who assume active roles in their care. Kaplan, Greenfield, and Ware (1989) studied a heterogeneous sample of 252 patients to examine the relationship between doctor-patient communication and patient health outcomes. Those patients who engaged in controlling behaviours when interacting with their physicians scored better on physiologic and subjective measures of health status. This same group of researchers, when studying a sub-sample of 45 patients with peptic ulcer disease, found that the more involved the patients were in patient-physician interaction the fewer the physical and role limitations they experienced (Greenfield, Kaplan, & Ware, 1985). If these findings of improved health outcomes are a result of patients engaging in their preferred patient roles, it is important to know what those preferred roles are. Continued refinement of tools to accurately identify and measure these preferences will allow health care providers to identify patient preferences and improve patient health outcomes.

Studies involving patients with breast cancer show that those who are offered choice in

their care experience benefit. Fallowfield, Hall, Maguire and Baum (1990) found less depression and anxiety among patients offered a choice of two surgical procedures as compared to those whose procedure was chosen by the surgeon. When studying couples, Morris and Ingham (1988) found that patients and their husbands, when offered a choice between two surgical options, had better psychosocial functioning than those not offered a choice. A second study using choice of surgery as the independent variable found that patients and spouses in the choice group were less anxious and depressed than choice in the control group (Morris & Royle, 1988).

More recent work has drawn some doubt over the hypothesis that patients given control over decision making will have more positive health outcomes. Fallowfield (1997), in a secondary analysis of earlier work (Fallowfield et al., 1990), discovered that patients who were satisfied with the information they received were the ones with the lowest psychological morbidity, not the patients who were offered decisional choice. The patients who were consistently most satisfied with information provision were seen by surgeons who had offered decisional choice, and thus perceived as better communicators. If decisional choice confers benefit, further understanding of decision making preferences for both individuals and families is important. As well, an understanding of the potential influence family function has on patient and family member decision making preferences needs to be explored.

### **Purpose of the Study**

Degner and Sloan (1992) found patients, when they became unable to make their own decisions, wanted their physician and family to work together in making treatment decisions. However, little is known about the roles patients and family members want to play in treatment and care decisions while the patient is still capable of making their own decisions.

Initially, preferences for decision making were measured in an "either/or" manner. The

respondent was asked to choose between a participative or non-participative role in decision making (Blanchard et al., 1988; Cassileth et al., 1980). More recently researchers have expanded the number of potential role preference responses along a continuum of active-collaborative-passive stances to elicit more subtle preferences (Degner & Beaton, 1987; Degner & Sloan, 1992; Rowland & Holland, 1989; Pierce, 1993).

One measure of decision making preferences that has been used widely in cancer research is a set of two card sort procedures (Degner, Sloan, & Venkatesh, 1997). These card sorts were developed using Degner and Beaton's (1987) qualitative research findings that suggested people have systematic preferences about keeping, sharing, or giving away control over health care decision making. The first card sort consists of five cards which engage the subjects in making paired choices of different roles they could play in relation to their physicians. The choices range from patient-controlled decision making to joint patient-physician decision making to physician-controlled decision making. The second card sort also consists of five cards, this time addressing the family/physician dimension (family-controlled to joint family-physician control to physician-controlled decision making), based on the assumption that the patient is too ill to participate in decision making (Degner et al., 1997b).

Hilton (1994), in one of the few studies to examine family decision making, used grounded theory methodology to explore the process of treatment decision making in families who had a family member with breast cancer. She identified four patterns of family decision making: deference to physician, minimal exploration, joint engagement, and extensive, deliberative examination. Family characteristics associated with the four decision making patterns were also identified. These decisional patterns suggest the characteristic of an active-collaborative-passive continuum similar to that found in individual decision making preferences (Degner & Beaton, 1987; Degner & Sloan, 1992; Rowland & Holland, 1989; Pierce, 1993).

While Hilton (1994) has identified the processes families use to engage in treatment decision making, it is important to find a way to quickly elicit families' decision making preferences as well. This would allow health care professionals to interact with families in a more appropriate and individualized manner with respect to the issue of decision making.

The literature on role preferences of family members in treatment decision making and measures of family members' role preferences in relation to patients with cancer is sparse. No work has been done to examine the variables which may affect these role preferences. Given the limited amount of research in this area, a descriptive design will be used. The purposes of the study are threefold. The first purpose is to modify Degner et al.'s (1997b) decision making preference card sort technique and assess its psychometric properties with a sample of cancer patients and their families. Secondly, the study will describe patients' and families' preferences for decision making. A third aim will be to determine differences in preferred decision making roles by selected sociodemographic characteristics and disease/treatment variables, level of family function, level of patients' symptom distress, and level of patients' functional ability.

### **Research Questions**

The study is designed to answer three questions:

1. To what extent is the modified Control Preferences Scale - Family (CPS-F) a reliable measure of patient preference for family member involvement in their care decisions and family member preference for involvement in patient care decisions?
2. What role do family members prefer to play in decision making with respect to a family member with cancer and what role do cancer patients prefer their family members to play with respect to their care decisions?

3. What variables are related to family member and cancer patient choice of decision making role?

### **Significance of the Study**

Many families face the diagnosis of cancer. If the CPS-F proves to be reliable and valid for use with this population, this study will result in a tool to delineate patients' and family members' role preferences for decision making. Once the tool has withstood subsequent testing and refinement, it can be used clinically to help nurses identify the decision making role that patients with cancer and their family members wish to play. Understanding how the patient and family want to make treatment and care decisions, and the variables that are related to those role preferences, will be helpful for clinicians to facilitate the decision making process. A program of research building on this work could eventually lead to intervention studies to help family members play more active and functional roles in their family member's care.

## CHAPTER 2

### LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Decision making behaviour has been studied primarily in the realms of marketing, economics, policymaking, and business and government management (Carroll & Johnson, 1990). Normative theories of decision making, which assume a highly rational procedure for decision making, do not appear to be the way decision making occurs in real life situations (Carroll & Johnson, 1990; Siminoff & Fetting, 1991). This rational model is hampered, in part, by humans' limited attention and memory. As well, researchers have found that people take previous decision making patterns into new situations, including those affecting their health (Carroll & Johnson, 1990; Hilton, 1994; Scanzoni & Szincovacz, 1980).

A review of the decision making literature was conducted using both electronic and hand searches. The focus for this review was decision making in cancer care situations, and included four areas: individual decision making, factors associated with individual decision making, family decision making, and family responses. Each area will be examined in turn. Following this review, the theoretical framework guiding this study will be discussed.

#### **Individual Decision Making**

This section will present literature that was reviewed related to individual decision making: decision making styles, preferences for participation in decision making, and health effects of decision making control.

#### **Decision Making Styles**

Descriptions of decision making styles that have emerged from the study of patients support the hypothesis that individuals in real situations use criteria other than rational utilities to govern their decision making. These styles are remarkably similar, ranging in degree from

passive to collaborative to active. Degner and Beaton (1987) classified decision making styles based on an extensive field study of patients with life-threatening illnesses. Three other styles were identified from studies of populations with breast cancer (Pierce, 1993; Reaby, 1998; Rowland & Holland, 1989).

Degner and Beaton (1987) conducted a study over a four-year period to examine how treatment decisions are made for people facing life-threatening illnesses. They identified four patterns of decision making practice: provider-controlled (passive), patient-controlled (active), family-controlled (active), and jointly-controlled (collaborative). Some of the patients studied also seemed to have preferences about which pattern of decision making they would choose.

A similar pattern emerged from the work of Rowland and Holland (1989): Type I ("you decide for me doctor" - passive), Type II ("I demand you do the X procedure" - active), Type III ("I can't decide, doctor" - passive), and Type IV ("given the options, your recommendations, and my preferences, I choose X" - collaborative). The Type III pattern does not fall as neatly into a passive-collaborative-active scheme, but is a response hypothesized to arise out of feeling overwhelmed by the diagnosis or the available treatment choices.

Pierce (1993) has described an unaided decision making process in women diagnosed with early stage breast cancer. A convenience sample of 48 women completed an open-ended questionnaire. They were instructed to "think aloud" back through their decision making processes, retrospectively tracing their thoughts and experiences. Using the constant comparative method described by Glaser and Strauss (1967), Pierce identified three decision styles: deferrer (passive), delayer (collaborative), and deliberator (active). The deferrer made her decision quickly and easily when one of the presented treatment options struck her as the obvious choice. Pierce identified this as "perceived salience". Of interest, deferrers frequently selected the treatment their physicians had recommended. The delayer exhibited some

similarities to Rowland & Holland's (1989) Type III; both of these groups displayed some anxiety over choosing between two or more treatment options. The deliberator took charge of her decisions and tended to develop a strategy for how to reach those decisions, which included an intensive information search.

Most recently, Reaby (1998) retrospectively studied the decision making patterns of 95 women who had undergone mastectomy and who had to make a decision regarding breast restoration. Five patterns were described based on interviews with the women: enlightened (active/collaborative), contented (passive), sideliner (passive), shifter (passive), and panic-stricken (passive). The enlightened patient, similar to Rowland & Holland's (1989) Type IV and Pierce's (1993) deliberator, sought information and weighed the alternatives in order to reach a decision. The contented patient, like Pierce's (1993) deferrer, also reached her own decision based on preference for a particular option; information seeking and deliberation of alternatives were absent. The sideliner chose whichever option was quick and easy to implement. The shifter was stressed, avoided discussion of breast restoration, and deferred decisional control to those she perceived as authorities on the subject. This pattern was similar to Rowland & Holland's (1989) Type I. Others made the decision for panic-stricken patients. It seemed that others had to assume control as the panic-stricken patients' extreme stress precluded the patients from even choosing to relinquish decisional control.

### **Preferences for Participation in Decision Making**

Studies undertaken in the area of cancer decision making have primarily focused on the individual receiving treatment. Research studies of individual's preferred roles in decision making have produced conflicting results. Some researchers reported that patients prefer to participate in decision making (Blanchard, et al., 1988; Cassileth et al., 1980; Charles, Redko, Whelan, Gafni, & Reyno, 1998; Degner & Russell, 1988; Hack et al., 1994; Llewellyn-Thomas,

McGreal, & Thiel, 1995; Strull et al., 1984; Ward et al., 1989). Others indicated that patients prefer to be passive in the decision making process and defer to their physicians (Beaver, Luker, Owens, Leinster, Degner, & Sloan, 1996; Bilodeau & Degner, 1996; Davison, Degner, & Morgan, 1995; Degner & Sloan, 1992; Ende et al., 1989; Stiggelbout & Kiebert, 1997; Storch & Dosseter, 1994).

Cassileth et al. (1980) studied 256 patients with cancer to determine their information and decision making participation preferences. These researchers used a questionnaire which posed an "either or" question (choose either "I want my doctor to decide about my treatment" or "I want to participate in decisions about my treatment") to determine preference for participation in decision making. The majority of patients (62.5 %) in this sample indicated a preference to participate.

Strull et al. (1984) examined 210 hypertensive outpatients' preferences for participation in decision making as well as their perceptions of actual participation in decision making using a self-administered questionnaire and an interview. Fifty-three percent of the respondents preferred to have input into their treatment decisions. However, only 37 % of the respondents believed that they had any real input into decisions about their treatment. This study is of particular interest because it is one of the few which addressed the issue of what clinicians think about patient involvement in decision making. In this study, the 50 clinicians (41 physicians and nine nurse practitioners and clinical pharmacists) who provided care for the respondents also completed questionnaires. These clinicians believed that 78 % of the patients wanted to help make decisions and that 80 % of the patients had actually participated in their treatment decisions. This substantial difference in patient and clinician perspectives obviates a need to assess individual patient preferences.

Blanchard et al. (1988) conducted a study to determine information and decision making

preferences of hospitalized adult cancer patients. Four hundred thirty-nine interactions were observed. The researchers found that 69 % of those studied wanted to participate in decision making about their care. The study question used to determine decision making preferences was again an “either or” question. Both this study and that done by Cassileth et al. (1980) may have missed subtleties in gradation of preference for decisional control with only two response options. Both Blanchard et al. and Cassileth et al. (1980) stressed the importance of making the distinction between preference for information and preference for decisional control. They strongly cautioned against using preference for information as a predictor of preference for participation in decision making.

A theoretical sample of 60 ambulatory oncology patients was used by Degner and Russell (1988) to measure preference for treatment control. A four-card sort procedure was used with each subject to determine preferences for keeping, sharing, or ceding control. Their data revealed 12 % of patients wanted to keep decision making control, 80 % wanted to share the control, and only eight % preferred to relinquish control. The use of four choices for decisional control allowed greater discrimination of patients’ preferred roles, in comparison to an “either or” question. However, the sample was not representative of the general cancer population. There were more breast cancer patients, and fewer patients with lung and bowel cancer than are found in the general cancer population, limiting the generalizability of the findings.

Twenty-two women with Stage I or II breast cancer were interviewed about decision making preferences with relation to choosing modified radical mastectomy or breast conserving surgery (Ward et al., 1989). These researchers developed fixed-response items to determine women’s preferences for participation in treatment decision making. Half of the women wanted to make the decision independently. The other half wanted to make the decision with someone else, such as the physician, spouse, or other family members. These patients were recruited

consecutively from one clinic at a midwestern university hospital. They had a mean age of 55 years, most were married, all were Caucasian, had a mean of 14.3 years of education, and all but two had household incomes of over \$20,000 per year. Given the small sample size and demographic profile of mostly married, well-educated Caucasians the generalizability of these findings is limited.

Hack et al. (1994) studied the relationship between preferences for decisional control and preferences for illness information in 35 women with stage I and II breast cancer. Using Degner and Sloan's (1992) card sort technique and a semi-structured interview, they found that 80 % chose an active or collaborative role in decision making. There was a significant relationship ( $z=2.219$ ,  $p<0.05$ , one-tailed) between preference for active roles in decision making and preference for detailed, maximal information. The authors concede that the converse, preference for a passive decision making stance predicting preference for minimal information, does not hold true. The small sample size, as well its heterogeneity, limit the generalizability of these study findings.

Llewellyn-Thomas et al. (1995) studied a group of 90 patients with colo-rectal cancer. These patients were asked to indicate their treatment decision making preference from five possible responses ranging from doctor decides alone to joint decision making to patient decides alone. Seventy-eight percent of the patients wanted some responsibility for decision making.

A qualitative study conducted at a regional cancer centre in Canada examined preferred treatment decision making roles in a purposive sample of 20 women with early stage breast cancer (Charles et al., 1998). Most of the women wanted to share decision making, but still retain control over the final decision. Despite their desire for decision making control, many of the women commented on their belief that physicians should have some decisional authority based on their expert knowledge. Small sample size limits the generalizability of these findings.

The contrary view that patients do not want to participate in the decisions regarding their treatment also has been supported in the literature. The first study to put forward this perspective was published in 1989 by Ende and colleagues. These researchers developed the Autonomy Preference Index (API) which consisted of two scales: an eight-item information seeking scale and a 15-item decision making scale. The decision making scale consisted of six general items, requiring a five-point Likert-type agree or disagree response, and nine items related to three vignettes of increasing medical acuity, requiring the respondent to indicate a preference to maintain, share, or give up decisional control on a five-point scale. This decision making scale was scored such that a score of zero indicated the lowest possible preference for decisional control and a score of 100 indicated the highest possible preference for control in decision making. A score of 50 indicated a neutral attitude toward preference for participation in decision making. Three hundred twelve of 803 patients randomly selected from a hospital-based ambulatory care clinic agreed to participate in a survey. The study sample's mean score on the decision making scale was 33.2+/-12.6, indicating an overall preference for a passive role in decision making. These researchers found no correlation between patients' desires for information and their preferences for decision making, supporting the earlier findings of Cassileth et al. (1980) and Blanchard et al. (1988).

The hypothesis that patients prefer a passive role in treatment decision making was supported by a large survey of newly diagnosed cancer patients and members of the general public, with no personal history of cancer (Degner & Sloan, 1992). Using their five-card sort technique, the researchers discovered that 59 % of cancer patients chose to let their physicians make treatment decisions whereas only nine percent of the general public chose this role. The researchers concluded that the presence of a life-threatening diagnosis such as cancer may affect one's decision making preferences.

End-of-life treatment decisions are a particular type of decision, but ones which must be made when cure is no longer realistic. Such is the reality still with many cancers. Storch and Dossetor (1994) mailed surveys to a simple random sample of 620 members of the general public, as part of a larger annual survey done by the University of Alberta's Department of Sociology, to determine their attitudes toward end-of-life decisions. The respondents were asked to agree or disagree with the statement, "I would rather leave the major decisions to my doctor" if faced with a serious illness, on a seven-point Likert-type scale. Four hundred forty eight surveys were returned for a 75.3 % response rate. Fifty-three percent of respondents agreed that they would leave major decisions to their physician. This sample was comprised of people asked to hypothesize what it might be like to face end-of-life decisions, not people who were in the real position of having to make those decisions. Based on this, the results should be viewed cautiously.

Davison et al. (1995) used a convenience sample of 57 men with prostate cancer to study the question of information and decision making preferences. Degner and Sloan's (1992) card-sort technique was used to elicit their preferences. Fifty-eight percent of the men preferred a passive role in decision making. Regardless of preference for decision making role, the majority of men preferred to be told "a fair bit to almost everything" about their disease and treatment. This echoes other studies which have found a universal desire among patients to be maximally informed about their disease and its treatment (Beisecker & Beisecker, 1990; Blanchard et al., 1980; Ende et al., 1989).

Bilodeau and Degner (1996) studied preferred treatment decision making preferences in a convenience sample of 74 Manitoban women who were within six months of a breast cancer diagnosis. The Control Preferences Scale (Degner & Sloan, 1992) was used to elicit the decision making preferences of this sample. Forty-three percent of the women chose a passive decision

making role, and only 20 % chose an active role.

Beaver et al. (1996) explored the decision making preferences of a convenience sample of 150 women newly diagnosed with breast cancer. Two hundred women with benign breast disease were studied as a descriptive comparison group. Degner and Sloan's (1992) card-sort procedure was utilized for determining decision making preferences. Beaver et al. found that 52 % of newly diagnosed women preferred a passive decision making role whereas 69 % of women with benign breast disease preferred an active or collaborative role.

A consecutive sample of 55 patients with cancer who were undergoing treatment at a radiotherapy clinic completed questionnaires to determine preferences for participation in treatment decision making (Stiggelbout & Kiebert, 1997). Patients were asked to indicate their preferred decision making role by choosing from five statements ranging from total physician control, to total patient control, of decision making. The mid-point statement reflected equal involvement of physician and patient in decision making. Sixty-one percent of the patients chose a passive decision making role, 13 % chose an active role, and 25 % chose the mid-point on the scale indicating a desire for equal involvement of patient and physician.

A study by Degner and colleagues (1997a) examined decision making preferences in 1012 women with breast cancer using Degner & Sloan's (1992) decision making card sort. Twenty-two percent preferred an active role whereas 44 % wanted a collaborative role. Thirty-four percent chose a passive role, indicating that these women wanted their physicians to make treatment decisions for them.

In summary, there is strong evidence on both sides of the question of what role patients want to play in their treatment decision making. Hack et al. (1994) found that patients themselves support the notion that no one decision making role is superior to another. Rather, patients need to choose the role they are most comfortable with. Given the variability of research

findings pertaining to decision making role preferences, it is important to assess each individual within their particular context to determine their decision making preferences.

### **Health Effects of Control in Decision Making**

A number of researchers have investigated the impact of patient control over treatment decision making. To date, the results are inconclusive.

A few studies suggest positive health effects for people who assume active roles in their care. Greenfield et al. (1985) studied a sample of 45 patients with peptic ulcer disease to determine the utility and effects of an intervention designed to train patients to take a more active role in their care. At the time of study enrollment, the physician-patient visit was audiotaped to classify interaction as controlling behaviour of other party, communicating information, or conveying emotion. At this first visit, the patients was also given a self-administered questionnaire to measure health status, preference for an active role in medical decision making, knowledge of disease, and satisfaction with care to fill out. At the next scheduled appointment, patients were randomly assigned to either the experimental group or the control group and given the appropriate intervention. The experimental group's intervention consisted of individualized information about their care (their medical record), an algorithm describing their disease management to interpret their medical record, and coaching in behavioural strategies to increase their participation in their care. The purpose of this intervention was to improve physician-patient communication. The control group was given a session, comparable in length to the experimental group's, consisting of general information about their disease's etiology and prevalence, and the nature and necessity of self-monitoring and self-care activities. Physicians were blind to the patients' group. The physician-patient visit immediately after the intervention session (experimental and control) was audiotaped and the patients were all given a quiz to measure their knowledge of peptic ulcer disease. Six to eight weeks after the second clinic visit,

all patients were mailed a questionnaire to measure their physical and role limitations due to poor health, ulcer-related pain, preference for involvement in medical decision making, and satisfaction with care. Patients in the experimental group controlled more of the physician-patient communication ( $p < 0.05$ ), were more effective in seeking information ( $p < 0.001$ ), and reported fewer physical and role limitations ( $p < 0.05$ ) than controls. No differences in patient satisfaction were found, either between groups or from before and after the intervention.

This same group of researchers replicated their 1985 study in a heterogeneous sample of 252 patients (breast cancer,  $n=43$ ; diabetes,  $n=59$ ; hypertension,  $n=105$ ; peptic ulcer disease,  $n=45$ ) to further examine the relationship between physician-patient communication and patient health effects (Kaplan et al., 1989). A similar study design was implemented: baseline physiologic measures were taken for the diabetic and hypertensive samples at the first appointment; no quiz was administered after the second appointment, a third appointment was added at which time the intervention was applied a second time followed by a physician-patient visit which was audiotaped and physiologic measures were repeated, and all patients were mailed a questionnaire to measure functional and subjective health status, preference for involvement in medical decision making, satisfaction with care, and knowledge of disease eight to twelve weeks after the last intervention session rather than a questionnaire six to eight weeks after the second appointment. Patients who asked more questions and made more attempts to direct the conversation and their physician's behaviour during the baseline visit reported fewer days lost from work, fewer health problems, and fewer functional limitations because of illness and rated their health as better at follow-up ( $p < 0.05$ ). Patients who demonstrated less patient control and less effective information seeking at the baseline visit had poorer health as measured by poorer control of diabetes and/or hypertension ( $p < 0.05$ ) at follow-up. After the intervention, patients in the experimental group were more effective in getting information from their physicians ( $p < 0.05$ )

and physician-directed communication was decreased ( $p < 0.05$ ). Both this and the previous (Greenfield et al., 1985) study suffer from small sample size and relatively short follow-up periods.

Studies involving patients with breast cancer also have shown that those who are offered choice in their care experience benefit. Fallowfield et al. (1990) studied 275 women with stage I or II breast cancer to examine differences in psychological distress between women allowed a choice of surgical treatment and those whose treatment was decided by their surgeon. One hundred eighteen patients in the sample were offered a choice; only 62 of these patients actually got to choose their treatment and the remaining 56 subsequently had the decision made by the physician because of breast size and tumor status. Psychological distress was measured at two weeks, three months, and 12 months, using the Hospital Anxiety and Depression Scale, Rotterdam Symptom Checklist, Spielberger State/Trait Anxiety Inventory, and semi-structured psychiatric interviews. Women who were given no choice showed greater anxiety and depression than the 118 women who initially were offered a choice. However, among the 118 women who were given an opportunity to choose, no difference in psychological distress was found between the women who chose their treatment and those whose treatment was decided for them for medical reasons.

The effect of treatment choice on pre-operative and post-operative psychological adjustment of couples has also been explored (Morris & Royle, 1988). A convenience sample of 30 women with stage I or II breast cancer and their husbands, 31 women with benign breast disease, and 20 general surgery patients with non-cancerous diagnoses were studied. Twenty of the breast cancer patients were given a choice of treatment (mastectomy or lumpectomy with radiation). The other ten women with breast cancer (who required mastectomy due to tumor position), those with benign breast disease, and those slated for general surgery served as the

control group. The women with breast cancer completed measures (Hospital Anxiety and Depression Scale, Rosenberg Self-Esteem Scale, and Rotterdam Symptom Checklist) one day prior to surgery and at two to three monthly intervals for five post-operative assessments. The husbands completed these same measures one day prior to their wives' surgery, and then at two, six, and 10-12 months post-operatively. The benign breast disease and surgery groups also completed these measures at their first visit, and then at six and 10 months. Women in the treatment group were less clinically anxious ( $p < 0.01$ ) and depressed ( $p < 0.05$ ) than the control group both pre-operatively and at the first post-operative assessment period. Husbands of women in the treatment group were also less anxious ( $p < 0.05$ ) and depressed ( $p < 0.05$ ) than the controls. Women offered a choice of surgery had anxiety and depression levels not significantly different from those of the benign breast disease and surgery groups. Although the trend of lower anxiety and depression scores continued for those women offered choice of surgery, significant differences between the groups disappeared at the second and third post-operative assessment points.

Morris and Ingham (1988) reported follow-up data on the Morris and Royle (1998) study. The sample consisted of 30 women with early stage breast cancer and 19 husbands. Twenty patients and 12 husbands were offered a choice of surgical treatment (mastectomy or lumpectomy); the remaining 10 women and seven husbands made up the control group who were offered no choice due to tumor location. Psychosocial functioning was measured using the Hospital Anxiety and Depression Scale, Rosenberg Self-Esteem Scale, and Rotterdam Symptom Checklist. These researchers found no difference between the groups with respect to self-esteem. Husbands in the control group reported more physical complaints pre-operatively ( $p < 0.05$ ); both patients ( $p < 0.05$ ) and husbands ( $p < 0.01$ ) in the control group reported more psychological complaints pre-operatively; and husbands ( $p < 0.05$ ) in the control group reported more

psychological complaints 10 months post-operatively. Both Morris and Royle's (1988) and Morris and Ingham's (1988) work are compromised by small sample size, non-random sampling, and relatively short-term follow-up.

A study of 60 men newly diagnosed with prostate cancer examined the effect of assisting patients with obtaining information on decision making preferences and anxiety and depression levels (Davison & Degner, 1997). Thirty men were randomly assigned to the self-efficacy information intervention group, who received written information with discussion, a question list they could use during discussion with their physician, and an audiotape to tape their medical consultation. The other 30 men comprised the control group and received only the information package as their intervention. All participants completed the Spielberger State-Trait Anxiety Inventory (STAI) and Centre for Epidemiologic Studies Depression Scale (CES-D) before the intervention and six weeks after the intervention. No significant differences for depression were found between groups, between times, or between group and measurement times. Total STAI scores were not significantly different between the groups either. However, the experimental group's state anxiety level decreased significantly ( $p < 0.005$ ) from intervention to six weeks post-intervention.

In summary, the studies which support the hypothesis that patients who are given choice in treatment decision making have better health outcomes, such as fewer physical and role limitations, less anxiety and depression, and fewer psychological complaints, are hampered by small sample size, non-random sampling and lack of long-term follow-up. Some of these studies' evidence, in fact, demonstrated a taper-off effect for anxiety and depression at approximately six months post-operatively (Morris & Royle, 1988). Fallowfield et al. (1990) speculated that patients who choose a treatment "wrongly", that is, choose a treatment and subsequently have cancer recurrence, may have to deal with emotional distress as a result of that

decision. Charles et al. (1998), in their qualitative study of 20 women with early-stage breast cancer, found that women expressed a similar sentiment - they felt stressed by having to make a treatment decision for fear of making a choice that would result in disease recurrence. Clearly then, the impact of active involvement in treatment decision making needs further study. As well, these studies did not address the issue of taking a passive role or choosing not to be involved in treatment choices, if that is preferred, on health outcomes. This, too, requires investigation.

### **Factors Associated with Decision Making**

Studies that have examined variables associated with decision making behaviour in health and illness have used observation, survey, questionnaire, and interview . The findings of these studies can be grouped into five sections: demographic variables, psychological characteristics, cancer consequences, information, and perceptions of health care providers.

#### **Demographic Variables**

Demographic variables appeared to play a role in decision making. Specifically, age, educational level, income level, gender, marital status, time from diagnosis, and religiosity have been identified in the literature as being associated with decision making.

Younger patients preferred more active involvement in treatment decisions (Beaver et al., 1996; Blanchard et al., 1988; Cassileth et al., 1980; Degner & Sloan, 1992; Degner et al., 1997a; Ende et al., 1989; Hack et al., 1994; Haug & Lavin, 1981; Llewellyn-Thomas, 1995; Stiggelbout & Kiebert, 1997; Storch & Dossetor, 1994). Hughes (1993) identified a difference in actual treatment choice (mastectomy versus lumpectomy with radiation) between age groups: mean age for the mastectomy group was 47.39 +/- 10.98 years and 51.23 +/- 10.75 years for the lumpectomy group. Haug (1979), in her work with the elderly, found that the older the person

was the less likely the person would be willing to challenge authority. Haug's finding is supported by Davison et al.'s (1995) examination of decision making preferences in men with prostate cancer. The older men tended to have a more passive stance, however it did not reach statistical significance.

Two studies have questioned the association between age and a more active role preference in decision making. Beisecker, Helmig, Graham, and Moore (1994) studied a convenience sample of 288 adult women receiving care at a suburban private women's health practice regarding their attitudes toward participation in decision making. These women, none of whom actually had breast cancer, were asked to respond to the Locus of Authority in Decision-Making: Breast Cancer questionnaire as if they had been diagnosed with breast cancer. The questionnaire was scored in a range: 0 indicating a belief that all decisions should be made by the physician, to 15 indicating a belief that decisions should be equally shared, to 30 indicating a belief that the patient should make all the decisions. The mean scale score was 12.49, indicating that the patients in this study were willing to grant greater decision making authority to physicians than to themselves ( $t=10.87$ ;  $p,0.001$ ). Beisecker (1988) studied attitudes and behaviours of 106 rehabilitation medicine patients in relation to decision making. She found that younger patients (<60 years) favoured joint decision making while the older patients favoured a passive role. However, when she measured actual decision making behaviour during physician-patient interaction there was no difference between older and younger patients in how they played their patient role. Given the small number of studies refuting the role of age in decision making preferences, and the fact that one study (Beisecker et al., 1994) used subjects who were to pretend they had breast cancer, the weight of evidence supports the idea that the younger the patient is the more likely that patient will want to pursue an active role in decision making.

Individuals with higher levels of education also preferred more control over decision

making (Beaver et al., 1996; Cassileth et al., 1980; Davison et al., 1995; Degner & Sloan, 1992; Hack et al., 1994; Haug & Lavin, 1981; Llewellyn-Thomas et al., 1995; Storch & Dossetor, 1994; Strull et al., 1984). Siminoff and Fetting (1991) found similar results, and reported that people with lower levels of education were more accepting of physicians' recommendations. Degner et al. (1997a) also found that the more educated patients were, the more likely they were to choose an active or collaborative decision making role. In fact, educational level was the best predictor of decision making preferences in their study (Degner et al., 1997a). Only one study (Stigglebout & Kiebert, 1997) refuted the association of decision making preferences and educational level. These researchers found no relationship between education level and preferences for treatment decision making. Stigglebout & Kiebert's small sample size of 55 consecutive patients, however, limits the generalizability of their findings. As with the variable age, the strength of evidence sides with the notion that better-educated people choose more active decision making roles.

Income level was a third demographic characteristic that has an association with decision making. People who have higher incomes tended to prefer a more active role in decision making (Beaver et al., 1996; Storch & Dossetor, 1994; Strull et al., 1984). Hughes, in her 1993 study, connected income level with decision making regarding treatment choice. Specifically, she learned that breast cancer subjects with lower household incomes were more likely to choose mastectomy over lumpectomy with radiation; she postulated this might have been related to a need to return to work sooner for fear of losing employment.

Gender was the fourth demographic characteristic that has been linked to decision making. Degner and Sloan (1992) found a trend for women to prefer more decisional control than men in their survey of 436 newly diagnosed cancer patients. In subsequent analyses, the source of gender effect was attributed to women with reproductive cancers. Llewellyn-Thomas

et al. (1995), in their study of 90 patients with colorectal cancer, found that the group of subjects who preferred an active role in treatment decision making contained more women ( $\chi^2 = 3.89$ ;  $p=0.05$ ). Stiggelbout & Kiebert (1997) also found that women preferred more active decision making roles than men. Twenty-seven percent of the women studied chose an active role and only 15 % of the men did. Conversely, 63 % of the men chose a passive role whereas only 22 % of the women did ( $p=0.01$ ).

Marital status has been examined in relation to decision making preferences in several studies, with inconclusive results. Davison et al. (1995), in their study of 57 men with prostate cancer, found a trend that men who were married preferred a passive role in treatment decision making. In 1996, Beaver et al. reported on a group of 150 women newly diagnosed with breast cancer. In this sample, marital status was not associated with decision making preferences. A third study (Degner et al., 1997a) demonstrated that, in their sample of 1012 women with breast cancer, married women were more likely to choose an active or collaborative role in treatment decision making. With this variation in study results, it is difficult at present to rely with any certainty on marital status as a predictor of decision making preferences.

Time from diagnosis has been linked with decision making preferences in a few studies. Davison et al. (1995), in their study of 57 men with prostate cancer, found that men recently diagnosed (0-13 weeks since diagnosis) were significantly more likely to prefer a passive role in treatment decision making than those who were diagnosed more than 13 weeks before participation in the study. Beaver et al. (1996) found that their sample of 150 women newly diagnosed (0-4 weeks since diagnosis) with breast cancer were more likely to prefer a passive decision making role when compared with the 200 women with benign breast disease. It would have been interesting to know whether a cohort of women with breast cancer who were temporally further away from diagnosis would have shown a difference in decision making

preference. Degner et al. (1997a) addressed this issue in their study of 1012 women with breast cancer. They found that the women who were less than six months from diagnosis preferred more passive decisional roles than those women more than six months from diagnosis. One might postulate that in the initial period following diagnosis, the patient is focused on coming to terms with the diagnosis, gaining information about the disease and its treatment, and is unable, or unwilling, to take an active role in treatment decision making.

Religiosity is the final demographic variable that has been associated with decision making. Only one study has examined this variable. Storch and Dossetor (1994) found that respondents to their survey who did not have an affiliation with a religious group were less likely to leave decision making to a physician. This study was a survey of the general population, and therefore it is difficult to know how to interpret this data for a cancer population.

In summary, younger age and higher educational level have a strong association with preference for an active role in decision making. Individuals with higher income levels also appear to prefer an active decision making role, although not as many studies have examined this relationship. In the few studies that have examined gender, women tend to prefer more active roles in decision making than men do, but the study sample sizes have been small. Study results reporting of the impact of marital status on decision making preferences has been inconclusive, with different studies showing conflicting results. Time from diagnosis appears to be a factor in decision making preferences, with patients further from diagnosis wanting a more active decision making role. Of the demographic variables associated with decision making preferences, religiosity has been studied the least and should be viewed with caution until further study can be done.

### **Psychological Characteristics**

Psychological characteristics have been identified as important to decision making behaviour. Janis and Mann (1977) found that the perceived magnitude of losses will impact on decision making. If an individual believes that undesirable consequences will occur regardless of the decision reached, the whole process of decision making will be short-circuited (Janis & Mann, 1982).

England and Evans (1992) examined the role of internal locus of control in relation to decision making. A convenience sample of 143 patients at a cardiovascular risk management clinic were given questionnaires which measured health locus of control and perceived decision control. The researchers found that when subjects had a sense of being in control of their health (internal locus of control) and responsibility for their health-related decisions, they tended to be more involved in decision making.

Emotional state has also been examined in relation to decision making. The ability to cope with one's diagnosis, treatment, and side effects may affect decision making (Gotay & Bultz, 1986; Schain, 1990). Hack et al. (1994), in their study of decision making in women with breast cancer, found patients' reasons for choosing a more passive decision making style included mental frailty and difficulty accepting their cancer diagnosis. Pierce (1993) interviewed 48 women with early stage breast cancer and revealed a link between level of anxiety and level of "decision conflict". If the women perceived there to be more than one good treatment option, or if women preferred a treatment option that was not offered by their physician, they experienced "decision conflict" which caused them distress.

Haug and Lavin (1981) examined the physician-patient relationship within the context of an increasingly consumerist perspective. A random multi-stage sample of 466 members of the general public completed self-administered questionnaires (demographics, authority dimension

of patient-physician relationship) and self-reports of behavioural challenge. They found that a higher level of health knowledge was associated with a desire for an active role in their care.

To summarize, perceived magnitude of loss, inevitable negative outcome, locus of control, emotional state, and level of health knowledge have all been shown to influence decision making behaviour. No study has combined these factors, therefore there is no understanding of the most salient factors associated with decision making preferences, nor how they might shape care decision participation. As well, more information is needed to understand how these factors may vary for individuals, and for members within a family.

### **Cancer Consequences**

A number of consequences of cancer have been noted in the literature including symptom distress, performance status, and functional ability/status. These concepts do not have universally accepted definitions. Even when the concept has been clearly defined, the operationalization of it may be inconsistent with the conceptual definition used. Symptom distress, performance status, and functional ability/status will be described in this section. These concepts will be discussed within the cancer context and in relation to decision making.

**Symptom distress.** Symptom distress is subjective, with the individual's perception of that distress being its true measure. Symptom distress has been defined by McCorkle and Young (1978) as "...the degree of discomfort from the specific symptom being experienced as perceived by the patient."

Much of the research related to symptom distress in cancer patients has focused on identification of the actual symptoms causing people discomfort and distress, as well as trying to quantify the level of symptom distress. McCorkle and Young's (1978) Symptom Distress Scale (SDS), one of the few tools devised specifically for cancer populations (McClement, Woodgate,

& Degner, 1997), has been used widely in the research literature for quantifying symptom distress (Breitbart et al., 1996; Kurtz, Kurtz, Given, & Given, 1996; Lobchuk, Kristjanson, Degner, Blood, & Sloan, 1997; Sama & Brecht, 1997; Whelan et al., 1997).

In a sample of 45 patients with a variety of cancer diagnoses, McCorkle and Young (1978) assessed symptom distress using their newly developed SDS, which contained 10 items. Of the patients, 62 % indicated that at least one symptom was causing a high level of distress. The most bothersome symptoms were bowel pattern, appearance, and appetite.

In a group of 56 lung cancer patients, McCorkle and Quint-Benoliel (1983) used the revised 13-item SDS to study symptom distress. In this group, fatigue was the most distressing symptom.

Krech, Davis, Walsh, and Curtis (1992) described symptoms in a sample of 100 patients with advanced lung cancer. Eighty-six percent of the sample reported pain and 70 % reported dyspnea.

Degner and Sloan (1995) described symptom distress in a sample of 434 consecutive newly diagnosed cancer patients. Overall ratings of symptom distress, using the SDS, were low. With a possible range of scores from 13 (lowest possible symptom distress) to 65 (highest possible symptom distress), the mean score was 23.06 with a standard deviation of 7.14 and a range of 13 to 50. The finding of low symptom distress may be a function of the sample studied, that is, newly diagnosed patients. Fatigue was reported as the most problematic symptom.

Kurtz et al. (1996) studied 216 outpatients with a variety of cancers. They used a modification of the SDS, asking patients to respond with "yes" or "no" to whether they had experienced any of the 13 symptoms within the last two weeks, to assess symptom distress. The three most distressing symptoms in this study were fatigue (81 %), pain (54 %), and insomnia

(51 %).

A study of 60 women with advanced lung cancer also used the 13-item SDS to measure symptom distress (Sarna & Brecht, 1997). Total SDS scores ranged from 14 to 44 (possible range: 13-65), with a mean total score of 25.5. The average number of symptoms rated as severe was 3.2. The most prevalent, and most seriously rated, symptoms were fatigue, outlook, frequent pain, and insomnia.

Whelan et al. (1997) studied care needs in a sample of 134 newly diagnosed cancer outpatients. Using the SDS, they found that 96 % of the patients reported at least one symptom as problematic. The mean total SDS score was relatively low at 23.6, with a standard deviation of 4.3. Moderate to intense distress from fatigue, outlook, insomnia, and cough were reported by more than 40 % of the study participants.

Lobchuk et al. (1997) examined symptom distress in a convenience sample of 37 lung cancer patients, using the SDS. The mean SDS score was 27.76 (s.d., 2.05). The three most distressing symptoms for these patients were fatigue, cough, and frequent pain.

A prospective randomized control trial tested the effects of structured symptom assessment in a group of 48 newly diagnosed advanced lung cancer patients, using symptom distress as one of the outcome variables (Sarna, 1998). The mean SDS total score was 25 (range, 14-44; s.d., 8). Fatigue was reported as the most severe, and most persistent, symptom at every time period from two months after diagnosis through to eight months after diagnosis.

Seventy-eight patients with terminal cancer and enrolled in a palliative care program were studied regarding their symptom distress (Kristjanson et al., 1998). Using the SDS, the mean SDS score was 29.6 (range, 13-52; s.d., 7.5). The three symptoms which caused the most distress to this group of patients were fatigue, pain frequency, and appearance.

A second focus of symptom distress research has been the relationship between increased symptom distress and increased number of symptoms with advancing cancer.

McCorkle and Young (1978), in their study of 45 cancer patients, found a trend where patients with metastatic disease seemed to have more symptom distress than those with localized cancer. Sixty-five percent of the patients with metastatic disease indicated severe distress from at least one symptom, as compared with 61 % of the patients with non-metastatic disease.

A contrary finding was reported by McCorkle and Quint-Benoliei (1983) in their study of 56 patients newly diagnosed with lung cancer. Using the SDS, patients reported less symptom distress at two months after cancer diagnosis (mean, 26.7; s.d., 8.4) than at one month after diagnosis (mean, 26.1; s.d., 8.4). These authors speculate that perhaps the patients had been able to assimilate the threatening aspects of their disease by the two month point post-diagnosis and therefore interpreted their symptom distress as decreased along with their anxiety about their diagnosis.

Curtis, Krech, and Walsh (1991) documented symptoms of 100 advanced cancer patients consulted to a palliative care service. They found that as patients' cancer advanced, the number of symptoms reported increased. Eighty-nine percent of the respondents had pain; 87 % of those had moderate to severe pain.

McCorkle et al. (1989) tested the effects of various levels of home care support in a sample of 166 patients with lung cancer. Symptom distress increased in all patients over time. As might be expected with this relationship between increasing symptom distress with advancing cancer, symptom distress has also been found to be greater among patients with recurrent cancer than among those in the earlier stages of the disease (Munkres, Oberst, & Hughes, 1992).

In their study of 434 consecutive newly diagnosed cancer patients, Degner and Sloan (1992) also found that patients with advanced disease at time of diagnosis had more distress than

those with early disease at time of diagnosis ( $t = -5.44$ ;  $p = 0.0001$ ).

A third area of symptom distress research was the predictive nature of symptom distress on survival. Reuben, Mor, and Hiris (1988) examined the correlation of symptoms and length of survival using National Hospice Study data, which contained information on 1,592 patients with terminal cancer. Dyspnea, problems eating/anorexia, dysphagia, xerostomia, and weight loss had independent predictive value on survival time (all  $p < 0.01$  except weight loss  $p < 0.09$ ).

Degner and Sloan (1995), in a sample of 434 consecutive newly diagnosed cancer patients, used a sub-sample of 82 patients with lung cancer to examine the relationship between symptom distress and survival. They too found a correlation between symptom distress and survival time from diagnosis ( $r = -0.49$ ;  $p = 0.0001$ ).

In summary, symptom distress research seems to have focused either on patients with lung cancer or on patients with a variety of cancer diagnoses. Regardless of what cancer diagnosis patients have, fatigue, pain, and insomnia were consistently rated as either the most frequent or the most distressing symptoms, or both. Mean SDS scores for lung cancer populations tend to be higher than mean SDS scores for varied cancer populations, perhaps because lung cancer tends to be diagnosed at later stages of disease. This notion is supported by the studies which have found that symptom distress becomes greater as cancer progresses. Lastly, increasing symptom distress has been found to be predictive of survival.

**Functional ability.** Functional ability can be described narrowly as physical functioning, that is, bathing, grooming, dressing, toileting, transferring, eating, and walking. A wider definition of functional status is the general ability of a person to meet her or his own needs in the community, including using a telephone, shopping, cooking, doing housework, traveling, self-administering medication, and dealing with financial matters (Calvani & Douris, 1991). Performance status and functional ability/status have been used interchangeably (Kukul,

McCorkle, & Driever, 1986), but performance status would be defined more narrowly as physical functioning.

As with symptom distress, researchers have studied cancer populations to determine the effect of the disease on functional ability. In cancer populations, functional ability is almost exclusively operationalized using the Karnofsky Performance Status Scale (KPS) (Karnofsky & Burchenal, 1949) or the Eastern Cooperative Oncology Group (ECOG) performance status rating (Zubrod, Schneiderman, Frie, & Brindley, 1960), which is based on the KPS.

One hundred thirty-four patients newly diagnosed with cancer were studied to determine their supportive care needs (Whelan et al., 1997). Patients with breast, colorectal, head and neck, lung, prostate, and nonmelanoma of the skin were randomly selected for this survey. Functional ability was measured using a modified version of the Rapid Disability Scale. Forty-one percent of the sample reported at least one need for day to day living, with home maintenance and house cleaning being the greatest needs.

Another study which examined functional status was reported by Lobchuk et al. (1997). Thirty-seven patients with lung cancer were studied. These researchers used the KPS to measure functional ability. It is scored from 0 to 100, with lower scores indicating greater disability. The mean KPS score for this group was 72.44 (s.d., 15.13), indicating ability to care for themselves but inability to carry on all normal activities.

Sarna and Brecht (1997) studied 60 women with advanced lung cancer, the majority of whom were receiving palliative care. In this sample of patients, 88 percent were able to maintain normal activity with minor difficulty (KPS > 70%). Sarna (1998) explored functional ability in another group of 48 patients with newly diagnosed advanced lung cancer. This group consisted equally of men and women. The KPS scores were similar for this group, with the mean score being 79 (s.d., 17).

In a study of 78 patients with stage III or IV cancer who were enrolled in a palliative home care program, Kristjanson et al. (1998) found that the mean KPS score was 63.1 (s.d., 14.4). At this level of functional ability, patients required occasional assistance with daily care.

A second area of research related to functional ability was the impact of advancing disease on functional ability. McCorkle et al. (1989) tested the effects of various levels of home care support in a sample of 166 patients with lung cancer. Functional status, as measured by the Enforced Social Dependency Scale (Benoliel, McCorkle, & Young, 1980), declined with advancing disease.

Another relationship that was noted was the predictive nature of functional status on survival. Reuben et al. (1988) examined data from the National Hospice Study, which contained information on 1,592 patients with terminal cancer. Functional status, measured with the KPS, was the most important clinical factor in estimating survival time ( $p < 0.01$ ).

A study of nursing home residents was done to identify factors predictive of death within 12 months of admission to nursing home (Lichtenstein, Federspiel, & Schaffner, 1985). Forty-nine pairs of decedent/survivor residents were matched for age, sex, race, nursing home, and diagnosis, which was not necessarily cancer. The pairs were not significantly different in terms of marital status, educational level, number of children, previous living arrangements, sensory impairment, physical handicap, or number of medications prescribed. The "survivors" were significantly more independent in terms of functional status, measured by ability to bathe, dress, walk/wheel, communicate needs, transfer, toilet, remain continent, and eat ( $p < 0.05$ ).

To summarize, functional ability has been proven to be an issue for people with cancer. In the studies which quantified functional ability with the KPS, the one palliative sample had more functional debility than the three lung cancer samples. Even at earlier stages of disease, there was some difficulty with patients meeting all of their functional needs. Similar to symptom

distress, functional ability has been noted to decline with advancing disease. This relationship was so strong that functional ability has been shown to be predictive of survival.

**Symptom distress and functional ability.** Some cancer research has examined the relationship between symptom distress and functional ability as well. The main finding has been an association of increasing symptom distress with decreasing functional ability.

Krech, Davis, Walsh, and Curtis (1992) described symptoms in a sample of 100 patients with advanced lung cancer. They found that the number symptoms (86 % of the sample reported pain and 70 % reported dyspnea) increased as patients' performance status, measured with the ECOG rating, declined.

Breitbart et al. (1996) studied pain and its medical correlates in a prospective cross-sectional survey of 438 ambulatory AIDS patients. They found that as reports of pain increased, functional ability measured with the KPS declined ( $t(432)=8.37, p,0.0001$ ).

Two other studies of lung cancer patients also supported the finding that as symptom distress increases, functional ability declines. Sarna and Brecht (1997) explored this association in 60 women with lung cancer. As global SDS scores increased, meaning more symptom distress, the KPS scores decreased, indicating more functional debility ( $r=-0.58$ ). Some individual symptoms were also correlated with KPS, most notably dyspnea ( $r=-0.48$ ) and bowel disruptions ( $r=-0.40$ ).

Sarna (1998) examined this relationship again in a sample of 48 lung cancer patients (50 percent male; 50 percent female). The Physical Functioning Scale (PFS), a 10-item self-report tool was used to subjectively measure physical functional status and the SDS was used to measure symptom distress. Greater functional limitations were associated with more symptom distress.

Kristjanson et al. (1998) also found that poorer functional status was associated with greater symptom distress. Greater debility, measured by lower KPS scores, was related to greater symptom distress, measured by higher SDS scores ( $t=-0.371$ ,  $p,0.001$ ).

A study of a lung cancer population has addressed a second area of research: the relationship between symptom distress, functional ability, and survival. Kukull, McCorkle, and Driever (1986) interviewed 53 patients with inoperable lung cancer. Using the SDS, these researchers found that the patients' symptom distress score one month after diagnosis was the most important predictor of survival (Chi-square=10.37;  $p=0.0013$ ). If symptom distress was removed from Kukull et al.'s stepwise cancer survival model, functional status, measured by the Enforced Social Dependency Scale, became the primary prognostic factor.

In summary, a strong association has been demonstrated between functional ability and symptom distress. Symptom distress increased as functional ability declined. Both of these factors have been identified as predictors of survival, but the amount of research evidence to support these findings was limited.

**Impact on decision making.** Physical state is affected by the particular disease, its treatment, and side effects, which in turn influences decision making (Gotay & Bultz, 1986; Schain, 1990). Some studies have examined the association between decision making and symptom distress, performance status, or functional ability. The results have been conflicting.

Haug and Lavin (1981), in examining the relationship between physician and patient, found that patients who subjectively reported being sicker tended to report more consumerist behaviour, including a preference for an active role in decision making. These researchers postulated that these subjects may have felt a stronger need to be involved in their care in an attempt to "get better".

Two studies support the opposite view. Blanchard et al. (1988) studied 439 interactions between physicians and hospitalized cancer patients. The ECOG rating scale was used to assess functional ability. They found that patients with lower functional ability, measured as “in bed more than half of the day or totally bed-ridden”, were more likely to prefer a passive role in decision making. Ende et al. (1989), in a survey of 312 ambulatory medical patients, found that more favourable health status was associated with stronger preferences for involvement in decision making ( $r=0.22$ ,  $p,0.0005$ ).

Degner and Sloan (1992), in their survey of 436 newly diagnosed cancer patients, studied the relationship between symptom distress and decision making. They found that symptom distress levels, as measured by the SDS, were not related to patients' role preferences for decision making. One might conjecture that because this was a sample of newly diagnosed cancer patients, there may not have been enough patients with advanced cancer, and presumably increased levels of symptom distress, to support the hypothesis that increased symptom distress would be related to a preference for less control in decision making.

The amount of research that has focused on the relationship between these cancer consequences and individual decision making role preferences is limited. As well, the findings have been contradictory. Given these findings, there is a need to explore the relationships between symptom distress, functional status, and decision making preferences so that clinicians can better understand these variables when interacting with patients and their families.

### Information

Several facets of information related to cancer care and decision making have been examined by researchers. Type and amount of information, source of information and how that information is perceived, and the effect of information provision on decision making preferences will be discussed.

Studies have indicated that there is a universal desire among patients with cancer to receive maximal information about their disease and its treatment (Bilodeau & Degner, 1996; Davison et al., 1995; Luker et al., 1995; Schapira, Meade, & Nattinger, 1997). The types of information which patients with cancer desire also have been remarkably similar across a number of studies. Davison et al. (1995), in a sample of 57 men with prostate cancer; Luker et al. (1995), in their group of 150 women newly diagnosed with breast cancer; Bilodeau & Degner (1996), studying 74 women recently diagnosed with breast cancer; and Degner et al.'s (1997a) study of 1012 women with breast cancer all found that the three most important types of information were advance of disease, likelihood of cure, and available treatment options. These studies have focused on breast and prostate cancers specifically. It is unknown whether these trends of desire for maximal information and types of information would be the same in other diagnostic groups.

The source of information is another aspect that has been explored. Ward et al. (1989), in their qualitative study of 22 women with Stage I or II breast cancer facing the decision of mastectomy or lumpectomy, found that physicians were the most frequently identified information source, followed by family, or friends, and nurses. People sources of information were ranked as more important than other sources such as journals, videos, pamphlets, and the media. Bilodeau and Degner (1996) also investigated this issue. They had 74 women recently diagnosed with breast cancer rank preferred sources of information. In general, they too found that personal sources of information were preferred over written sources. The specific order in which women ranked preference of information source was: physicians, nurses, friends or relatives, brochures, medical textbooks or journals, videotapes, radio or television programs, women's magazines, and newspapers.

Hughes (1993) examined the relationship between information source about breast cancer treatment alternatives and treatment selection in a sample of 71 women with stage I or II

breast cancer. Treatment choice, either lumpectomy or mastectomy, was not related to the amount of information given to patients at their clinic visit, but rather was related to the amount of information received prior to their clinic visit. Women who chose mastectomy had received significantly ( $p < 0.01$ ) more information prior to their clinic visit than the group of women who chose lumpectomy. Information subjects received prior to their clinic visit, which subjects subsequently based their treatment choices on, most frequently came from sources such as family, friends, the media, and educational brochures. Given the range of information sources, some formal and some informal, it would seem prudent to assess the patient's prior information with respect to their disease and its treatment.

An issue related to source of information that has received attention in the literature is the impact of a physician recommendation. Ward et al. (1989), in their qualitative study of 22 women with Stage I or II breast cancer, found that even though the women in their study wanted partial or complete control over decision making regarding surgical treatment, some women wanted their surgeon's opinion about which option the surgeon preferred. Similar results were reported by Charles et al. (1998) in their qualitative study of 20 women with early stage breast cancer. In this group, women again wanted to make the final treatment decision, but wanted their physician's recommendation. Focus groups which Schapira et al. (1997) used as part of their study exploring the effects of information on decision making echoed the strong influence that the physician has on patients' decision making.

Further support for the importance of physician recommendation is found in Siminoff and Fetting's (1991) study of 100 women with breast cancer. They found that the stronger the patient rated the physicians's treatment recommendation, the more likely she was to accept it. Hughes (1993) found that although subjects who received an explicit recommendation were as likely as the others to opt for either surgery ( $p < 0.05$ ), many subjects who did not receive

explicit recommendation stated that their decisions were heavily influenced by clinician recommendation. This means that even when a specific recommendation was not made (as observed by the researcher), subjects may have perceived that one was made and subsequently included that in their deliberations of treatment choice. A third study that examined the impact of physician recommendation was reported by Johnson et al. (1996). In their sample of 76 women newly diagnosed with breast cancer, 80 % wanted a role in decision making, 74 % wanted their surgeons to make a recommendation, and 94 % followed the physician recommendation when one was made.

A third issue is the effect of information on decision making preferences. Although in a study of renal patients (155 pre-dialysis, 103 dialysis, and 147 transplant), Caress (1997) found that when subjects were asked to give rationale for their decision making preferences, 56 comments suggested that inadequate knowledge contributed to their mostly passive decisional roles. Likewise, in their 1991 study of 100 women with breast cancer, Siminoff and Fetting found that women who addressed the issue of risk associated with treatment choices and who had a better grasp of treatment benefits were more likely to choose an active role in decision making. Thirdly, a grounded theory study aimed at describing decision behaviour in women with breast cancer found that those who sought out information and those who examined the risk associated with treatment choices were more active in treatment decision making (Pierce, 1993).

Schapira et al. (1997) tested the effect of information provision on decision making preferences. Thirty-two men between the ages of 50 and 85 years who did not have prostate cancer were recruited from primary care outpatient clinics at a veterans' hospital. These men viewed an information videotape whose topics included anatomy of the prostate gland, cause of prostate cancer, treatment options, treatment efficacy, and management of possible treatment side effects. A pre- and post-test was administered to the men. There was also a pre- and post-video

interview to discuss the men's attitudes toward decision making. A statistically significant increase in knowledge was noted following the videotape intervention. As well, men's decision making attitudes changed after watching the videotape. Before viewing the videotape, 28 % of the men indicated that they would defer decision making to their physician; only 16 % indicated this after viewing the videotape. An increased percentage also indicated they would pursue joint decision making (22 % after videotape; 3 % before videotape).

Davison and Degner's (1997) study of 60 men newly diagnosed with prostate cancer lends strength to the assertion that information provision can impact decisional preferences. Thirty of the men were randomized to the experimental group; the other 30 to the control group. The experimental group received a list of potential questions that they could ask their physician about their cancer and its treatment and then were directed to the information in a written information package. They were encouraged to read this information prior to the consultation with the physician. The control group were only given the information package and shown what it contained. The preferred decision making roles of both groups were assessed prior to receiving the control or experimental intervention, and these results showed no statistical significance between the two groups. Six weeks after the initial encounter, subjects were asked what decisional role they actually assumed in the decision making process with their physician. The experimental group indicated that they had assumed a more active role than their control group counterparts ( $\chi^2=11.316$ ,  $p<0.001$ ). These results support the assertion that providing informational support can alter individuals' decision making behaviour.

In summary, patients with cancer almost invariably wanted maximal information about their disease and its treatment, with the most frequently sought after topics being advance of disease, likelihood of cure, and treatment options. Cancer patients seemed to prefer people sources of information, such as physicians, nurses, family members, and friends, over other

sources such as videotape, pamphlets, or journals. Physician recommendation was often sought by the patients, and when sought very likely followed. Lastly, the provision of information to patients with cancer has been shown to result in more active decision making roles for patients.

### Perceptions of Health Care Providers

Perceptions of health care providers also appears to affect decision making. Physician recommendation has been identified as a significant factor in patients' treatment choice (England & Evans, 1992; Siminoff & Fetting, 1991). Statements from interviews of patients indicated that faith in their physician, rather than objective evidence of the benefits of one treatment over another or an understanding of how the physician arrived at the treatment recommendation, was a seminal factor in their decision making processes (Caress, 1997; Hack et al., 1994; Siminoff & Fetting, 1991). Siminoff and Fetting also noted that the stronger the patient perceived the physician's recommendation to be, the more likely the patient would be to accept that recommendation. As well, Siminoff and Fetting suggested that the less confident the physician appeared and the more the patient knew about treatment, the more likely the patient would diverge from the physician's recommendations.

A few researchers have examined patient perceptions of health care in relation to decisional role preferences. Caress (1997), in her study of 462 renal patients, found that positive experiences with health care providers and a perception of clinical expertise were identified as factors which swayed patients toward a passive decision making stance. Conversely, patients who doubted their physician's competence or had experienced a "medical error" were more likely to prefer an active role in their treatment decision making (Caress, 1997; Haug & Lavin, 1981). Haug and Lavin also noted that if patients tended to reject authority in general terms, they would choose a more active stance in regard to their health care.

To summarize, these studies indicate that physicians are in a position of authority and

trust, and that patients are influenced by what physicians say, particularly in relation to treatment options. However, if patients' faith in physicians is compromised, the patient-physician relationship is affected and patients may attempt to assume a more active role in their care decisions.

### **Family Responses to Cancer**

The family, not merely the patient, experiences the crisis, long-term effects, and uncertainties of cancer. The family is the patient's primary support, emotionally and often physically. However, the family is affected by the demands and stressors placed on them by the cancer as well (Lewis, 1986). Research into the responses of family members when another member has cancer has been approached in a variety of ways, guided by numerous theoretical perspectives. What has emerged from the literature is a patchwork of interesting findings, but without a systematic, consistent framework in which to situate them. Two areas of literature related to family responses to cancer seem to be: needs of families who have a member with cancer and alterations in family functioning which occur following a cancer diagnosis. These two content areas will be the focus of this section.

#### **Family Needs**

The needs of family members of cancer patients have been well documented in the literature. These needs appear to separate into two distinct groups: needs related to the patient and family members' needs for psychosocial support.

**Patient-related needs.** The primary need related to the patient that is repeatedly reported by families is their need to know that the patient's symptoms are in control, that the patient is comfortable (Halliburton, Larson, Dibble, & Dodd, 1992; Hinds, 1985; Kristjanson, 1989; Lewis, Pearson, Corcoran-Perry, & Narayan, 1997; Wellisch, Fawzy, Landsver, Paasnau,

& Wolcott, 1983; Wright & Dyck, 1984). This finding of needing to know the patient is comfortable appears to encompass all phases of the cancer trajectory. Two of these studies (Hinds, 1985; Wellisch et al., 1983) were carried out in home care populations, indicating a relatively advanced stage of cancer. Halliburton et al.'s (1992) study examined needs of families during cancer recurrence. A fourth study (Wright & Dyck, 1984) examined family members' concerns of 45 patients, 15 each in the diagnostic, recurrent, and terminal stage. They found that the need to know the patient is comfortable was not statistically different between groups. Kristjanson (1989) surveyed 210 family members of 120 patients with advanced cancer. The highest ranked patient-related need was relief of the patient's pain. Lewis et al. (1997) studied the scope of decisions elderly patients with cancer and their caregivers encountered as outpatients. Thirty-four percent of the phone calls received from elderly patients or their caregivers by cancer centre nurse coordinators were to discuss symptom management issues.

A second patient-related need reported by families was for information related to the patient's condition. Half of Wright and Dyck's (1984) sample (next-of-kin of 45 hospitalized adult cancer patients) identified a need for information as a problem. Hinds (1985) found that families needed information about: the disease process (25% of sample), expectations for care at home (20%), treatment side effects (15%), injections (10%), and nutrition (10%).

Lastly, a need for families to have access to resources to manage patient care was identified. Wellisch et al. (1983) found that, in their sample of 447 married cancer patients receiving home care, families needed both equipment and trained home care providers to assist with the patients' home care needs. When patients were 70 years old or older, families were significantly more likely ( $p=0.031$ ) to be overwhelmed by home care needs. Hinds (1985), in her sample of 83 family members looking after cancer patients at home, also found a need for help with home care, specifically that 21 % of her sample had no access to respite from their

caregiving role.

**Psychosocial support.** Family members' needs for psychosocial support has also been well-documented. One of the major findings was the psychological distress encountered when there were unresolved patient care issues. Hinds (1985) found that 53 % of her sample reported psychological distress over patient suffering, uncertainty about disease course, and insecurity about their ability to provide adequate care to their family member with cancer. Wright and Dyck (1984) reported that families found the anguish of watching a loved one suffer from poor symptom control the most difficult part of their cancer experience. In this sample, this anguish increased with the disease stage: 20 % of family members reported distress over patient suffering from symptoms at the diagnostic stage, whereas 53 % reported this distress at the terminal stage. Cooper (1984) supports this finding. In her sample of 15 lung cancer patients and their spouses, feelings of helplessness as they watched their spouses deteriorate was the second most reported emotion.

Fear is another emotion encountered by family members. Gotay (1984), in a sample of 73 women with cancer and 39 partners, found that fear of cancer was the primary concern for both patients and partners. Some feared the diagnosis itself; others feared the possibility of cancer progression or recurrence. Fear of death was the second-ranked concern for partners of women with cancer; women with cancer ranked the fear of death much lower than their partners. Wright and Dyck (1985) identified fear of the future as a concern for family members. This is similar to the fears of cancer and death reported by subjects in Gotay's study, whose fears of the future included dealing with recurrence of disease and possible death.

Cassileth et al. (1985) examined the relationship between the psychosocial status of cancer patients and their close relatives in 201 patient-relative pairs. Using self-report tests of anxiety, mood disturbance, and mental health, these researchers found that patients and their

matched relatives (either spouse, parent, child, sibling, or other close relative) had highly correlated scores ( $r=0.28 - 0.42$ ;  $p<0.0001 - 0.000001$ ), indicating that the psychological status of patients and their next-of-kin are related. They also found that psychological response was significantly related to treatment status. Anxiety, mood disturbance, and mental health scores demonstrated decreasing psychological well-being as patients moved from follow-up care to active treatment to palliative care. This finding was reflected in the scores of these patients' next-of-kin. Given these findings, Cassileth et al. postulated that supportive care given to one part of the patient-relative pair should confer positive benefit to the other member of the pair.

Cooper's (1984) study of 15 patients with lung cancer and their spouses contradicts Cassileth et al.'s (1985) findings of parallel psychological status between patient and next-of-kin. Cooper (1984) found that twice as many spouses as patients reported signs of stress, including nervousness, sleeplessness, decreased appetite, inability to concentrate, and irritability. She speculated that spouses experienced more distress because of less support for spouses of cancer patients in both formal and informal support networks.

Greater distress among caregivers than patients was supported in work done by Given and Given (1992) in their study of 49 patients with breast cancer and 49 caregivers. These dyads were followed for a six-month period, over which time depression, using the CESD-20, was measured at intake and at six months. Patients, whether newly diagnosed or with recurrent disease, were less depressed at the six month point than at intake. Conversely, caregivers became more depressed from intake time to the six month follow-up. As well, caregivers of patients with recurrent disease were more depressed at both time points than were the patients with recurrent disease.

In summary, the research showed that the families' priority need is knowledge that the patient is comfortable. Other important needs included information about the patient's treatment

and care and the availability of equipment and human resources for home care. Family members' distress related to patient suffering, adequate patient care, fear about the cancer itself and fear of the possibility of death has been documented. There was conflicting information regarding the psychological status of the patient and family members - one study indicated that psychological status of the patient and family member moves in tandem, whereas two others indicated that family members suffer greater psychological distress than do patients. A few studies suggested that some of these needs remain constant throughout the cancer trajectory, while other needs change with the phases of the disease. Given these findings, and the contradiction within, more study is required in this area. As well, research needs to examine the relationships between these family needs and how families function within the cancer context.

### **Alterations in Family Function**

Alterations in family functioning are an inevitable response to a diagnosis of cancer in the family. Although different theoretical frameworks have guided studies in this area, similar functional characteristics of these families have been reported. The domains of family function to be discussed in this section are: general functioning, roles, communication, and affective function.

**General functioning.** General family function, not surprisingly, is compromised by a cancer diagnosis in the family. Arpin, Fitch, Browne, and Corey (1990) studied 216 chronically ill people who had recently been referred to either oncology, rheumatology, or gastroenterology clinic. The prevalence of family dysfunction, measured by the Family Assessment Device, was 30 %, inflated in comparison to community norms. The prevalence of family dysfunction for the sub-sample of cancer patients was 34 %, which was not significantly different from the other two sub-samples of chronically ill people ( $p=0.55$ ). For the cancer sub-sample, the dimensions of family function which were most impaired were problems with behaviour control (51 %),

communication (42 %), and affective involvement (41 %).

Kristjanson, Leis, Koop, Carriere, and Mueller (1997) examined the effect of demographic variables on family function among 72 family members of 72 patients with advanced cancer. They found that family member's age, patient's gender, and family member's educational level were related to family function. Older family members (>51 years) perception of family function was more positive than that of younger family members ( $t=3.55$ ,  $p=0.0007$ ). Family members of female patients reported better family functioning than did family members of male patients ( $t=2.94$ ,  $p=0.0046$ ). Lastly, family members with high school education or less reported better family functioning than family members with a college education ( $t=2.10$ ,  $p=0.0403$ ). Interestingly, family members with a graduate degree reported slightly higher family function than those with lower levels of education.

To summarize, a cancer diagnosis seems to impact negatively on family function with specific negative effects on behaviour control, communication, and affective involvement. As well, better family function is reported by older family members, better educated family members, and family members of female patients. However, there is limited research in this area and sample sizes are small. Therefore, these findings should be viewed with caution, and further study to support or refute the findings needs to be done.

**Roles.** Family roles have been studied because of an assumption that a cancer diagnosis, with its subsequent treatment, side effects, and trajectory, will necessitate reallocation of roles for the family. Vess, Moreland, and Schwebel (1985a,b) conducted a longitudinal study to assess the effects of cancer on family role functioning. The families they studied were those which had a parent with a primary diagnosis of cancer who had children under the age of 20 years living at home and a spouse willing to participate. Of 81 families approached, 54 families completed the initial battery of instruments: Washington Family Role Inventory (Nye, 1976), Marital

Communication Inventory (Bienvenu, 1979), Family Environment Scale (Moos & Moos, 1981), and an audiotaped semi-structured interview. They found that families at different stages in the family life cycle allocate roles differently ( $\chi^2=31.27$ ;  $p<0.0001$ ) because of differences in resources. Another finding was that higher levels of communication between spouses were positively correlated with better family cohesion ( $r=0.457$ ;  $p=0.001$ ), less family conflict ( $r= -0.517$ ;  $p=0.001$ ), less role conflict ( $r= -0.512$ ;  $p=0.001$ ), less role strain ( $r= -0.214$ ;  $p=0.013$ ), and more competent role enactment ( $r=0.241 - 0.481$ ;  $p=0.001 - 0.040$ ), supporting the value of open communication between spouses. A third finding was that families who used achieved roles (role a family member takes on because of ability) rather than ascribed roles (role that a family member gets because of some characteristic over which one has no control, like gender or age) prior to the parent's cancer diagnosis had higher scores on the family cohesion scale ( $p=0.0375$ ), and better enacted role competence by both wives ( $p=0.0274$ ) and husbands ( $p=0.0169$ ). A partially supported finding was that families with adolescents or older children reported better family cohesion, less family conflict, less role conflict, and less role strain (Vess et al. 1985a).

In their follow-up study done five months later, Vess et al. (1985b) mailed the same three instruments, but omitted the semi-structured interview. Twenty-nine of the original 54 couples responded. This follow-up sample was substantially different from the original sample: the follow-up group showed higher levels of communication and family cohesion and lower levels of family conflict, role strain, and role conflict. Families using achieved role assignment methods prior to cancer diagnosis of a parent showed less family conflict ( $p=0.02$ ), better role competence ( $p=0.02$ ), and higher levels of marital communication ( $p=0.03$ ). Families with older children who could take on expanded roles in the family reported significantly lower levels of family conflict than did the families with younger children ( $p=0.01$ ). Families with higher levels of inter-spouse communication reported better family cohesion ( $r=0.25$ ;  $p<0.01$ ), less family

conflict ( $r = -0.32$ ;  $p < 0.01$ ), less role conflict ( $r = -0.32$ ;  $p < 0.01$ ), and higher role competence for husbands ( $r = 0.34$ ;  $p < 0.01$ ).

A study of 15 lung cancer patients and their spouses reported similar findings. Ten of the 15 couples in Cooper's (1984) study reported role changes, with either the spouse or children taking over the patient's responsibilities. Some of the male patients had difficulty with this enforced dependence, while none of the three female patients expressed this concern.

Wellisch, Wolcott, Pasnau, Fawzy, and Landsverk (1989) abstracted data from 837 patient records where the patients had cancer, were homebound, and had at least one family member (either spouse, sibling, or adult child) involved in their care at home. They found that if family members were overwhelmed by the caretaking role, the patient was more likely to report role adjustment problems ( $r = 0.12$ ;  $p = 0.01$ ).

Lastly, Northouse, Dorris, and Charron-Moore (1995) examined factors affecting couples' adjustment to recurrent breast cancer in 81 women and 74 husbands. These researchers found that women with less education had more difficulty enacting their various roles ( $r = -0.28$ ;  $p < 0.05$ ). Women currently receiving treatment reported more role adjustment problems than women not on treatment ( $t = 2.51$ ;  $df = 78$ ;  $p < 0.02$ ). As well, husbands who reported less symptom distress in their wives ( $t = 2.92$ ;  $p < 0.005$ ), less hopelessness ( $t = 4.04$ ;  $p < 0.001$ ), and no health problems of their own ( $t = 2.44$ ;  $p < 0.02$ ) reported fewer problems with role adjustment.

In summary, families who used an open communication style appeared to manage role allocation better than those who used closed communication. Families who allocated roles based on achievement were better able to enact those roles competently. Stage in the family life cycle also affected families: families with adolescent and older children were better able to weather role reallocation than families with younger children. The ability of the family to manage roles affected the patient: if family members were overwhelmed by their role responsibilities, patients

had role adjustment problems. Female patients with lower levels of education and those who were currently receiving treatment had more role adjustment problems. Spousal role adjustment was positively affected by perceptions of low symptom distress in the patient, higher levels of hope, and a lack of personal health problems. Although there is theoretical literature to support the categorization of decision making as a type of role enacted by families, the empirical literature related to family roles does not articulate the assignment, process, or components of a decision making role specifically. Therefore further work is needed to understand the relationship between family role function and how families make decisions so clinicians can assist families through the decision making process in a way that is appropriate to each family.

**Communication.** Communication among family members is an essential aspect of family function. Spiegel, Bloom, and Gottheil (1983) studied 54 women with metastatic breast cancer to examine the role of family environment on adjustment to cancer. The women were assessed at baseline, four months, eight months, and twelve months using the Family Environment Scale (Moos & Moos, 1981), the Profile of Mood States scale (McNair, Lorr, & Drappelman, 1971), and a family checklist and belief systems scale developed for this study. Women's spouses, or other family members, were administered The Family Environment Scale at baseline. Forty-two of the 54 women were married. Seventy-four percent of this sub-sample reported that they could discuss their illness at home, demonstrating an open communication style. This result was derived from the family checklist in which the patient rated her own and her spouse's view of the family. Only 34 % of the patients described their spouses as willing to discuss their illness at home. Given these disparate findings, it is difficult to know what the actual communication about this issue was like in the homes of these couples.

Cooper (1984) interviewed 15 lung cancer patients and their spouses to explore the effect of a lung cancer diagnosis on family relationships. She found a discrepancy between patient and

spouse reports of frequency of communication. Patients perceived the couple as talking more than did the spouses. This reflects the finding that spouses generally reported that they were not sharing their feelings with the patients as a means of protecting their patient-spouses. This closed communication style resulted in feelings of isolation for the spouses.

A third study to examine communication was undertaken by Thorne (1985). Using a phenomenologic approach, Thorne found that families chose to use the same communication patterns that they used prior to diagnosis of cancer in a family member. Whether this pattern was open or closed was not important to the families. What was important was to continue with the previous pattern as part of their attempt to achieve or retain normalcy in their lives.

Lewis, Woods, Hough, and Bensley (1989) examined the effects of maternal chronic illness on the family from the spouse's perspective. Spouses of women with nonmetastatic breast cancer (n=19), fibrocystic breast disease (n=16), and diabetes (n=13) were interviewed. All of these families had young school-age children. Families characterized by frequent communication and discussion within the family were associated with more frequent illness demands, better levels of marital adjustment, and healthier functioning both for the children and the family unit.

In summary, the literature related to communication is contradictory. Several studies have indicated the utility of open communication whereas others have identified the protective benefits of closed communication. Another researcher has reported that what is important to families is maintaining normalcy by using previous communication patterns following a cancer diagnosis in the family. Family communication is a necessary part of family decision making. Understanding families' communication patterns may allow researchers to link this to family decision making preferences.

**Affective function.** Much has been studied about emotion and the family cancer experience. Cooper (1984) found that 13 of 30 (43%) subjects perceived no change in their marital relationship and 14 of 30 (47%) perceived an increase in closeness. Spiegel et al. (1983) examined 42 married women with metastatic breast cancer and reported 87 % of them enjoyed family life, 73 % could openly express joy at home, and 65 % were satisfied with their marriages. Only two percent of these women reported frequent arguing at home. Those women who died within one year of the study reported more expressiveness, perhaps because their impending deaths compelled the families to confront issues they otherwise may have ignored. Overall, Spiegel et al. found that a family atmosphere of open discussion of feelings and problems, minimal conflict, and little emphasis on moral-religious orientation predicted less mood disturbance in the patient in the following year ( $F=6.65$ ;  $p<0.01$ ).

Wellisch et al. (1989) had similar findings from the data abstracted from 837 patient records of homebound patients with cancer who had at least one family member (spouse, sibling, or adult child) involved in their care at home. Family problems such as family conflict, role burden, and family mood disturbance accounted for 14.4 % of the variance in patient mood disturbance. These researchers concluded that the family that alternates between open conflict and emotional distress created the most difficulty for the patient's psychological adjustment.

Thorne (1985) reported a wide discrepancy of how families dealt with emotional reactions. She found that families often made a conscious decision to either openly express feelings, or not to express feelings. Emotional support was also managed in different ways by the families. Some indicated that the patient supported the family, and some that the family supported the patient. Some families indicated the pattern of emotional support remained constant throughout the disease process, whereas others described shifting supportive behaviour depending on various circumstances over the course of the cancer experience.

In a study of 111 mothers with one or more school-age or adolescent children at home, Lewis and Hammond (1992) assessed the impact of maternal breast cancer on the family. These mothers were interviewed on three occasions, four months apart. Marital adjustment, measured with the Spanier Dyadic Adjustment Scale, improved over time (multivariate  $F=4.10$ ,  $p<0.05$ ). Family functioning, measured by the FACES-II, did not change over time. Mothers' mood was also measured, using the CES-D. Mood also did not change over time. Maternal depressed mood was related to poorer family function and poorer marital adjustment.

Overall it appears that families who deal openly with their feelings and problems, and who minimize family conflict, may facilitate psychological adjustment for patients and family members. Findings related to the direction of emotional support within the family was less consistent. Sometimes the patient supported the family; sometimes the family supported the patient. These support roles were static in some families, whereas other families reported changes in the flow of emotional support over time. Depression in the patient has been demonstrated to negatively affect family function and marital adjustment. This work points to the need to further identify determinants of affective function within the family. This will facilitate the ability to intervene with families to improve or support their affective functioning, and perhaps to enable families to better engage in decision making.

### **Family Decision Making**

Literature in the area of family decision making is sparse. Blustein (1993) believes that families, by virtue of their relationship with the patient, are well placed to act as decision making proxy for the incompetent patient. He also believes that family members are uniquely qualified to advocate for the competent patient and assist this family member in decision making. He cautions, however, that family members may bring their own agendas to this process. This section will review the family decision making literature, organized into three sub-sections:

decision making styles, preferences for participation in decision making, and factors associated with decision making preferences.

### **Decision Making Styles**

One study was found which examined the ways families make decisions when a family member has been diagnosed with cancer. Using a qualitative approach, Hilton (1994) interviewed 55 families to examine family decision making processes in early stage breast cancer treatment, at a time when the patient is presumably competent. A theme that emerged from family coping was family decision making. Four decision making patterns became evident, ranging from a passive decision making role to an active one and included the following: “defer to physician”, “minimal exploration”, “joint engagement”, and “extensive examination”. These four patterns had distinct characteristics, each influencing the way families made decisions, the nature of the decision process, and the outcome of decision making. Families who were involved in treatment decisions expressed little difficulty making those decisions and were satisfied both with the process and outcome of their decision making. Another finding was that families, for the most part, carried previous decision making patterns into the cancer decision making process. However, some families who were previously active participators tended toward passivity because they believed they had no choice. Hilton also found that family decision making, like individual decision making (Schain, 1990; Siminoff & Fetting, 1991), was affected by factors other than rationality alone.

### **Preferences for Participation in Decision Making**

**Competent patient.** The literature reviewed has been organized into two content areas. These are end-of-life decision making and treatment decision making.

A random sample of 800 outpatients was surveyed about their experience and decision

making preferences regarding do-not resuscitate orders (Ebell et al., 1990). The response rate was 51 %. Patients ranked spouse, physician, and children, in that order, as their preference for persons with whom they would like to discuss this sort of decision. This lends support to the notion that the family plays an important role in decision making of individuals within their family system.

Another study explored this same issue. Four hundred randomly-selected hemodialysis patients were interviewed in person to examine patient preferences for whom to involve in advance care planning (Hines, Glover, Holley, Babrow, Badzek, & Moss, 1999). Study results indicated that 50 % of patients reported having discussed end-of-life decisions with family members, whereas only six percent reported having discussed this issue with their physicians ( $p < 0.001$ ). Further, the results showed that more patients desired family member involvement in advance care planning than physician involvement (91% versus 36%,  $p < 0.001$ ).

Lewis et al. (1997) studied the scope of decisions which elderly patients with cancer and their family caregivers were making. Over a 16-week period, cancer centre nurse coordinators logged phone calls from elderly patients with cancer and their caregivers. Of these calls, 61 % were initiated by the family caregiver, indicating some level of involvement of the family member in decision making for, or with, the patient.

The second content area was preferences in relation to treatment decision making. Degner and Russell (1988) studied a theoretical sample of 60 patients with cancer to explore the question of control over treatment decisions. Using a card sort procedure, the patient was presented with four alternative choices of patient-family control: family and patient have major responsibility for treatment decision making; physician, family, and patient share decision making; physician and family share decision making; and family alone makes decisions. Using unfolding theory, 39 of the 60 respondents' preferences could be used. This data showed a

strong preference for the patient and family to be included in the decision making, either with or without the physician, and almost non-existent support for leaving the decision making to the family, with or without the physician. In other words, the patients wanted to be included in decision making about their care and did not want the physician and family, in collaboration or independently, to be doing it on their behalf.

In Hilton's (1994) qualitative study of 55 families in which a family member had been diagnosed with early stage breast cancer, four decision making patterns emerged ranging from passive to collaborative to active. Approximately half these families deferred decisions to their physician, while the other half participated in the decision making process.

A third study which examined decision making preferences interviewed 55 patients receiving radiotherapy for cancer and 53 persons accompanying them (Stiggelbout & Kiebert, 1997). The persons accompanying the patients were only identified as "companions", so it is impossible to know how many of them were actual family members. Degner and Sloan's (1992) card sort procedure was modified in this study. The five decision making statements were printed on a sheet of paper, and the respondents were asked to pick the statement that best reflected their preference. The modal response was "the physician should make the decision, but strongly consider my opinion", chosen by 42 % of the patients and 41 % of the companions. For patients, 61 % chose a passive decision making role, 25 % a collaborative role, and 13 % chose an active role. Among the companions, 46 % chose a passive role, 24 % a collaborative role, and 30 % an active role. Although not statistically significant, there was a trend of companions preferring a more active role than the patients.

To summarize, patients want their family members involved in end-of life decision making, although the extent of involvement may vary. Physicians have also been identified as persons with whom to share this decision making, although not as strongly as family

involvement. With respect to treatment decision making, the results were mixed. One study reported that patients wanted to be involved in treatment decision making. Patients also wanted their families to be involved in this process and, to a lesser degree, wanted their physicians involved (Degner & Russell, 1988). Another study found that only half of the patients wanted themselves or their families involved in treatment decision making. A third study found that the majority of patients and their companions preferred passive decision making roles (Stiggelbout & Kiebert, 1997). Given the small number of studies undertaken, and the contradictory findings, more work in this area is required.

**Incompetent patient.** One study was reviewed regarding decision making preferences once patients are no longer able to participate in their own decision making. Degner and Sloan (1992) surveyed 436 newly diagnosed cancer patients and 482 members of the general public, with no personal history of cancer, to elicit individuals' preferences for decision making about their treatment and individuals' preferences for their treatment decision making when they were no longer competent to decide themselves. A five card sort technique was used. To answer the question of people's preferences for decisional control when no longer capable themselves, the response choices were: family decides; family decides but considers physician's opinion; family and physician share decision; physician decides but considers family's opinion; and physician decides. They found both groups (51 % of patients and 46 % of the public) preferred their family and physician to share in the decision making. Ten percent of patients wanted their families to dominate the decision making, while 40 % of the public preferred their families to dominate. Among the sub-sample of cancer patients, those who preferred an active role in their own decision making preferred their family assume control when they were not able ( $r=0.72$ ;  $p=0.000$ ).

### **Factors Associated with Decision Making Preferences**

Minimal study has been done with regard to the factors which may be associated with decision making preferences within families. The limited work which has been carried out has examined four areas, those of demographics, information, time from diagnosis, and disease advancement. These four areas will be reviewed in this section.

In a study reported in 1992, Degner and Sloan surveyed 436 newly diagnosed cancer patients and 482 members of the general public, with no personal history of cancer, to elicit individuals' preferences for decision making about their treatment and individuals' preferences for their treatment decision making when they were no longer competent to decide themselves. In the sub-sample of patients with cancer, female and younger patients preferred more family involvement in decision making than male or older patients. The role that age and gender played in this study of family decision making preferences is the same as the associations found between age (Beaver et al., 1996; Blanchard et al., 1988; Cassileth et al., 1980; Degner & Sloan, 1992; Degner et al., 1997a; Ende et al., 1989; Hack et al., 1994; Llewellyn-Thomas et al., 1995) and gender (Degner & Sloan, 1992; Llewellyn-Thomas et al., 1995) for individual decision making preferences.

A second study reported on these same demographic factors. Stigglebout and Kiebert (1997) interviewed 55 patients receiving radiotherapy for cancer and 53 persons accompanying them. The persons accompanying the patients were identified as "companions", so it is impossible to know how many of them were actual family members. Younger participants preferred more active decision making roles than the older ones ( $p < 0.006$ ). Likewise, more women than men preferred an active role in decision making. Among the female participants, 27 % chose an active role, 34 % chose a collaborative role, and 40 % chose a passive role. Among men, 15 % chose an active role, 22 % collaborative, and 63 % passive ( $p < 0.01$ ).

Information also played a role in family decision making. Pierce (1993) used a grounded theory approach (Glaser & Strauss, 1967) to explore the decision making process of 48 women with early stage breast cancer. Patients described decision conflict (i.e. consideration of more than one treatment option) when family members expressed their views of the “right” decision. The most prevalent response to decision conflict was to seek out more information related to the treatment options.

Time since diagnosis has been reported to have an effect of family decision making. Sims et al. (1992) described the experiences of families caring for an ill family member in the home, one focus being a description of the families' decision making. A grounded theory approach was used with the 17 families studied. These researchers found that most caregivers were passive decision makers initially, but they became more active as they became more familiar with their new situation and the needs of care recipients. Beaver et al. (1996) and Davison et al.(1995) found the same passivity in newly diagnosed patients making their own decisions.

Similar findings were also reported by Barry and Henderson (1996) in their study of seven patients with cancer who were in the final stages of their illness. Degner and Sloan's (1992) five decision making cards were used to generate discussion about preferred decision making roles of the patients. These researchers found that patients chose more active in decision making roles as time passed, despite the lack of correlation between changes in physical status and decision making preferences. In the interviews, patients indicated that the preference for increased decision making involvement was related to the increased knowledge about their disease.

The fourth area explored was the impact of disease advancement on family decision making. Labrecque, Blanchard, Ruckdeschel, and Blanchard (1991) studied interactions between

cancer patients and their oncologists during follow-up appointments. Their results were based on 43 out-patients visits, 21 % of those including a family member being present. When a family member was present, the patient was more likely to have lung cancer than other types ( $\chi^2=39.09$ ,  $p<0.001$ ), poorer performance status as measured by ECOG ( $\chi^2=45.61$ ,  $p<0.001$ ), and undergoing active treatment ( $\chi^2=22.46$ ,  $p<0.001$ ). These researchers speculated that the family members were present in order to provide support to the patient, both physically and emotionally. Part of this support may have been to gain information regarding the patient's disease, in an effort to assist with decision making.

Sims and colleagues (1992) found that family decision making processes changed when a family member becomes ill, despite attempts to maintain past decision making roles. Caregivers identified this loss of mutual decision making as a contributor to their sense of isolation and burden. As well, these researchers identified differences in family decision making processes depending on who was the sick family member. When parents cared for children, or when spouses cared for spouses, there was consensus on their right to decide. However, when children cared for parents, stress emerged as siblings negotiated among themselves for rights and roles as parental caregivers. Group decision making appeared to be the norm for siblings choosing treatment for parents; if consensus could not be achieved, discord resulted.

In summary, younger age and being female are associated with a greater preference for family involvement in decision making; these variables are also associated with a more active decision making role for individuals. Information-seeking was the most common strategy for families who had conflict regarding a treatment decision. Decision making style may change over time, initially being quite passive and becoming more active over time. Lastly, families tend to use the same decision making style pre-illness and post-illness, although sometimes they are forced by circumstances to change. Often the circumstance requiring change is disease

advancement. This change has been noted to cause distress. Given the number of variables affecting family decision making and the apparent similarities between individual and family decision making, it is important to study other variables which may impact on family decision making. Development of tools to measure family decision making preferences is also a priority.

### **Theoretical Framework**

Researchers and clinicians agree that illness generally (Blustein, 1993; Erstling, 1985; Muller & Desmond, 1992; Sholevar & Perkel), and cancer specifically (Cooper, 1984; Hilton, 1994; Morra, 1985; Northouse, 1984; Quinn & Herndon, 1986; Schain, 1990), sends reverberations throughout the entire family. As well, there is evidence that previous decision making experiences and family contextual factors affect decision making processes within the family unit (Scanzoni & Szincovacz, 1980). Therefore, two theoretical frameworks provide conceptual guidance for this study: Family Systems Theory and Scanzoni and Szincovacz's Developmental Sex Role Model (Fig. 1).

According to Family Systems Theory, the family is defined as a small group of interrelated, interdependent people who belong to a single unit with the purpose of achieving family goals (Friedman, 1992). Sholevar and Perkel (1990) maintain that the family functions within the broader social system and evolves over the life cycle. As a result of the intricate interconnectedness of the family system, a change in one member of the system inevitably results in change to the entire system (Friedman, 1992; Quinn & Herndon, 1986; Sholevar & Perkel, 1990). Sholevar and Perkel (1990) view the family system as the primary source of support for a patient.

Within the family system there are smaller sub-systems. Two or more family members constitute a sub-system, and an individual may belong to more than one sub-system, for example:

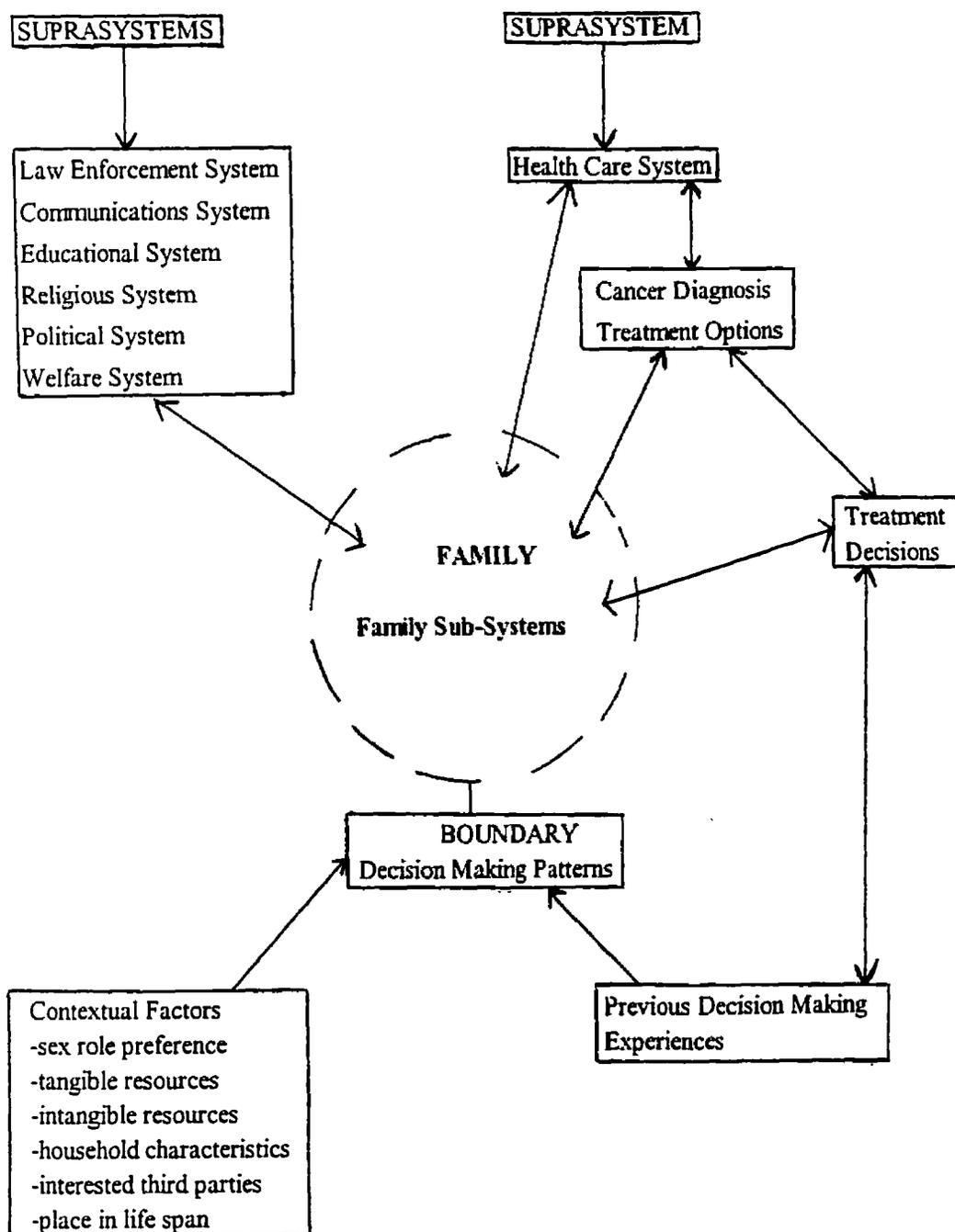


Figure 1. Conceptual Model

mother-father, mother-son (Artinian, 1994). The family system differentiates and carries out its functions through these sub-systems. Each individual has differentiated roles and different levels of power in these sub-systems (Friedman, 1992).

The family system also functions as part of the larger social system, the supra-systems. These supra-systems include health care, religious, political, educational, welfare, communications, and law enforcement (Friedman, 1992).

Family systems are open systems, as they exchange materials, energy, and information with their environment, or supra-systems (Friedman, 1992). The degree to which the family is open varies, and is dictated by family boundaries. Family boundaries are defined by attitudes, values or rules which affect the family's interaction with the supra-systems (Artinian, 1994). These boundaries are the means by which a family adapts to outside demands and internal needs. Input from the supra-systems is screened. The family takes the inputs it needs and uses these within the family system to survive and grow (Friedman, 1992).

Family decision making may be a characteristic that defines a family's boundaries. Family Systems theorists have examined the benefits of more open or closed boundaries. Generally, healthy families are those whose boundaries are neither too rigid nor too diffuse (Friedman, 1992). Attitudes, values, and rules defining the family's boundaries in relation to family decision making have not been addressed specifically by Family Systems Theory. However, Scanzoni and Szincovacz (1980), in their Developmental Sex Role Model, delineate the variables they purport to be involved in the family decision making process.

Scanzoni and Szincovacz (1980) state that previous decision making experiences and family contextual factors affect the decision making process. The contextual factor of sex role preference of husband and wife is the primary factor that impacts on family decision making.

They describe the traditional and modern gender role preferences that either spouse may adhere to, and their effects on decision making. Other elements included in this model are tangible resources, such as education, income, and job status, and intangible resources, such as self-esteem. These resources affect the balance of power in family relationships. Household characteristics, such as religion, interested third parties, and place in the life span are also hypothesized to affect how decisions are made within the family unit. Scanzoni and Szincovacz address household characteristics in relation to alternative lifestyles, allowing for a variety of definitions of the family.

There are four assumptions embedded in Family Systems Theory. These are:

1. The family is perceived to be greater than the sum of its parts.
2. Families have homeostatic mechanisms to maintain stability. Equilibrium is the preferred state.
3. Family systems evolve and change in response to stress inside and outside the system.
4. Individuals within the family are interdependent parts of the family system.

The theoretical framework derived from Family Systems Theory and Scanzoni and Szincovacz's (1980) developmental sex role model provide the basis for understanding the dynamics of family decision making. This will allow for examination and description of the impact particularly of symptom distress, functional ability, and family function on family decision making.

### Summary

A literature review pertaining to decision making of individuals and families who have encountered a cancer diagnosis has been presented. Individual decision making styles, although using a variety of terminology, seemed to support the theory that decision making preferences

can be conceptualized as a continuum ranging from passive to collaborative to active roles. Research focused on individual decision making preferences has been divided between studies supporting preference for active roles and those supporting passive ones. One group of patients volunteered that neither a passive nor active role was superior, but that people had to choose what was best for them. Some researchers have attempted to demonstrate positive health effects for patients who assumed an active role in decision making. This research was inconclusive, and did not address potential health effects of assuming collaborative or passive decision making stances.

Demographic variables seemed to have an association with decision making preferences. The strongest evidence showed that younger patients and those with higher educational levels preferred more active roles in decision making. Higher income and being female also have been associated with preference for active decision making stances, however the weight of this evidence is less strong. Other demographic variables have produced conflicting results, and further study needs to be done to clarify their effects. Psychological characteristics, such as emotional state and perception of their disease, have been studied in relation to decision making behaviour. Individuals who had difficulty accepting their cancer diagnosis chose passive roles.

Symptom distress and functional ability have been researched in relation to decision making preferences. In general terms, symptom distress worsens and functional ability declines as cancer advances, to the point of being predictive of survival. The limited research addressing decision making in advanced cancer suggested that patients tended to choose more passive roles in decision making.

Information is integrally related to decision making preferences. The majority of people preferred maximal amounts of information, regardless of their decision making preferences. A few studies supported the hypothesis that those who are better informed about their disease

preferred more active decisional stances. Information, in terms of amount, when and how it is presented, and how it is perceived also affected choice of decision making roles. The patient's perception of health care providers is one factor which affected how information is perceived. Studies showed that patients, for the most part, trust their physicians and are interested in knowing their physician's opinion of the best treatment option, and often follow their physician's recommendation. However, if that trust is eroded, patients tended to adopt more active decision making roles.

Families responded to cancer in a number of ways. Of paramount importance was the family's need to know that their loved one was comfortable. Secondary concerns were adequate information and support for families to enable them to help the patient. Family members of cancer patients tended to endure more psychological distress than the patients themselves. In some instances, their distress continued even once the stressful event had passed.

Family function was negatively affected by a cancer diagnosis. Role reallocation, because of the effects of cancer and its treatment on the patient, seemed inevitable. How the family coped with this reallocation seemed to depend on the resources available to the family, especially the ability of other family members to assume the patient's roles. How families managed communication and emotions varied. It seemed that open management of both communication and emotions provided a more healthy environment for the patient and family. However, one researcher identified the continuation of previous communication and emotional exchange patterns as more important than whether these patterns were open or closed.

Research of family decision making preferences has been limited. Similar decision making styles have been noted in families as in individuals, ranging from passive to collaborative to active. Families have also reported carrying previous decision making styles into the new context of cancer treatment and care. Sometimes disease circumstances forced families to

change their decision making styles, which created distress for them. Patients have identified their families, and to a lesser extent their physicians, as individuals they would want involved in their treatment decision making.

Much of the research that has been reviewed in this chapter, especially studies of the family, has utilized systems theory as a conceptual basis. Family Systems Theory provides a basis for understanding how families interact. Scanzoni and Szincovacz's (1980) model provides more specific guidance about the factors within the family that impact on decision making.

## **CHAPTER 3**

### **METHODOLOGY**

This chapter describes the methods used in this research study. The first section will discuss the choice of research design. This will be followed by a description of the study population and sample. Third, recruitment and data collection procedures will be discussed. Instrumentation will comprise the next section. This chapter will conclude with sections describing data accuracy, data analysis, and ethical considerations.

#### **Research Design**

A descriptive correlational design was used to address the research questions. The purposes of this study were:

1. to modify Degner and Sloan's (1992) Control Preference Scale (CPS), a decision making preference card sort technique, for use with cancer patients and their family members to assess patient preference for family member involvement in care decisions and family member preference for involvement in patient care decisions,
2. to assess the modified tool, the Control Preferences Scale-Family (CPS-F), for its test-retest reliability. This was accomplished by administering the CPS-F to participants twice, with one day between the first and second administration time (see Figure 2),
3. to describe patients' and families' decision making preferences, and
4. to determine differences in preferred decision making roles based on selected demographic characteristics and disease/treatment variables, level of family function, level of symptom distress, and level of functional ability.

|                                      | Time 1  |               | Time 2  |               |
|--------------------------------------|---------|---------------|---------|---------------|
|                                      | Patient | Family Member | Patient | Family Member |
| Mental Status                        | X       |               | X       |               |
| Demographic Data Forms               | X       | X             |         |               |
| CPS-F                                | X       | X             | X       | X             |
| Family Function                      | X       | X             |         |               |
| Symptom Distress                     | X       | X             |         |               |
| Functional Ability 1                 | X       | X             |         |               |
| Functional Ability 2                 | X*      | X*            |         |               |
| Decision Making Involvement Question |         | X             |         | X             |

\*Functional Ability 2 was administered only if the participant scores 100% on the Functional Ability 1 instrument.

**Figure 2.** Research Design

The independent variables in this study were: demographic variables, disease/treatment variables, patients's symptom distress, family functioning, and patient's functional ability. The dependent variables were patient and family role preferences for treatment and care decision making.

### **Population and Sample**

The population under study was patients with breast, colorectal, lung, and prostate cancer. These four cancer diagnoses represent the three most prevalent cancers in adult men and women (National Cancer Institute of Canada, 1999). Also under study was the family member that the patient identified as their most significant other in terms of decision making. The aim was to recruit a convenience sample of 60 patient-family member pairs. Based on a 3 x 2 Chi-square analysis,  $\alpha=0.05$ ,  $df=2$ , and  $n=120$  subjects, there was a 100 percent chance of detecting a large effect (0.5) and an 85 percent chance of detecting a medium effect (0.3) (Cohen, 1977).

The sample for this study was drawn from Riverview Health Centre's (RHC) palliative care unit and palliative home care program and two teaching units, Family Medical Centre (FMC) and Kildonan Medical Centre (KMC), of the Department of Family Medicine at the University of Manitoba. Recruitment proved slower than anticipated, and the plan of accessing the third teaching unit (Parklands) in Dauphin, Manitoba was deemed too difficult for data collection due to its distance from Winnipeg. Therefore a family practice clinic in Winnipeg was approached, and the Maginot Medical Centre (MMC) became the fourth recruitment site for this research project.

The following inclusion criteria were used for patients: medically diagnosed with breast, colorectal, lung, or prostate cancer; 18 years of age or older; able to speak, read, and write the English language; and a patient of one of the aforementioned recruitment sites. Patients of one physician were excluded from this study as he was the spouse of the investigator.

Criteria for the inclusion of family members were: identified by the patient as the person with whom the patient discusses decisions with the most; and able to speak, read, and write the English language.

There were two research settings for this study. The first was the palliative care unit. Patients who were on the unit and agreed to participate in this study were interviewed on the unit, as was their family member. Some patients or family members preferred to be interviewed at home and in those cases arrangements were made to facilitate this. As well, if the patient was discharged from the palliative care unit before the second data collection point, arrangements were made for the second interview to be done at the patient's home. Patients of the palliative home care program and patients of the family practice clinics were interviewed at their convenience in their homes, as was their designated family member.

### **Recruitment and Data Collection Procedures**

Verbal approval for the study was received from the patient care manager of the palliative care unit at RHC, from the coordinator of the palliative home care program at RHC, from the Director of Research at the Department of Family Medicine, University of Manitoba, and from Dr. W. Blight at the Maginot Medical Centre. Requests for access to participants were granted by N. Kasian at RHC, Dr. S. Hauch at FMC, Dr. J. Kernahan at KMC, and Dr. W. Blight at MMC.

#### **Recruitment Protocol**

**Recruitment of subjects from the palliative care unit.** The investigator provided the patient care manager of the palliative care unit with the criteria for patients and family members which would make them eligible for inclusion in this study. The investigator attended the palliative care unit three times a week to meet with the patient care manager and identified

potential subjects. Subjects who met the criteria were approached by a unit staff member to explain the study and to elicit their wish to participate, or not participate, in the study (see Appendix A). If patients were deemed incompetent (Mini Mental Status Examination score of <24/30), family members were approached directly and invited to participate in the study.

**Recruitment of subjects from the home care setting.** The investigator provided the home care office with the criteria for patients and family members which would make them eligible for inclusion in this study. If patients were deemed incompetent (Mini Mental Status Examination score of <24/30), family members were approached directly and invited to participate in the study. Participants were approached by mail. The investigator provided a letter to the home care office which requested permission to release the study participants' names to the investigator as possible participants in this study (see Appendix B). If the patient or family member did not wish their names released to the investigator, they were to contact the home care office. Once a week, the home care office provided the investigator with a list of names and telephone numbers of only those subjects who had not denied release of their names. The investigator contacted these subjects by telephone to set up a home visit appointment and to answer any questions they had about the study.

**Recruitment of subjects from the family practice clinics.** The investigator provided the designated staff member at each clinic with the criteria for patients and family members which would make them eligible for inclusion in this study (FMC and MMC had computerized databases which facilitated retrieval of patient information. KMC had no such system. Identification of eligible patients at KMC was done by reviewing the physicians' weekly appointment lists and retrieving those who were eligible.). If patients were deemed incompetent (Mini Mental Status Examination score of <24/30), family members were approached directly and invited to participate in the study. Participants were approached by mail. The investigator

provided a letter to the clinics which requested permission to release study participants' names to the investigator as possible participants in this study (see Appendix C). If the patient or family member did not wish their names released to the investigator, they were to contact the secretary. Once a week, the secretary provided the investigator with a list of names and telephone numbers of subjects who had not denied release of their names. The investigator contacted these subjects by telephone to set up a home visit appointment and to answer any questions they had about the study.

**Non-participants.** In order to compare participants with non-participants, the age, diagnosis, sex, and recruitment location were noted for those patients who chose not to participate.

#### **Data Collection Protocol**

Following are the protocols for data collection. Although the protocols are discussed as if both patient and family member were always present at the same time, there were some occasions in which the two were interviewed on the same days, but at different locations. Two experienced registered nurses assisted with some of the data collection.

**Palliative care unit.** If the patient and family member agreed to participate, the investigator and participant chose a time to meet. At the time of the meeting, the investigator provided a written consent for the patient (see Appendix D) and a disclaimer for the family member (see Appendix E). Once the consent and disclaimer had been read, understood, and signed, the patient and family member were administered the instruments. Once all the instruments were completed, the investigator arranged a time for a return visit the following day.

**Home care program.** If the patient and family member agreed to participate, a home visit was scheduled at a convenient time. At the first home visit, the investigator provided a

written consent for the patient (see Appendix D) and a disclaimer for the family member (see Appendix E). Once the consent and disclaimer had been read, understood, and signed, the patient and family member had the instruments administered. Once all instruments were completed, the investigator arranged a time for a return home visit the following day.

**Family practice clinics.** If the patient and family member agreed to participate, a home visit was scheduled at a convenient time. At the home visit, the investigator provided a written consent for the patient (see Appendix D) and a disclaimer for the family member (see Appendix E). Once the consent and disclaimer had been read, understood, and signed, the patient and family member had the instruments administered. Once all instruments were completed, the investigator arranged a time for a return home visit the following day.

### **Instruments**

Eight instruments were used in this study (see Figure 2). The first examined the patients' mental status. The second measured demographic characteristics of the participants. The third instrument measured patients' and family members' decision making role preferences and were completed by both patients and family members. Measures of family function, symptom distress, and functional ability were also be filled out by all participants. The final instrument was administered to family members only; it elicited family members' perceptions of their ill family members' involvement in decision making. All participants were requested to complete the instruments without conferring with their family member. This was done to capture each individual's responses, unaffected by their family member's opinions.

#### **Folstein Mini-Mental Status Examination (MMSE)**

The Folstein Mini-Mental Status Examination (Folstein, Folstein, & McHugh, 1975) (see Appendix F) was administered at the outset of both interviews to assess the patients' ability to respond reliably. Folstein et al. reported a mean of 27.6/30 for normal elderly persons and means

of 9, 7, 19, and 25 for patients with dementia, depression with cognitive impairment, and affective disorders respectively, supporting the measure's discriminant validity. Test-retest reliability was also reported by Folstein et al. Bruera, Fainsinger, Miller, and Kuehn (1992) reported that patients capable of responding reliably on self-reports of pain intensity had scores of 24/30 or higher on the MMSE. Patients were interviewed for this study if their score was equal to or greater than 24/30. Completion of this measure required approximately five minutes.

### **Demographic Data Forms**

Demographic data was obtained from patients (see Appendix G) and family members (see Appendix H) at the first interview in order to describe the sample and to determine if relationships existed between certain demographic variables and decision making role preferences. The demographic variables which have been identified as having a relationship with decision making role preferences include age, level of education, and income level. Gender and religiosity have been suggested as other variables, but the evidence is not as strong as for the first three. Rationale for examination of these potential relationships have been described in Chapter 2. Completion of the demographic data forms took approximately five minutes.

### **Control Preferences Scale - Family (CPS-F)**

The CPS-F was modified from Degner et al.'s (1997b) Control Preferences Scale (CPS). The CPS uses a measurement model referred to as unfolding theory. Unfolding theory (Coombs, 1976) is based on the hypothesis that each person has a particular position, called an "ideal point", on a psychological continuum. This ideal point (I scale) can be determined by engaging the person in paired comparisons of stimuli which fall on this continuum. Degner et al.'s CPS is predicated on the hypothesis that individuals have systematic preferences, which form a continuum, for keeping (active), sharing (collaborative), or giving away (passive) decision making control for health care choices (Degner & Beaton, 1987).

The CPS consists of five cards, each containing a statement describing one of five potential roles in decision making (see Appendix I). Role preferences range from the patient keeping control (active) through shared control between patient and physician (collaborative) to giving away control to the physician (passive). The CPS is easy to administer and has demonstrated reliability and validity (Beaver et al., 1996; Davison & Degner, 1997; Davison et al., 1995; Degner & Sloan, 1992; Degner et al., 1997a; Hack et al., 1994).

Degner and colleagues (1997b) described three methods for administering the card sort. The “comparing every possible subset of two” method was deemed too burdensome for the sample being studied. The “random-order presentation of cards” was rejected because of its higher error measurement and because a direct test of the hypothesis was required to demonstrate the psychometric properties of the CPS-F. The “fixed order presentation” was chosen because of its utility in clinical populations and its shorter time period for administration.

The five cards of the CPS-F (see Appendix J and Appendix K) each described a role (active, collaborative, passive) that a person could assume in making decisions about care. Each card was assigned a letter (A,B,C,D,E) and was placed in a fixed order: BDCEA. The first two cards presented to the subject were B and D. The subject was asked to choose the preferred card. Degner et al.’s (1997b) card sort procedure continues as follows:

The preferred card is placed on top on the nonpreferred card. Then the next card is removed from the deck and placed beside the new stack of two cards. The subject is asked to compare the new card with the most preferred card. If the subject still prefers the previous card over the new one, the previous card is flipped over and the new card is compared to the next one in the new stack. If the subject prefers the new card, it is placed between the two cards in the new stack; if the previous second card is preferred, the new one is placed last in the new stack. The process continues until the subject’s

entire preference order is unfolded (pp. 9-10).

One hundred twenty permutations are possible with a five item scale, but only eleven of these are valid. The valid permutations of the CPS, from most active to least active, are: ABCDE, BACDE, BCADE, BCDAE, CBDAE, CDBAE, CDBEA, CDEBA, DCEBA, DECBA, and EDCBA. If one of the eleven valid permutations is chosen, the response is said to have fallen on the metric. A proportion of 50 % plus one valid preference orders are required to justify the acceptance of the scale (Degner et al.). As well, Coombs (1976) required a reversal to be present to justify the scale. That is, both extremes of the scale (ABDCE, EDCBA), which are reversals of each other, must be present.

One further question was asked of participants regarding the CPS-F, the “pick one” question. The five cards were placed in front of the participants, from most active role to least active. The participants were asked to indicate which of the five cards best represented their most preferred decision making role.

Patients and family members completed the CPS-F at both interviews. The patient and family member completed the CPS-F independently of each other. They were asked to not discuss the card sort with each other until after the second administration of the instrument. The CPS-F took approximately five minutes to administer.

#### **Family Assessment Device (FAD)**

The FAD (Epstein, Baldwin, & Bishop, 1983) is a measure of family function. The FAD reflects the six dimensions described in Epstein, Bishop, and Levin’s (1978) McMaster Model of Family Functioning (MMFF). The MMFF is a clinically oriented, systems theory-based conceptual model of family functioning. The originators of the MMFF believe healthy family function can be described by a set of positive attributes: problem solving, the families’ ability to resolve problems and the steps used to do so; communication, the effectiveness, extent, clarity,

and directness of the families' information exchange; roles, the allocation and accomplishment of family tasks; affective responsiveness, the families' ability to experience emotions; affective involvement, the families' concern and empathy for one another; and behaviour control, the families' standards and latitude for appropriate behaviour (Epstein et al., 1978).

Psychometric testing has been carried out on the FAD. Internal consistency reliability for the sub-scales, measured by Cronbach's alpha, ranged from 0.72 to 0.92 (Epstein et al., 1983). Miller, Epstein, Bishop, and Keitner (1985) conducted test-retest reliabilities which ranged from 0.66 to 0.76, indicating acceptable reliability. Discriminant validity has been demonstrated by Epstein et al. as well as by Sawyer, Sarris, Baghurst, Cross, and Kalucy (1988). The FAD has been used primarily as a research tool in a wide variety of populations (Arpin et al., 1990; Friedman et al., 1997; Gowers, Jones, Kiana, North, & Price, 1995; Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990; Keitner et al., 1995; Kreutzer, Gervasion, & Camplair, 1994; Morris, 1990; Stevenson-Hinde & Akister, 1995; Waller, Slade, & Calam, 1990).

The general functioning sub-scale of the FAD has been identified as a quick measure of overall health or pathology of the family (Tutty, 1995). This sub-scale consists of 12 items: one from problem solving, four from communication, two from roles, one from affective responsiveness, three from affective involvement, and one from behaviour control (Epstein et al., 1983). Miller et al. (1985) found that a score of  $\leq 2.0/4.0$  was the cut-off point for healthy families. Byles, Byrne, Boyle, and Offord (1988) tested this sub-scale in a random sample of 1,869 Ontario families and found that construct validity and internal consistency reliability were supported. Subsequently, Kristjanson et al. (1997) found high internal consistency (Cronbach's  $\alpha=0.93$ ) for this sub-scale. The general functioning sub-scale of the FAD was the instrument used to assess family function in this study (see Appendix L).

The FAD general functioning sub-scale (FAD-GFS) was administered to all participants

during the first interview. This 12-item questionnaire has a Likert-type scale with four response options: strongly agree, agree, disagree, and strongly disagree. The FAD-GFS took approximately five minutes to complete.

### **Symptom Distress Scale (SDS)**

McCorkle and Young's (1978) Symptom Distress Scale (SDS) consists of 13 symptoms (see Appendix M). Each symptom is described on a 5 x 7-inch card with a five-point Likert-type format ranging from 1 (normal or no distress) to 5 (extreme distress). Descriptive words operationalize each point on the scale. The SDS is scored cumulatively, with the lowest symptom distress score being 13 and the highest being 65. This scale was developed in a population of ambulatory cancer patients, and reliability levels have been assessed by Cronbach's alpha ranging from 0.74 to 0.90 (Kristjanson et al., 1998; Lobchuk et al., 1997; McCorkle & Quint-Benoliel, 1983; McCorkle et al., 1989; McCorkle & Young, 1978; Peruselli et al., 1993). The SDS has been used widely in oncology populations as a research and clinical tool (Kristjanson et al., 1998; Lawrence, Gilbert, & Peters, 1996; Lobchuk & Kristjanson, 1997; Lobchuk et al., 1997; McCorkle, Hughes, Robinson, Levine, & Nuamah, 1998; Peruselli, Paci, Franceschi, Legori, & Mannucci, 1997; Sarna, 1998; Sarna & Brecht, 1997; Whelan et al., 1997).

The SDS was completed by all participants at the first interview. Most participants completed the SDS as a paper-and-pencil exercise as it appears in Appendix M. If patients were too weak to complete the SDS independently, the SDS was presented in a "flash card" format. Participants were instructed to choose the one response of five possible responses that best reflected their, or their ill family member's, level of symptom distress for each of 13 symptoms. The investigator recorded their responses. Cohen and Mount (1992) suggested that when asking patients in the palliative stage of illness to rate symptom distress, asking the question in the context of "over the past two to three days" may provide the truest response. Given this

information, participants in this study were asked to rate their, or their ill family member's, level of symptom distress based on how they have been feeling for the past two to three days. The SDS required approximately five minutes to complete when done as a paper-and-pencil task. It required more time if the investigator used the flash card format.

### **Katz Index of Activities of Daily Living (Katz Index)**

The Katz Index (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) assesses independence in six activities: bathing, dressing, toileting, transfer, continence, and feeding (see Appendix N). It was originally developed for use in elderly persons with stroke or hip fracture (Katz et al.), but has frequently been used to measure severity of illness, to evaluate the effectiveness of treatment, and to predict the course of illness (McDowell & Newell, 1987). Scoring involves translating the three-point scale responses into a "dependent/independent" classification. The overall performance is then summarized as one of eight categories, indicating amount of dependency and its relative importance (Katz, Downs, Cash, & Grotz, 1970). A simplified scoring system counts the number of activities in which the person is dependent, resulting in a scale from zero to six (0=independent in all six functions; 6=dependent in all six functions) (Katz, S. & Akpom, C. A., 1976).

Katz et al. (1963) assessed inter-rater reliability, reporting that differences between observers occurred once in 20 evaluations or less. Guttman analyses were done in Sweden on 100 patients, with the coefficient of scalability ranging from 0.74 to 0.88 (Brorsson & Asberg, 1984). Their scalability findings suggest that the Katz Index forms a cumulative scale. Although limited reliability or validity testing has been reported, it is one of the tools most tested (Kidd & Yoshida, 1995) and is the most widely used of all the functional indices (McDowell & Newell, 1987).

An attempt was made to find a measure of functional ability that has been used specifically with cancer populations. A number were found, however they were generally long (22-139 items). These instruments (Affleck, Aitken, Hunter, McGuire, & Roy, 1988; Cella et al., 1993; Schag & Heinrich, 1988; Schipper, Clinch, & McMurray, 1984) also included items other than those strictly related to a narrow definition of functional ability (marital, sexual, and psychosocial domains). Given the shortcomings of the tools designed for cancer populations, the proven utility of the Katz Index in geriatric populations (Katz et al., 1963; Katz et al., 1970), which the sample in this study will primarily be, and the beginning use of the Katz Index in oncology populations (Peruselli et al., 1997), the Katz Index (Katz et al., 1963) was used in this study.

The Katz Index was completed by all participants at the first interview. Most participants completed it as a paper-and-pencil exercise as it appears in Appendix N. If patients were too weak to complete the Katz Index independently, it was presented in a "flash card" format. Participants were instructed to choose the response that best reflected their, or their ill family member's, level of functional ability for each of the six activities. The investigator recorded their responses. Katz et al. (1970) directed investigators to instruct the participants to record the most dependent degree of performance during a two-week period. Given Cohen and Mount's (1992) recommendation for palliative populations, participants will be instructed to base their responses on the most dependent degree of performance in the past two to three days. The Katz Index took three to five minutes to complete.

#### **Five Instrumental Activities of Daily Living (IADL)**

This study included patients with a wide range of functional abilities. The Katz Index (Katz et al., 1963) assessed rudimentary activities of daily living. While the Katz Index may be sensitive in a palliative population where patients are quite limited in their abilities, the scale

does not distinguish differences in patients with higher functioning, such as home care or ambulatory patients (McDowell & Newell, 1987). A second tool, the IADL (Fillenbaum, 1985), was used to distinguish higher levels of function.

The IADL (Fillenbaum, 1985) is a screening tool used to assess independence in activities required for independent living. The tasks included in this tool are more complex and demanding than those found in the Katz Index (Katz et al., 1963). The five items assessed in the IADL are travelling, shopping, meal preparation, housework, and handling money (see Appendix O). The IADL is a Guttman scale, with the coefficient of scalability ranging from 0.68 to 0.76. The order of items from most difficult to least difficult is housework, travel, shopping, finances, and cooking. The IADL is scored out of five. A score of 5/5 indicates independence in all five functions; a score of 0/5 indicates dependence in all five (Fillenbaum).

The IADL was administered to participants whose score on the Katz Index was 0/6, indicating independence in all six functions. Participants completed the IADL as a paper-and-pencil exercise as it appears in Appendix O. Participants were instructed to choose the response that best reflected their, or their ill family member's, level of ability for each of the five activities. The investigator recorded the responses. Given Cohen and Mount's (1992) recommendation for palliative populations, participants were instructed to base their responses on the most dependent degree of performance in the past two to three days. The IADL took less than five minutes to complete.

#### **Decision Making Involvement Question**

A single question was asked of family members at both Time 1 and Time 2 to elicit their perception of how involved their ill family member actually was in treatment and care decision making (see Appendix P). Their response was graded as a four point scale. There was room for comments on the questionnaire page as well.

### **Data Accuracy**

All interview data in this study was entered into the Statistical Package for the Social Sciences (SPSS) for analysis. The accuracy of the data was assessed and enhanced using three methods. First, the entire SPSS data set was visually checked for missing values. The missing data points were checked against the interview instruments. This procedure reduced the set of missing values to those where the information was not provided by the study participants.

Second, to verify data accuracy, ten percent (13 out of 127) of the original interviews were randomly selected and checked against the data entered into the SPSS database. The error rate for data entry was 0.18 % (two errors in 13 interviews, each with a total of 84 data points).

Third, using SPSS, frequency counts were run on all the variables. This procedure identified "out of bound" errors. Several data entry errors of this type were discovered and corrected.

### **Data Analysis**

The data was analyzed in three phases. First, descriptive statistics were used to describe the characteristics of the sample. Frequency distributions, ranges, means, and standard deviations were examined.

Second, psychometric properties of the CPS-F were assessed to answer Research Question 1: To what extent is the CPS-F a reliable measure of patient preference for family member involvement in their care decisions and family member preference for involvement in patient care decisions? Using unfolding theory, dimensionality of the CPS-F was examined at each time point for patients and family members. If 50 % plus one of the subjects' preference orders fell on the metric, the CPS-F was considered justified (Degner et al., 1997).

To assess test-retest reliability, patients and family members whose preference orders fit

the model, as outlined in the description of the CPS-F, were assigned an ordinal score from one to eleven. The Time 1 and Time 2 scores were correlated to determine if a significant relationship exists ( $p < 0.05$ ). Further confirmation of the CPS-F's stability over time was tested by examining subjects' "first choice" role preference (the first letter of the string variable) at Time 1 and Time 2. Spearman's rho (Hassard, 1991) was used to examine the test-retest reliability. The "pick one" role preference elicited when placing the five cards in front of the participant was also examined for its test-retest reliability.

Convergent validity of the CPS-F was also examined. The two "first choice" preferences elicited using the card sort procedure and the "pick one" preferences were correlated to assess the convergent validity. The "pick one" procedure is quicker than the card sort procedure, and thus favourable in clinical situations. If the "pick one" procedure is found to be as accurate as the card sort procedure in determining role preferences, the "pick one" procedure could be used clinically.

Psychometric properties of other instruments were also examined. Cronbach's alpha coefficient was used to assess the internal consistency of the MMSE, SDS, and FAD. For well-established instruments, the criterion level for the coefficient alpha was 0.80 or above (Burns & Grove, 1993).

The third phase of data analysis was to address the remaining two research questions. Research Question 2 asked: What role do family members prefer to play in decision making with respect to a family member with cancer and what role do cancer patients prefer their family members to play with respect to their care decisions? This question was answered by examining the data used to determine the CPS-F's psychometric properties. That is, the preference orders that subjects expressed in the card sort procedure, as well as their "first choice" and "pick one" role preferences answered this question.

Research Question 3, “What variables are related to family member and cancer patient choice of decision making role?”, was answered by examining relationships between the CPS-F responses and demographic data, FAD, SDS, Katz Index, and IADL scores using the Chi-square.

### **Ethical Considerations**

Written permission from the Ethical Review Committee of the Faculty of Nursing, University of Manitoba, was sought and received. All study participants received verbal and written information about the study. Participants were informed of the voluntary nature of their involvement, and of their ability to withdraw at any point during the study. Assurance was provided that participation or non-participation would not influence the care patient-subjects received.

Patient-subjects signed a written consent; family member-subjects were given a written disclaimer. Copies of signed consents have been stored in a locked drawer, accessible only to the investigator. Information on questionnaires was identified by a coded number, not by subject name. The list of subject names and code numbers were kept in a separate locked drawer from the data with code numbers. Raw data was accessible only to the investigator and her thesis committee. Another protection for subject confidentiality was to group any data where the cell size is less than five subjects. All this data will be kept under lock for seven years.

The external member of the investigator’s thesis committee, Dr. M. Harlos, no longer has a clinical practice at the Riverview Health Centre. No instances of his clinical involvement with study subjects occurred, and therefore no concern of coercion based on power relationships. Dr. B. Kvern, a family physician at one of the family practice clinics of the Department of Family Medicine, University of Manitoba, is the spouse of the investigator. As a result, none of his patients were to be approached to be subjects in this study to avoid concern of coercion based on a power relationship. However, some of Dr. Kvern’s patients were inadvertently sent letters of

invitation to participate in this study. Upon discovery of this, the investigator drafted a letter to apologize to those patients, indicating the letters were sent in error and that they did not meet the inclusion criteria.

Participation in this study may have sensitized participants to unresolved issues with relation to decision making. For example, a patient and family member may have had conflicting views on how the family ought to manage care decisions, and completing the CPS-F and FAD may have caused these views and feelings to surface. If such a situation arose, the participant(s) were to be offered a referral to an appropriate health care professional from their site of origin (i.e. Riverview Health Centre or the teaching units). No such situations arose.

### **Summary**

This chapter has described the methods that were used to conduct a study into family preferences in care decision making. The CPS-F enabled the investigator to understand the role patients and family members want to assume in care decisions. The FAD, SDS, Katz Index, and IADL assisted in determining relationships between family function, symptom distress, and functional ability and decision making preferences.

## **CHAPTER 4**

### **FINDINGS**

This chapter reports the findings of this study. The first section will describe the demographic characteristics of the study participants. Known characteristics of the non-participants will be compared to those of the participants. The final sections of this chapter will present results pertaining to each of the research questions in turn:

**Research Question 1: To what extent is the CPS-F a reliable measure of patient preference for family member involvement in their care decisions and family member preference for involvement in patient care decisions?;**

**Research Question 2: What role do family members prefer to play in decision making with respect to a family member with cancer and what role do cancer patients prefer their family members to play with respect to their care decisions?; and**

**Research Question 3: What variables are related to family member and cancer patient choice of decision making role?**

#### **Study Sample**

Data were collected from January 1997 to June 1997 and from October 1997 to March 1998. Participants were recruited from five sites - two palliative care programs and three family practice clinics. The palliative care programs were the Riverview Palliative Care Unit (PCU) and the Riverview Palliative Home Care Program (PHC). The three family practice clinics were Family Medical Centre (FMC), Kildonan Medical Centre (KMC), and Maginot Medical Centre (MMC).

A total of 180 patients were recruited to participate in this study (selection criteria have been described in Chapter 3). Of the 180 patients, 64 consented to the study (non-participants

will be discussed later in this section). Three of the 64 participants were eliminated from the analysis. Two patients died before the second interview could be done and before their identified family member could be contacted. A third patient did not meet the inclusion criteria. These three participants were removed from the study and data analysis was carried out on the remaining 61 patients and their family members. Table 1 describes the recruitment location of study participants.

Table 1: Recruitment Location of Study Participants

| Recruitment Location     | Frequency | Valid % |
|--------------------------|-----------|---------|
| RHC Palliative Care Unit | 13        | 21.7    |
| RHC Palliative Home Care | 8         | 13.3    |
| Family Medical Centre    | 12        | 20.0    |
| Kildonan Medical Centre  | 11        | 18.3    |
| Maginot Medical Centre   | 16        | 26.7    |
| Missing                  | 1         | 0       |
| TOTAL                    | 61        | 100.0   |

### Demographic Characteristics of Participants

**Patients:** The patient sample can be described as older, with two thirds being 60 years of age or older, and over half being retired. There were similar numbers of men and women. A substantial proportion of the patients were married (74.6%). This sample of patients was reasonably well-educated, with one third having completed high school and another third having continued on to college (see Table 2). The modal household income for patients was \$21,000-30,000 (see Table 3). The median was \$31,000-40,000. The ethnic and religious backgrounds of the patients were quite homogenous. Greater than 80% of the sample identified themselves as

Table 2: Demographic Characteristics of Study Participants

| Characteristic        | Patients  |         | Family Members |         |
|-----------------------|-----------|---------|----------------|---------|
|                       | Frequency | Valid % | Frequency      | Valid % |
| <b>Age</b>            |           |         |                |         |
| 18-29 years           | 0         | 0       | 1              | 1.6     |
| 30-39                 | 0         | 0       | 5              | 8.2     |
| 40-49                 | 11        | 18      | 16             | 26.2    |
| 50-59                 | 8         | 13.1    | 15             | 24.6    |
| 60-69                 | 19        | 31.1    | 14             | 23      |
| ≥70                   | 23        | 37.7    | 10             | 16.4    |
| <b>Sex</b>            |           |         |                |         |
| Male                  | 29        | 47.5    | 21             | 34.4    |
| Female                | 32        | 52.5    | 40             | 65.6    |
| <b>Marital Status</b> |           |         |                |         |
| Married/Common-law    | 44        | 74.6    | 53             | 86.9    |
| Divorced/Separated    | 4         | 6.8     | 1              | 1.6     |
| Never married         | 3         | 5.1     | 5              | 8.2     |
| Widow(er)             | 8         | 13.6    | 2              | 3.3     |
| Missing               | 2         | 0       | 0              | 0       |
| <b>Education</b>      |           |         |                |         |
| ≤Grade 8              | 7         | 12.1    | 6              | 9.8     |
| Some high school      | 14        | 24.1    | 12             | 19.7    |
| High school graduate  | 17        | 29.3    | 12             | 19.7    |
| Some college          | 3         | 5.2     | 11             | 18      |
| College graduate      | 12        | 20.7    | 10             | 16.4    |
| Graduate degree       | 5         | 8.6     | 10             | 16.4    |
| Missing               | 3         | 0       | 0              | 0       |

Table 3: Secondary Demographic Characteristics of Study Participants

| Characteristic           | Patients  |         | Family Members |         |
|--------------------------|-----------|---------|----------------|---------|
|                          | Frequency | Valid % | Frequency      | Valid % |
| Income                   |           |         |                |         |
| <\$20,000                | 13        | 21.8    | 5              | 8.3     |
| \$21,000-40,000          | 24        | 42.1    | 23             | 38.3    |
| \$41,000-60,000          | 9         | 15.8    | 16             | 26.7    |
| >\$60,000                | 11        | 19.3    | 16             | 26.7    |
| Missing                  | 4         | 0       | 1              | 0       |
| Occupation               |           |         |                |         |
| Homemaker                | 6         | 10.2    | 11             | 18      |
| Professional             | 11        | 18.6    | 18             | 29.5    |
| Retired                  | 31        | 52.5    | 13             | 21.3    |
| Other                    | 11        | 18.7    | 19             | 31.1    |
| Missing                  | 2         | 0       | 0              | 0       |
| Ethnic Group             |           |         |                |         |
| European                 | 21        | 36.2    | 19             | 31.1    |
| British                  | 23        | 39.7    | 28             | 45.9    |
| French                   | 8         | 13.8    | 4              | 6.6     |
| Aboriginal               | 2         | 3.4     | 2              | 3.3     |
| Asian                    | 0         | 0       | 0              | 0       |
| Other(includes Canadian) | 4         | 6.9     | 8              | 13.1    |
| Missing                  | 3         | 0       | 0              | 0       |

Table 3: Secondary Demographic Characteristics of Study Participants (cont)

| Characteristic | Patients  |         | Family Members |         |
|----------------|-----------|---------|----------------|---------|
|                | Frequency | Valid % | Frequency      | Valid % |
| Religion       |           |         |                |         |
| Catholic       | 25        | 43.1    | 17             | 27.9    |
| Protestant     | 22        | 37.9    | 29             | 47.5    |
| Jewish         | 1         | 1.7     | 0              | 0       |
| Other          | 0         | 0       | 6              | 9.8     |
| None           | 10        | 17.2    | 9              | 14.8    |
| Missing        | 3         | 0       | 0              | 0       |

European, British, or French, and only 3.4% identified themselves as Aboriginal, 6.9% as other, and zero as Asian. Over 80% of the patients indicated an affiliation with the Catholic or Protestant faiths. Table 4 describes clinical characteristics of the patients. Patients were fairly equally distributed between the four diagnostic categories, with breast cancer being slightly over represented and colorectal cancer slightly under represented. Similarly, there was equal distribution with respect to time since cancer diagnosis. Approximately one third of the study participants were within a year from diagnosis, another third were one to five years since diagnosis, and the final third were greater than five years since diagnosis. To summarize, the patient group could be characterized as older, retired, married, middle-income, well-educated European Christians with cancer.

**Family members:** Table 2 shows that the family member group was younger than the patient sample with one half of the family members being between 40 and 59 years old. Another quarter of the group was 60 to 69 years of age. Women were better represented than men in the family member group, comprising two thirds of the total. Most (86.9%) of the family members

Table 4: Clinical Characteristics of Study Participants

| Characteristic                 | Patients  |         | Family Members |         |
|--------------------------------|-----------|---------|----------------|---------|
|                                | Frequency | Valid % | Frequency      | Valid % |
| <b>Diagnosis</b>               |           |         |                |         |
| Breast                         | 21        | 34.4    |                |         |
| Colorectal                     | 9         | 14.8    |                |         |
| Lung                           | 15        | 24.6    |                |         |
| Prostate                       | 16        | 26.2    |                |         |
| <b>Time Since Diagnosis</b>    |           |         |                |         |
| <6 months                      | 10        | 16.7    |                |         |
| 6-12 months                    | 10        | 16.7    |                |         |
| 1-3 years                      | 14        | 23.3    |                |         |
| 3-5 years                      | 8         | 13.3    |                |         |
| >5 years                       | 18        | 30      |                |         |
| Missing                        | 1         | 0       |                |         |
| <b>Relationship to Patient</b> |           |         |                |         |
| Spouse                         |           |         | 42             | 68.9    |
| Son                            |           |         | 1              | 1.6     |
| Daughter                       |           |         | 10             | 16.4    |
| Sibling                        |           |         | 2              | 3.3     |
| Other                          |           |         | 6              | 9.8     |

were married. One fifth of this group completed high school, and over half this group continued with post-secondary education. The family members as a group were more affluent than the patient group; their modal household income was greater than \$60,000 and their median was \$41,000-50,000. Only a fifth of the family members were retired. Managers and professional workers comprised over a third of this group, and another fifth identified themselves as

homemakers. Like the patient group, the family members also were homogenous with respect to ethnic and religious backgrounds. Over 80% identified themselves as European, British, or French and about three quarters identified themselves as Catholic or Protestant (see Table 3). Table 4 displays that the relationship to the patient was most commonly spousal (68.9%). To summarize, the family member group could be characterized as middle-aged, married, affluent women who are well-educated, of European descent and Christian.

### Non-participants

A total of 180 patients were recruited to participate in this study. Table 5 shows that sixty-four (35.6%) patients consented (three were later eliminated) to participate in the study; 116 (64.4%) did not consent. Non-participants were fairly equally distributed between recruitment sites (10 to 20%), with the exception of the PHC which represented 35.3% of the non-participants. The participant and non-participant groups were compared on their known characteristics. Using the Mann-Whitney U, there were no significant differences between the two groups with respect to diagnosis, sex, or recruitment location. There was, however, a significant difference for age ( $p=0.015$ , two-tailed); the non-participant group was older than the participant group.

Table 5: Participants and Non-Participants by Recruitment Location

| Location | Participants |         | Non-Participants |         | %Yes |
|----------|--------------|---------|------------------|---------|------|
|          | N            | Valid % | N                | Valid % |      |
| PCU      | 15           | 23.8    | 21               | 18.1    | 38.2 |
| PHC      | 8            | 12.7    | 41               | 35.3    | 16.3 |
| FMC      | 12           | 19      | 19               | 16.4    | 38.7 |
| KMC      | 11           | 17.5    | 12               | 10.3    | 47.8 |
| MMC      | 17           | 27      | 23               | 19.8    | 41   |
| Missing  | 1            | 0       | 0                | 0       | 0    |
| TOTAL    | 64           | 100     | 116              | 100     | 100  |

### Psychometric Testing

#### Control Preferences Scale - Family (CPS-F)

Potentially, 122 participants (61 patients, 61 family members) could have completed the CPS-F. However, at Time 1, six respondents failed the MMSE so the remainder of the interview was not conducted, and one respondent refused to complete the CPS-F. At Time 2, in addition to the seven respondents noted at Time 1, one respondent was unable to complete the CPS-F due to fatigue. Therefore, 115 participants completed the CPS-F at Time 1 and 114 at Time 2.

**Dimensionality.** Among the patient group at Time 1, 34/54 (63.0%) were on the metric. At Time 2, 37/53 (69.8%) were on the metric. Both of these percentages meet the criteria of 50% plus one (Coombs, 1976), supporting the unidimensionality of the underlying construct of keeping, sharing, or ceding decisional control. There was no reversal present in the patient group; the most active end (ABCDE) of the continuum was present, but not the most passive end (EDCBA).

For family members at Time 1, 45 of 61 (73.8%) responses were on the metric. At Time 2, 48/61 (78.7%) were on the metric. A reversal was present in the family member group. The percentage of responses on the metric by both groups, at both interview times, met the criteria of 50% plus one (Coombs, 1976), thereby supporting the unidimensionality of the construct.

**Test-Retest Reliability.** Two measures of test-retest reliability were undertaken to assess the CPS-F's stability over time. First, responses that fell on the metric were assigned an ordinal score from one (string variable ABCDE, indicating most active stance) to eleven (string variable EDCBA, indicating most passive stance). The ordinal scores for patients were compared from Time 1 to Time 2 and were found to be similar (Spearman's  $\rho = 0.896$ , two-tailed  $p = 0.01$ ), supporting the CPS-F's reliability. The family member group scores, too, were correlated (Spearman's  $\rho = 0.832$ , two-tailed  $p = 0.01$ ), thereby also supporting the CPS-F's reliability.

In order to further confirm the CPS-F's stability over time, test-retest reliability was carried out on the first letter of the string variable of those participants whose responses fell on the metric. The patient group demonstrated good correlation of Time 1 and Time 2 results (Spearman's  $\rho = 0.750$ , two-tailed  $p = 0.01$ ). The family member group demonstrated high correlation as well (Spearman's  $\rho = 0.864$ , two-tailed  $p = 0.01$ ). Therefore reliability of the CPS-F is further supported, based on the first letter in the string variable.

Test-retest reliability of the "pick one" procedure at Time 1 and Time 2 was also examined. The "pick one" procedure followed the card sort procedure. It involved the participant looking at all five cards laid on a table and being asked to pick the card which most closely reflected their decision making preference. Correlation for the patient group supported the reliability of the "pick one" method (Spearman's  $\rho = 0.864$ , two-tailed  $p = 0.01$ ). The family group also showed a significant correlation (Spearman's  $\rho = 0.610$ , two-tailed  $p = 0.01$ ).

**Convergent validity.** The first letter of the string variable was examined in relation to the “pick one” letter, for those responses that fell on the metric, at Time 1 and Time 2. For the patient group, no difference between Time 1 responses was noted (Wilcoxon signed rank sum = 15.00, two-tailed  $p = 0.317$ ). Time 2 responses approached a significant difference (Wilcoxon signed rank sum = 4.00, two-tailed  $p = 0.059$ ). Similar results were noted for the family member group (Time 1: Wilcoxon signed rank sum = 27.50, two-tailed  $p = 1.000$ ; Time 2: Wilcoxon signed rank sum = 0.00, two-tailed  $p = 0.059$ ).

#### **Folstein Mini-Mental Status Exam (MMSE)**

**Internal consistency.** Cronbach’s alpha was used to determine the internal consistency of the MMSE, which was administered to the patient group at both interviews. At Time 1, the alpha coefficient was 0.78. At Time 2, it was 0.56. The Time 1 alpha score approaches the 0.80 criterion value for reliability (Burns & Grove, 1993), but the Time 2 score does not. However, only those patients who scored 24/30 or greater were administered the MMSE at Time 2, which decreased the variability (MMSE at Time 1: mean =27.69, variance=14.78, s.d.=3.84; MMSE at Time 2: mean=29.17, variance=1.95, s.d.=1.40) of the possible scores and thus drove down the alpha score.

#### **Family Assessment Device (FAD)**

**Internal consistency.** Both the patient and family member groups completed the FAD at the first interview. The Cronbach’s alpha for the patient group was 0.84, and 0.89 for the family member group. The aggregate data from both groups resulted in an alpha of 0.87. These alpha scores are reliable based on a criterion value of 0.80 (Burns & Grove, 1993) for established instruments.

### Symptom Distress Scale (SDS)

**Internal consistency.** Both the patient and family member groups completed the SDS at Time 1. The alpha for the patients was 0.80, and 0.86 for the family members. The aggregate data from both groups resulted in an alpha of 0.86. These alpha scores are reliable based on a criterion value of 0.80 (Burns & Grove, 1993).

### **Preferences for Participation in Decision Making**

#### **Patients**

At Time 1, the most common choice that fell on the metric was BCADE (10/54 or 18.5%). This reflected a desire of patients to take an active role in decision making in relation to their family member. Table 6 displays the distribution of patient decision making preferences.

Table 6: Decision Making Preferences - Patients

| Letter | First Letter of String Variable |        | "Pick One" Letter |        |
|--------|---------------------------------|--------|-------------------|--------|
|        | Time 1                          | Time 2 | Time 1            | Time 2 |
| A      | 23.4%                           | 29.7%  | 16.7%             | 18.9%  |
| B      | 52.9                            | 45.9   | 44.4              | 41.5   |
| C      | 23.5                            | 21.6   | 33.3              | 35.8   |
| D      | 0                               | 2.7    | 3.7               | 1.9    |
| E      | 0                               | 0      | 1.9               | 1.9    |

23.4% of the valid strings had A as the first letter, 52.9 % had B, and 23.5% had C. There were no valid strings with a passive stance; that is, no D or E as the first letter of the string. Therefore, fully three quarters of the patients chose to take an active stance (letter A or B) in decision making with their family member. The remaining quarter chose a collaborative (letter C) decision making stance, and no one chose a passive role.

At Time 2, the most common valid choice was ABCDE (11/53 or 20.8%). Here, 29.7%

of the valid strings had A as the first letter, 45.9% had B, 21.6% had C, and 2.7% had D (see Table 6). No one chose a valid string beginning with E. Again, three quarters of the patients chose an active stance in decision making with their family member. Slightly less than one quarter chose a collaborative stance, and a single patient participant chose a passive stance. There was a trend from Time 1 to Time 2 of patients moving to a more active decision making stance.

Table 6 displays the results of the “pick one” responses as well. The modal choice was card B (44.4%). Collapsing the responses into the three categories of active, collaborative, and passive, 61.1% chose an active stance, 33.3% collaborative, and 5.6% passive.

The “pick one” responses at Time 2 were similar (see Table 6). Again, the modal choice was card B (41.5%). An active stance was chosen by 60.4%, collaborative by 35.8%, and passive by 3.8%. The trend of moving to a more active decision making stance from Time 1 to Time 2 was less apparent with the “pick one” procedure.

### **Family Members**

At Time 1, the most common choice that fell on the metric was DCEBA (21/61 or 34.4%). This reflected a desire of family members to take a passive decision making role in relation to their family member with cancer. Table 7 shows that 60.0% of the family members chose a passive stance, 31.1% a collaborative stance, and only 8.9% an active stance. At Time 2, the most common choice that fell on the metric was DCEBA (21/61 or 34.4%), again indicating that this group of family members preferred to be passive in decision making with their family member with cancer. 56.3% of family members chose a passive stance, 35.4% chose a collaborative stance, and 8.4% chose an active stance (see Table 7).

With respect to the “pick one” procedure responses of family members at Time 1, Table 7 shows that the modal choice was card D (45.9%). This reflects the aforementioned preference

Table 7: Decision Making Preferences - Family Members

| Letter | First Letter of String Variable |        | "Pick One" Letter |        |
|--------|---------------------------------|--------|-------------------|--------|
|        | Time 1                          | Time 2 | Time 1            | Time 2 |
| A      | 6.7%                            | 4.2%   | 4.9%              | 1.6%   |
| B      | 2.2                             | 4.2    | 4.9               | 6.6    |
| C      | 31.1                            | 35.4   | 41                | 31.1   |
| D      | 48.9                            | 54.2   | 45.9              | 59     |
| E      | 11.1                            | 2.1    | 3.3               | 1.6    |

of a passive decision making role. Collapsing the responses into the three categories of active, collaborative, and passive, 49.2% chose a passive stance, 41.0% a collaborative one, and 9.8% an active stance. Table 7 shows the "pick one" responses at Time 2 moved to a slightly more passive stance. Again, the modal choice was card D (59.0%). Collapsing the responses into three categories, 60.6% chose a passive stance, 31.1% collaborative, and 8.2% active. There appeared to be a trend from Time 1 to Time 2 of becoming more passive in decision making preference.

#### **Decision Making Involvement Question (DMIQ)**

A single question was asked of family members at both Time 1 and Time 2 to elicit their perception of how involved their ill family member actually was in treatment and care decision making. Their responses were graded on a four point scale of "not at all", "somewhat", "quite a bit", and "totally". There was room for comments on the questionnaire page as well.

Table 8 displays the frequencies of the responses to the DMIQ. At both Time 1 and 2, two thirds of family members perceived their patient family members as "totally" involved in decision making. Another one fifth perceive them to be "quite a bit" involved. Only a very few were perceived to be "somewhat" or "not at all" involved in decision making.

Table 8: Responses to DMIQ

| DMIQ Response | Time 1 |         | Time 2 |         |
|---------------|--------|---------|--------|---------|
|               | N      | Valid % | N      | Valid % |
| Not at all    | 5      | 8.2     | 4      | 6.6     |
| Somewhat      | 3      | 4.9     | 1      | 1.6     |
| Quite a bit   | 12     | 19.7    | 14     | 23      |
| Totally       | 41     | 67.2    | 42     | 68.9    |
| TOTAL         | 61     | 100     | 61     | 100     |

Next, the DMIQ responses were examined in relation to family members' valid responses to the CPS-F. Chi-square analysis was used to examine this relationship. No statistically significant differences were noted. However, Table 9 demonstrates there was a trend of family members taking more passive decision making roles when the patients were perceived to be active in their own decision making involvement (DMI).

Table 9: Family Members' Decisional Preferences in Relation to Perception of Patients' DMI

| DMIQ Response | Time 1 |               |         | Time 2 |               |         |
|---------------|--------|---------------|---------|--------|---------------|---------|
|               | Active | Collaborative | Passive | Active | Collaborative | Passive |
| Not at all    | 4      | 0             | 0       | 3      | 0             | 0       |
| Somewhat      | 0      | 0             | 3       | 0      | 0             | 0       |
| Quite a bit   | 0      | 2             | 6       | 1      | 4             | 6       |
| Totally       | 0      | 12            | 18      | 0      | 13            | 21      |
| TOTAL         | 4      | 14            | 27      | 4      | 17            | 27      |

Qualitative data from the DMIQ supported the above-noted trend. Over one third of the family member participants (23/61 or 37.7%) made comments in the space provided. The comments almost exclusively indicated that as their loved one's capacity to make decisions

diminished, the family members would engage in a more active decision making role on their loved ones' behalf. A few comments also linked family members' increased role in decision making in relation to their loved ones' failing physical well-being.

### **Preferences Off the Metric**

Although greater than 50% plus one of participant responses fell on the metric and thus justified the unidimensionality of the scale, a substantial percentage of patient and family member responses fell off the ABCDE metric. The notable string for the patient group was CBADE, indicating a collaborative stance. At Time 1, 16.7% (9/54) of the patient group chose this string. At Time 2, 17% (9/53) of patients chose this string. The most notable non-metric string chosen by family members was DCBEA, indicating a passive stance. 13% (8/61) family members chose this string at Time 1, and 8.2% (5/61) at Time 2.

### **Variables Related to Preferences for Participation in Decision Making**

This section will respond to Research Question 3: What variables are related to family member and cancer patient choice of decision making role? Therefore, differences in preferred decision making roles will be examined in relation to selected sociodemographic characteristics and disease/treatment variables, level of family function, level of patients' symptom distress, and level of patients' functional ability.

### **Demographic Variables**

**Patients.** In examining the influence of demographic factors on decisional control, only education achieved statistical significance. All patients with more education than a high school diploma chose an active decision making stance at Time 2 ( $\chi^2=6.5$ , 1 df,  $p=0.011$ , Fisher's Exact Test=0.013). At Time 1 a similar trend was evident, but did not reach statistical significance.

There were several other trends, although statistically non-significant. Sex seemed to be

related to decision making preferences. Women (85% at Time 1; 83% at Time 2) were more likely to choose an active stance than men (64% at Time 1; 62% at Time 2).

Religious affiliations also seemed to be related to decisional preferences. Catholics tended toward a more active decision making stance, whereas Protestants were split between active and collaborative stances. Almost all patients who indicated no religious affiliation chose an active stance.

**Family Members.** Demographic factors were not significantly related to decisional control among this group of participants. However, two interesting non-significant trends were noted.

As discussed earlier, passive decision making was the norm for family members. This passive stance, however, was adopted more often by male family members (72% at Time 1; 76% at Time 2) than by females (52% at Time 1; 45% at Time 2).

The family member's relationship to the patient also had an impact on decision making preferences. Spouses of the patient (63% at Time 1; 56% at Time 2) chose a more passive decision making role as compared to non-spouses (53% at Time 1; 57% at Time 2).

#### **Family Assessment Device (FAD)**

The general functioning sub-scale of the FAD was used in this study as a measure of family function. Mean scores can range from 1.00, indicating healthy functioning, to 4.00, indicating unhealthy functioning (Epstein et al., 1983). The cut-off score established for healthy family functioning was  $\leq 2.00/4.00$ , meaning that more of the test items were endorsed in a healthy direction rather than an unhealthy one (Miller et al., 1985).

Fifty-five of the 61 patients completed the FAD. The six who did not complete the FAD had failed the MMSE. The mean score for the FAD among the 55 patients was 1.75 (s.d.=0.48, range=2.25). All 61 family members completed the FAD. The family members' mean FAD

score was 1.73 (s.d.=0.45, range=1.83). These mean scores indicate healthy family functioning among both the patient and family member groups.

Chi-square analysis was used to examine the relationship between decision making preferences and family function. No statistically significant differences were found in decision making preferences by family function, for patients or family members.

### **Symptom Distress Scale**

The SDS, used in this study as a measure of symptom distress, is scored from 13, indicating least symptom distress, to 65, indicating greatest symptom distress (McCorkle & Young, 1978). Symptom distress was measured at Time 1. Patients completed the SDS to indicate their level of symptom distress; family members completed it to indicate their perception of the patient's symptom distress level.

**Patients.** Fifty-four of the 61 patients completed the SDS. Six patients failed the MMSE, and one patient did not respond to all 13 items on the SDS. The mean SDS score among the 54 patients was 23.48 (s.d.=7.12, range=30), indicating relatively low levels of symptom distress.

SDS scores at Time 1 had no statistically significant relationship to decision making preferences. However, at Time 2, those with higher symptom distress chose a more passive stance (unpaired, two-tailed,  $t=-2.046$ , 34 df,  $p=0.049$ ). The 28 patients who chose an active decisional role had a mean SDS score of 22.11; the 8 who chose a collaborative role had a mean SDS score of 28.00.

**Family Members.** All 61 family members completed the SDS. The mean score for the SDS in this group was 27.07 (s.d.=9.28, range=35), indicating relatively low levels of distress.

At Time 1, family members who perceived their patient family member's symptom distress as higher chose more passive decision making roles (unpaired, two-tailed,  $t=-2.042$ ,

39 df,  $p=0.048$ ). The 14 family members who chose a collaborative decisional role had a mean SDS score of 22.57; the 27 who chose a passive role had a mean score of 28.44. At Time 2, there were no significant differences.

Therefore, as patients' symptom distress increases, both patients and family members chose a more passive decision making stance.

#### **Katz Index of Activities of Daily Living (Katz Index)**

The Katz Index was dichotomized (independent in all six functions; dependent in at least one function) to examine the potential relationship between decision making preferences and functional ability.

**Patients.** Table 10 shows a non-significant trend of functional independence.

Preference for a more active decision making stance was noted, particularly at Time 2.

Table 10: Decision Making Preference By Katz Index-Determined Functional Ability - Patients

| Functional Ability | Decision Making Preference |               |        |               |
|--------------------|----------------------------|---------------|--------|---------------|
|                    | Time 1                     |               | Time 2 |               |
|                    | Active                     | Collaborative | Active | Collaborative |
| Independent        | 22                         | 6             | 23     | 4             |
| Dependent          | 4                          | 2             | 5      | 4             |

**Family Members.** Table 11 shows a non-significant trend of perceived functional independence in patients with a more passive decision making preference in family members.

Table 11: Decision Making Preference By Katz Index-Determined Functional Ability - Family Members

| Functional Ability | Decision Making Preferences |               |         |        |               |         |
|--------------------|-----------------------------|---------------|---------|--------|---------------|---------|
|                    | Time 1                      |               |         | Time 2 |               |         |
|                    | Active                      | Collaborative | Passive | Active | Collaborative | Passive |
| Independent        | 0                           | 11            | 21      | 1      | 13            | 21      |
| Dependent          | 4                           | 3             | 6       | 3      | 4             | 6       |

#### **Five Instrumental Activities of Daily Living (IADL)**

The IADL was also dichotomized (independent in all five functions; dependent in at least one function) to examine the potential relationship between decision making preferences and functional ability.

**Patients.** A non-significant trend of functional independence with preference for a more active decision making role was noted (see Table 12).

Table 12: Decision Making Preference by IADL-Determined Functional Ability - Patients

| Functional Ability | Decision Making Preference |               |        |               |
|--------------------|----------------------------|---------------|--------|---------------|
|                    | Time 1                     |               | Time 2 |               |
|                    | Active                     | Collaborative | Active | Collaborative |
| Independent        | 15                         | 3             | 16     | 2             |
| Dependent          | 8                          | 3             | 8      | 3             |

**Family Members.** A non-significant trend of perceived functional independence in patients with a more passive decision making preference in family members was noted (see Table 13).

Table 13: Decision Making Preferences by IADL-Determined Functional Ability - Family Members

| Functional Ability | Decision Making Preference |         |        |               |         |
|--------------------|----------------------------|---------|--------|---------------|---------|
|                    | Time 1                     |         |        | Time 2        |         |
|                    | Collaborative              | Passive | Active | Collaborative | Passive |
| Independent        | 8                          | 11      | 0      | 9             | 13      |
| Dependent          | 3                          | 9       | 1      | 4             | 7       |

### Summary

The results can be summarized as follows:

1. The modified Control Preferences Scale, the CPS-F, formed a unidimensional scale.
2. The CPS-F proved to be reliable over time.
3. The "pick one" procedure was reliable over time.
4. The MMSE did not achieve minimally acceptable reliability standards for an established instrument.
5. The internal consistency of the FAD in this sample was acceptable.
6. The internal consistency of the SDS in this sample was acceptable.
7. Three quarters of patients chose an active decision making stance in relation to their family members. Almost all of the remaining patients chose a collaborative role.
8. Sixty percent of family members chose a passive decision making stance in relation to their patient family member. Another third chose a collaborative stance.
9. Family members, for the most part, perceived their patient family members as being involved in their own decision making.

10. A trend of family members preferring more active decision making roles when they perceived their patient family members as less actively involved in their decision making was noted.
11. Qualitative responses to the DMIQ suggested family members take, or are prepared to take, more active decisional stances as their patient family members' cognitive abilities deteriorate.
12. Patients with more education chose a more active decision making stance ( $\chi^2=6.5$ , 1 df,  $p=0.011$ , Fishers's Exact Test= $0.013$ ).
13. A trend of female patients choosing more active decisional roles than males was noted.
14. Family members' decisional roles were not significantly related to demographic variables. However, there was a trend of spouses and males tending toward more passive decision making stances than non-spouses and females.
15. No relationship between family function and decision making preferences was found.
16. Patients with higher symptom distress chose more passive decision making roles at Time 2 (unpaired, two-tailed,  $t=-2.046$ , 34 df,  $p=0.049$ ).
17. Family members who perceived their patient family members as having increased symptom distress chose more passive decision making roles at Time 1 (unpaired, two-tailed,  $t=-2.042$ , 39 df,  $p=0.048$ ).
18. Both measures of functional ability showed non-significant trends toward more active decision making preferences, for both patients and family members, when functional ability was greater.

## CHAPTER FIVE

### DISCUSSION

The purposes of this study were threefold. The first purpose was to modify Degner et al.'s (1997b) decision making preference card sort and assess its psychometric properties with a sample of cancer patients and their families. Second, the study aimed to describe patients' and families' preferences for decision making. A third purpose was to determine differences in preferred decision making roles by selected sociodemographic characteristics and disease/treatment variables, level of family function, level of patients' symptom distress, and level of patients' functional ability. Family Systems Theory and Scanzoni and Szincovacz's (1980) developmental sex role model provided the theoretical framework for understanding the dynamics of family decision making in this study.

This chapter will discuss the major findings of this study, and situate these within the literature. Limitations of this study will then be addressed, followed by implications for nursing practice and recommendations for further research.

#### **Major Findings**

This section will discuss the major findings of this study. First, findings related to the study sample and non-participants will be addressed. Then findings as they relate to each of the study's three research questions will be dealt with.

#### **Study Sample**

Demographic characteristics of the study participants were compared to demographic profiles developed by the Winnipeg Regional Health Authority (WRHA) in 2000. Age was difficult to compare due to differences in age categories used. According to WRHA data, 14% of all people (or 19% of people 20 years of age or older) within the Winnipeg Health Region (WHR) were 65 years of age or older. 68.8% of the patients, and 39.4% of the family members,

in this study were 60 years of age or older. An increased proportion of older people would be expected in a study of this nature because cancer tends to occur in older segments of the population. In a 1999 publication, the National Cancer Institute of Canada (NCIC) estimated that 70% of new cancer cases, and 81% of cancer deaths, in 1999 would be diagnosed in Canadians 60 years of age or older.

The interesting finding with respect to sex was that a higher proportion of women (two thirds of the family members were female) were the family members identified when patients were asked with whom they discussed their health care decisions the most. Spouse (68.9%) was the most common relationship of patient and family member. However, ten times as many daughters, as compared to sons, were the family member identified for this study. This supports the societal notion that women take on the caregiving role for family members.

The marital status of study participants was different from the WRHA profile (see Table 14). More study participants were married, less were divorced or separated, and more were widowed when compared to the WHR residents. This may be reflective of the relatively older age of the study participants. An alternate explanation may be that the study sample represents a stabler group, with respect to social support, than the WHR population as a whole.

Table 14: Comparison of Marital Status of Study Participants and WHR Population

| Marital Status     | Patients | Family Members | WHR Population |
|--------------------|----------|----------------|----------------|
| Married/Common-law | 74.6%    | 86.9%          | 51.0%          |
| Divorced/Separated | 6.8      | 1.6            | 10             |
| Never married      | 5.1      | 8.2            | 32             |
| Widow(er)          | 13.6     | 3.3            | 7              |

Both level of education and household income are used as relative indicators of affluence. Educational attainment was difficult to compare due to different educational

categories. In the WHR, 55% of people aged 25 years or older had more than a high-school education. In contrast, only 34.5% of patients, and 40.8% of family members, had more than a high school education. This may be a function of the study sample being an older population than the whole population of the WHR. In fact, WRHA data showed that only 28% of women, and 36% of men, aged 65 years and older had more than a high school education.

Household income also differed (see Table 15). Upon examination of income categories by percentage, it appears that the study sample is less affluent than the WHR population. This is reinforced by a slightly lower median income for the study sample. However, if age is taken into account (a large proportion of the study sample was aged 65 years or older), it appears that the study sample may be more affluent. Median income is a good measure of this as it indicates the income level at which half of the group is above and half is below.

Table 15: Comparison of Household Income of Study Participants and WHR Population

| Household Income                       | Patients        | Family Members  | WHRA                                   |
|--|-----------------|-----------------|--|
| <\$20,000                              | 21.8%           | 8.3%            | 14.0%                                  |
| \$21,000-40,000                        | 42.1            | 38.3            | 25                                     |
| \$41,000-60,000                        | 15.8            | 26.7            | 25                                     |
| >\$60,000                              | 19.3            | 26.7            | 36                                     |
| Median                                 | \$31,000-40,000 | \$41,000-50,000 | \$46,698                               |
| Median for People<br>65 Years or Older | Not Available   | Not Available   | \$13,200 - females<br>\$18,605 - males |

### Non-participants

A total of 160 patients were recruited for participation in this study. Of these, 116 (64.4%) did not consent to participate. A number of explanations may account for this high number of patients who did not consent.

Non-participants were noted to be older than those who agreed to participate (Mann-Whitney U,  $p=0.015$ , two-tailed). Although no data were collected, perhaps non-participants were also sicker. This potential explanation was supported by nurse and physician protection of patients at both in-patient and out-patient sites. Some nurses and physicians indicated that certain patients met the study criteria but the nurse or physician would not allow access to those patients because they were too sick or too overwhelmed by their current situation. Therefore, consent was withheld by the health care providers, not the patients themselves.

This study recruited participants through the patients. The patients then were asked to identify their family member with whom they discussed their health care decisions most. Some patients may have been unwilling to commit a family member to participation in the study, and hence declined participation. Patients living at home were recruited by letter. If the patient's condition was poor, it is likely that family members were helping with, or assuming, the patient's daily activities, including handling their mail. These family members may have been protecting their patient family member, or themselves, from the perceived burden of study participation.

McCorkle, Packard, & Landenburger (1985) encountered similar behaviour from physicians, and to a lesser extent family members, in a study of patients newly diagnosed with lung cancer. Of 136 eligible patients who were approached to participate, 25 of the 73 (34%) non-participants were due to physician refusal. Physicians who refused access to particular patients cited poor physical or emotional condition. Another 6 (8%) non-participants were due to family member refusal on the basis of poor physical health.

### Research Question 1

Research Question 1 was “To what extent is the CPS-F a reliable measure of patient preference for family member involvement in their care decisions and family member preference for involvement in patient care decisions?”. This study demonstrated that the CPS-F is a unidimensional and reliable scale.

Previous studies (Beaver et al., 1996; Degner & Sloan, 1992; Degner et al., 1997a) have found the original CPS to form a unidimensional scale, with a range of 58 to 63% of respondents choosing a decision making preference that fell on the psychological dimension of keeping, sharing, or ceding decisional control. All of these, along with this study’s results ranging from 63.0 to 78.7% of responses falling on the metric, surpassed the 50% plus one criteria set out by Coombs (1976).

Two other modifications of the CPS have been developed (Dozenko, 1998; Pyke-Grimm, Degner, Small, & Mueller, 1999), and they too have met Coombs’ (1976) criteria. Dozenko modified the CPS for use with husbands of women who had recently undergone surgery for breast cancer. The statements in the modified CPS ranged from husband and wife keeping decisional control (active) through shared control with the physician (collaborative) to ceding decisional control to the physician (passive). In a sample of 70 husbands, 49 (70%) of the preference orders fell on the dimension.

A second modification was developed by Pyke-Grimm et al. (1999). Their tool, the CPS-P, was used to elicit preferences of custodial parents making treatment decisions for their children with cancer. These statements ranged from the parent making treatment decisions for the child (active) through the parent and physician sharing decision making (collaborative) to the physician making the decisions (passive). In their sample of 77 parents, 52% of responses were

on the metric at the time of diagnosis and 59% of the responses were on the metric at the time of the interview.

There is a fair range in the percentage of responses that fell on the metric when using one of the CPS modifications. Both this study and Dozenko's (1998), which had higher percentages of preferences on the metric, posed the question to the participants in terms of current decision making. Pyke-Grimm et al.'s (1999) study asked participants to "think back" to their child's time of diagnosis, ranging from 3 to 12 months, and identify their decision making preference retrospectively. Only 52% of these responses fell on the metric. Perhaps asking for retrospective preferences was more confusing, or difficult to recall, thus resulting in fewer preferences being on the dimension.

An interesting finding in the present study was that a higher percentage of family member responses fell on the metric than patient responses, at both interview times (family members: 73.8% at Time 1, 78.7% at Time 2; patients: 63.0 and 69.8% respectively). No other known studies have examined decision making preferences between family members, thus comparison to other studies is impossible. One explanation for this difference may be family members who were, for the most part, healthy were better able to concentrate and process the information required in order to complete the CPS-F.

A related finding is the increase in the percentage of valid responses by both patients and family members at the second interview. This may represent a learning effect where the participants, having had a day to think about the CPS-F, had a clearer conception of the scale at Time 2. This same effect of an increase in valid responses occurred in Pyke-Grimm et al.'s (1999) work. Here, the parents were asked to respond to the CPS-P twice in the interview (once to retrospectively describe their decision making preference at the time of their child's diagnosis

and a second time for the present). Again, this increase in valid responses may have occurred due to a better understanding of the scale when responding the second time.

Two measures of test-retest reliability were undertaken in this study and demonstrated that the CPS-F is a reliable instrument. The first measure was of the ordinal scores at Time 1 and Time 2. Results from the patient group (Spearman's  $\rho=0.896$ , two-tailed  $p=0.01$ ), the family member group (Spearman's  $\rho=0.832$ , two-tailed  $p=0.01$ ), as well both groups combined (Spearman's  $\rho=0.927$ , two-tailed  $p=0.01$ ) demonstrated the CPS-F's stability over time. The second measure examined the correlation of Time 1 and Time 2 responses of the string variable's first letter for those participants whose responses fell on the metric. The patient (Spearman's  $\rho=0.750$ , two-tailed  $p=0.01$ ), family member (Spearman's  $\rho=0.864$ , two-tailed  $p=0.01$ ), and aggregate results (Spearman's  $\rho=0.901$ , two-tailed  $p=0.01$ ) all supported the reliability of this instrument. There are no known studies of the CPS, or its modifications, which have examined test-retest reliability, and therefore the present study's results cannot be compared.

A test of convergent validity was also carried out to examine the validity of the CPS-F. This was done by comparing the first letter of the string variable to the "pick one" letter, for those responses falling on the metric, at Time 1 and Time 2. Separately, the patient (Time 1: Wilcoxon signed rank sum=15.00, two-tailed  $p=0.317$ ; Time 2: Wilcoxon signed rank sum=4.00, two-tailed  $p=0.059$ ) and family member groups (Time 1: Wilcoxon signed rank sum=27.50, two-tailed  $p=1.00$ ; Time 2: Wilcoxon signed rank sum=0.00, two-tailed  $p=0.059$ ) showed no differences, although both groups at Time 2 approached a significant difference. These first tests provided tentative support for the validity of the CPS-F. When the two groups were combined, no difference was found at Time 1 (Wilcoxon signed rank sum=30.00, two-tailed  $p=0.491$ ). However, at Time 2 a significant difference was noted (Wilcoxon signed rank sum=5.50, two-tailed  $p=0.008$ ). This difference was due to both patients and family members taking a more

active stance with the card sort technique than with the “pick one” method at Time 2. No other known studies of the CPS or its modifications have examined convergent validity, making any comparisons impossible.

### **Research Question 2**

This section will discuss the major findings which relate to Research Question 2, which queries “What role do family members prefer to play in decision making with respect to a family member with cancer and what role do cancer patients prefer their family members to play with respect to their care decisions?”.

Patients in this study chose a highly active decision making stance. Three quarters of this group, whose responses fell on the dimension of keeping, sharing, or ceding decisional control in relation to their family member, chose an active role (a string variable starting with either card A or B) at both Times 1 and 2. In fact, there was a total of only one passive decisional stance (a string variable starting with either card D or E) chosen by the patient group. This study is the only one known to examine decision making preferences between patients and their family members.

Other studies have examined these preferences, but in the context of patients’ decision making preferences in relation to their physicians. These studies have found a much lower percentage of participants preferring an active role in decision making, ranging from 12 to 31.4% (see Table 16). One explanation for this marked difference in patient decision making preferences is a difference between the patient-family member relationship in this study and the patient-physician relationship in the studies noted in Table 16. The patient-physician relationship involves a substantial power differential. In contrast, the patient-family member relationship is one of relatively equal power between the two. As well, patients have identified the expert knowledge of their physicians as a factor in decision making (Bilodeau & Degner,

Table 16: Preference for Active Decision Making Roles of Patients in Relation to their Physicians

| Study                          | Sample                                       | Sample size | Active Preference |
|--------------------------------|--|-------------|-------------------|
| Degner & Sloan (1992)          | newly diagnosed cancer                       | 436         | 12.0%             |
| Hack et al. (1994)             | stage I or II breast cancer                  | 35          | 23                |
| Davison et al. (1995)          | within 6 months of prostate cancer diagnosis | 57          | 19                |
| Llewellyn-Thomas et al. (1995) | resectable adenocarcinoma of colon           | 90          | 31.4              |
| Beaver et al. (1996)           | within 4 weeks of breast cancer diagnosis    | 150         | 20                |
| Bilodeau & Degner (1996)       | recently diagnosed with breast cancer        | 74          | 20                |
| Davison & Degner (1997)        | newly diagnosed with prostate cancer         | 60          | 25                |
| Degner et al. (1997)           | breast cancer                                | 1012        | 22                |

1996; Charles et al., 1998; Ward et al., 1989). These two factors may explain the more active role patients prefer to take when making health care decisions with their family members.

Sixty percent of family members in this study chose passive decision making stances in relation to their patient family members. Another third chose collaborative stances. Of note, most family members perceived their patient family members as being involved in their own decision making. As a result, family members may not have perceived a need to be involved in the decision making. As well, based on anecdotal information, family members seemed to take a "patient's body, patient's decision" attitude toward patient decision making.

Although there are no other known studies which examine decision making preferences between patients and family members, limited work has been done to elicit patient preferences for others' involvement in their decision making. Ebell et al. (1990) surveyed 800 outpatients about decision making preferences with respect to do not resuscitate orders. Patients identified spouse, physician, and children, as their ranked choices. When 400 hemodialysis patients were interviewed to examine patient preferences for involvement in advance care planning (Hines et al., 1999), 50% of patients indicated they had discussed such issues with family members and only 6% had discussed such issues with their physicians ( $p < 0.001$ ). As well, Hines et al. also found that 91% of patients desired family member involvement in advance care planning. Both of these studies support the idea that patients value family member input in health care decision making.

A third study (Degner & Russell, 1988) explored decisional control in 60 patients with cancer. Here, patients had a strong preference for patient and family to be involved in decision making. However, patients did not want decisions made without their input. This finding is similar to the results of this study. Table 17 shows that most study participants, both patients and family members, chose a "sharing" stance (first letter choice of B, C, or D) rather than a total "control" or "cede" position (A or E). About three quarters of patients preferred some decision making involvement from their family member (first letter choice of B, C, or D), but there were no patients who wanted to cede decision making (first letter choice of E). Similarly, almost all family members wanted input into the patients' decision making (first letter choice of B, C, or D), but few preferred a stance where the family member was controlling the decision making process (first letter choice of A or B).

Table 17: Decisional Preferences of Patients and Family Members

| First Letter of String Variable | Time 1  |               | Time 2  |               |
|---------------------------------|---------|---------------|---------|---------------|
|                                 | Patient | Family Member | Patient | Family Member |
| A                               | 23.4%   | 6.7%          | 29.7%   | 4.2%          |
| B                               | 52.9    | 2.2           | 45.9    | 4.2           |
| C                               | 23.5    | 31.1          | 21.6    | 35.4          |
| D                               | 0       | 48.9          | 2.7     | 54.2          |
| E                               | 0       | 11.1          | 0       | 2.1           |

Another finding was that family members were willing to become more active in, or assume, the decision making role if cognitive deterioration of their patient family member occurred. One study found that patients wanted their families involved when they were no longer able to make their own decisions. Degner & Sloan (1992) surveyed 436 newly diagnosed cancer patients to determine their preferences for their treatment decision making when they became incompetent. The range of available responses were: family decides; family decides but considers physician's opinion; family and physician share decision; physician decides but considers family's opinion; and physician decides. They found 51% of patients preferred their family and physician to share in the decision making. Another 10% of patients wanted their families to dominate the decision making. Those patients who preferred an active role in their own decision making preferred their family assume decisional control when they were no longer able to ( $r=0.72$ ,  $p=0.000$ ).

### **Research Question 3**

The third research question was: "What variables are related to family member and cancer patient choice of decision making role?". This section will identify the major findings related to this question, and discuss them within the context of other studies.

**Demographic variables.** Only one demographic variable, patients' educational level, had a statistically significant relationship with decision making preference. Educational level, as well as several non-significant trends, will be discussed in this section.

All patients with more education than a high school diploma chose an active decision making stance at Time 2 ( $\chi^2=6.5$ , 1 df,  $p=0.011$ , Fisher's Exact Test=0.013). A non-significant trend toward more active decision making preferences for those patients with more education than a high school diploma existed at Time 1. This relationship did not exist for the family member group. The association of higher educational level and more active decision making preferences for patients in relation to their physicians has been noted in the literature as well (Beaver et al., 1996; Davison et al., 1995; Degner & Sloan, 1992; Hack et al., 1994) In Degner et al.'s study (1997a), the best predictor of patients' decision making preferences in relation to their physician was educational level.

One interesting trend was that female patients (85% at Time 1; 83% at Time 2) were more likely to choose an active decision making stance (A or B) than male patients (64% at Time 1; 62% at Time 2). The literature supports this finding, both for patient-physician decision making (Degner & Sloan, 1992; Llewellyn-Thomas et al., 1995) or family decision making (Degner & Sloan, 1992). Passive decision making was the norm for family members. However, this stance was adopted more often by male family members (72% at Time 1; 76% at Time 2) chose passive decision making stances of D or E) than female family members (52% at Time 1; 45% at Time 2). Although no known research has addressed this question of decision making preferences in the context of family members, the trend of males being more passive than females in relation to treatment decision making has been noted in the individual decision making literature (Degner & Sloan, 1992; Llewellyn-Thomas et al., 1995).

A second interesting trend was the relationship between decision making preference and the family member's relationship to the patient. Spouses chose more passive decisional stances than non-spouses. One explanation for spouses choosing a more passive role may be that spouses know the patient better than a non-spouse, and feel more comfortable with ceding decisional control to the patient. No other known study has examined this relationship. The studies which have been done explore the marital relationship of the patient and its impact on patient decision making preference. One study found a trend of passive decision making preference among married men with prostate cancer (Davision et al., 1995). A second study found no relationship between the marital status of 150 women with breast cancer and their decisional preference (Beaver et al., 1996). A third study of 1,012 participants found that married women with breast cancer were more likely to choose an active or collaborative role in decision making when compared to their unmarried counterparts (Degner et al., 1997a).

**Symptom distress.** One of the most striking findings was the impact of symptom distress on decision making preferences. Patients who ranked their symptom distress higher chose more passive decision making roles at Time 2 (unpaired, two-tailed,  $t=2.046$ , 34 df,  $p=0.049$ ). At Time 1, patients with more symptom distress also chose more passive roles, but the relationship was not statistically significant. As well, family members who ranked their patient family members' symptom distress higher also preferred more passive decision making roles at Time 1 (unpaired, two-tailed,  $t=-2.042$ , 39 df,  $p=0.048$ ). This same trend, although non-significant, was noted at Time 2.

No known studies have specifically examined the relationship between symptom distress and decision making preferences. However, a strong association has been demonstrated between increased symptom distress and decreased functional ability (Breitbart et al., 1996; Krech et al., 1992; Kristjanson et al., 1998; Sarna, 1998; Sarna & Brecht, 1997). Therefore, the limited

research done to describe the relationship between functional ability and decision making preferences may have some applicability to a relationship between symptom distress and decision making preferences. The findings, however, have been contradictory. One study found that patients who subjectively reported being sicker preferred an active decisional role (Haug & Lavin, 1981). Conversely, another study found that patients with a lower ECOG score, indicating poorer functional ability, were more likely to prefer passive decisional roles (Blanchard et al., 1988). A third study found that more favourable health status was associated with stronger preferences for decisional control (Ende et al., 1989). Although not statistically significant, this study found trends with both functional ability measures indicating more active decision making preferences, among patients, when functional ability was higher. Family members who scored their patient family members' functional ability as independent preferred more passive decisional roles.

### **Study Limitations**

Several limitations, related to both the study sample and the research instruments utilized for this study, will be discussed.

#### **Study Sample**

Generalizability of study findings are limited by small sample size and use of non-probability sampling. Small sample size increases the risk of sampling error and the use of non-probability sampling raises the concern of representativeness of the population (Burns & Grove, 1993).

The sample of 61 patient-family member pairs was recruited from a palliative care program and three family medicine clinics within Winnipeg. It is not known whether this sample would produce systematic variation from samples including participants from rural Manitoba. Therefore, it may be wise to generalize this study's findings only to people in Winnipeg with the

four cancer diagnoses noted in Table 18. As well, this sample is slightly under-representative of colorectal cancers and slightly over-representative of breast cancers, based on National Cancer Institute of Canada's (1999) estimated new cases for major cancer sites (see Table 18).

Table 18: Comparison of Cancer Diagnosis in Study Sample and NCIC (1999) Data

| Diagnosis  | Study Sample | NCIC Data |
|------------|--------------|-----------|
| Breast     | 34.4%        | 23.9%     |
| Colorectal | 14.8         | 23.5      |
| Lung       | 24.6         | 28.1      |
| Prostate   | 26.2         | 24.6      |

Consideration needs to be given to those who chose not to participate in this study. The non-participants are known to be older than those patients who participated. Given the protecting which nurses, physicians, and perhaps family members did, one might speculate that the non-participants were not only older but maybe sicker as well. Bruera (1994), in discussing ethical issues related to palliative care research, referred to the vulnerability of this population, noting that palliative patients suffer severe physical and emotional symptomatology and that their families also endure much psychosocial distress. These factors may in turn limit these patients' and families' ability or willingness to participate in research.

### **Research Instruments**

Some methodological difficulties were encountered with three of the research instruments.

**Control Preferences Scale (CPS-F)**. Based on observation by the investigator, the CPS-F proved confusing for sicker patients, despite the patients' ability to meet the cut-off criteria for the MMSE. The patients who had difficulty with the CPS-F seemed to have less

difficulty with the “pick one” procedure. Although using the “pick one” procedure may be easier and quicker for the patient, the disadvantage is it provides less specificity than the CPS-F. With the CPS-F, one can determine a participant’s first choice of decision making preference as well as their second through fifth choices.

**Symptom Distress Scale (SDS).** The SDS, overall, proved to be an easily-administered and easily-understood instrument. One finding was that only the lower end of the scale was used by this study’s sample. The mean SDS score for patients was 23.5; the mean for family members was 27.1. The range of scores (patient scores ranged from 13 to 43; family member scores ranged from 13 to 48) also was at the low end of the potential range of 13 to 65. This finding was also noted by Kristjanson et al. (1998) and Lobchuk et al. (1997), both of whom were studying patients undergoing palliative care.

A few limitations of the SDS were observed. First, some participants asked for a “zero” option on the scale. These were individuals who believed that they were not experiencing the symptom at all, and did not think the SDS allowed them to reflect that in their scoring of the scale. These participants’ SDS scores, therefore, would be higher than the participants’ perceived level of symptom distress. This same issue was noted by Lobchuk (1995).

A second observed limitation of the SDS was the inability to discriminate between symptom distress related to the cancer and symptom distress related to other causes, for example pain due to arthritis. McCorkle and Young (1978) acknowledge that their SDS does not differentiate between symptom distress due to cancer and that due to cancer treatment, but rather define symptom distress as “the degree of discomfort from the specific symptom being experienced as perceived by the patient” (p.374). Perhaps there is no need to discriminate between the causes of the symptoms. By returning to McCorkle and Young’s (1978) definition, what is important is that the person is experiencing the symptom. The converse may also be

valid because the meaning which is attached to a symptom may impact on the degree of distress a person experiences. For example, if a person perceives their pain to be related to arthritis the meaning that person attaches to the pain may be that it is part of the same chronic condition that he/she has dealt with for years and therefore is no more distressed about it now than before. However, if that same person perceives the pain to be related to his/her cancer, the meaning that now is attached to the pain may be that the cancer has worsened or spread which in turn may create an increased level of distress.

A third observation with scale administration was that the wording of some of the scale items conflicted with the directions given to participants. Based on Cohen and Mount's (1992) work with palliative care populations, the investigator directed participants to respond to each item in the context of how they had been feeling for the past 2-3 days. This proved confusing for some, as the item for appearance required the participant to comment on their appearance over a longer time period. This was resolved by encouraging the participants to respond to that particular item in terms of how they are feeling about their appearance since cancer diagnosis.

**Family Assessment Device (FAD).** The general functioning sub-scale of the FAD was, for the most part, also easily administered and easily understood. Some participants found the negatively worded statements confusing. The investigator attempted to deal with this confusion by having the participant reread the statement slowly and reflect upon it.

### **Clinical Recommendations**

This study has implications for the nursing care of patients with cancer, as well as their families. First, nurses must elicit from patients what their decision making preference is. Although this study provides some evidence that education, gender, relationship to patient, and level of symptom distress may be related to decision making preferences in families, this is not

conclusive. Nurses should continue to use tools such as the CPS and CPS-F to understand patient preferences with respect to decision making.

Second, fully three quarters of both patients and family members in this study chose a decision making role which involved shared decision making by the patient and family member. Nurses need to include not only the patient in discussions related to treatment decisions, but need to ensure that they ask the patient which family members should be included in these discussions. Davison and Degner (1998) propose specific steps to facilitate patient and family member involvement in decision making.

Third, as described in this study, periods of increased symptom distress may be crisis points for the patient and family. Nurses need to be aware of changing levels of symptom distress and be prepared to intervene with support to patients and families at these times. Interventions would include attempting to decrease the symptom distress as well as providing emotional support to the patient and family during this increasingly difficult time. The patient and family may require repeated explanations of what is happening to the patient and of what treatment options are available. As well, reassessment of decision making preferences may be appropriate. In this study, most family members indicated that they were prepared to take on a more active decision making role as their patient family members' physical and cognitive deteriorated. However, this change in role may create additional stress for the family member at a time which is already emotionally burdensome.

The investigator observed a pattern among study participants of a need to talk about their cancer experiences, and in some cases a need for answers related to their cancer diagnosis or treatment. Although study participants were not directly questioned as to why they chose to raise these issues with the investigator, perhaps the investigator was perceived as a non-threatening health care professional who could help them. Conversely, the participants may have believed

that they were assisting in the research by sharing their experiences. It did seem, however, that these people had a need to talk. Johnson et al. (1996) found that among a group of 76 women newly-diagnosed with breast cancer, 45 percent of the women indicated that they did not inform their physician or other health care providers about specific fears they had related to their diagnosis. As a result, these women were not offered counseling. Nurses need to be sensitized to the possibility that patients may not be assertive in voicing their needs, and ensure that patients are given opportunities to discuss their concerns related to their cancer. It may be necessary for nurses to create these opportunities by initiating discussions with patients which normalize their concerns about their disease.

#### **Recommendations for Future Research**

Several recommendations for future research can be made based on the findings of this study. First, a larger sample could be used in a replication study. A random sampling technique could be used to strengthen the methodology, as could broadening the inclusion criteria to the entire province. These changes to the methodology may allow other associations between decision making preferences and sociodemographic characteristics and disease/treatment variables, level of family function, level of patients' symptom distress, and level of patients' functional ability to be identified.

A second recommendation would be to undertake longitudinal studies in an attempt to better understand the impact of changes to the variables noted above on decision making preferences. Specific time points at which to gather data would need to be determined, but would probably include the period immediately following diagnosis, during treatment phases, as well as at regular timed intervals. The end point for data collection would be either patient cure or patient demise.

Intervention studies in which nurses facilitate patient and family member preferred decision making roles would further knowledge related to family decision making. Patient and family member outcomes such as satisfaction with care, quality of life, anxiety, and depression could be tracked to determine the effectiveness of such interventions.

Lobchuk et al. (1997) concluded, in their article describing congruence between patient and family member perceptions of symptom distress, that these families must employ some effective form of communication in order to assess symptom distress in a similar fashion. Communication is one of the dimensions of family function that is assessed with the FAD. No statistically significant differences were found between the general functioning sub-scale of the FAD (level of family function) and decision making preferences. This may have been, in part, due to lack of variability in participant responses to the FAD, as almost all participants ranked their family function as healthy. Research using the communication sub-scale of the FAD may produce some statistically significant findings with respect to decision making preferences.

### Conclusion

Dealing with cancer is an emotional and stressful experience, both for the patient and the family. Decision making is an inevitable part of the experience, and the consumer movement has resulted in the option to participate actively in this process. A number of variables have been found to affect treatment decision making preferences. However, there is a lack of information on the family's role in decision making. The purposes of this study were to modify Degner et al.'s (1997b) CPS for use with cancer patients and their family members, to describe patient and family member decision making preferences, and to identify differences in preferred decision making roles by selected variables.

The CPS-F was found to be a unidimensional and reliable instrument. Using this instrument, patients were found to choose highly active decisional roles in relation to their family member. Congruent with this, family members chose passive decisional roles. Family members, however, were prepared to engage in more active roles when they perceived their patient family member as deteriorating either cognitively and/or physically. Another interpretation of the data is that three quarters of both patients and family members chose decisional roles which included input from the other (they chose either B, C, or D as their first choice), rather than a total control or total cede role (A or E as first choice). This finding lends support to the importance of the family's role, and thus the importance of including the family in decision making discussions.

Although higher levels of education were found to be associated with more active decision making preferences for patients in this study, more research is necessary to determine the relationship between demographic variables and family decision making preferences. To date, individual assessment is the best method for determining family decision making preferences.

One of the most striking findings of this study was the movement toward more passive decision making roles by both patients and family members when symptom distress increased. This creates a situation where nurses must support the patient and family through this difficult period, both in terms of symptom management and assistance with decision making.

Implications for nursing practice and research have been discussed. Further research in which patient and family member decision making preferences could be facilitated may result in higher levels of satisfaction with care, better quality of life, and decreased levels of anxiety and depression.

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**APPENDIX A****INVITATION TO SUBJECTS TO MEET INVESTIGATOR TO DISCUSS PROJECT****(to be used by Ward Staff)**

Margaret Kvern is a registered nurse and a Master of Nursing student at the Faculty of Nursing, University of Manitoba. She is doing research here about the involvement patients and family members want to have in making decisions about patient care. She is also interested in what affects patients' and family members' choices about involvement in making these decisions.

Information is strictly confidential. Whether or not you decide to participate will in no way influence the care you, or your ill family member, will receive.

Margaret would like to talk to you about participating in her study. Would you be willing to speak with her so that she can explain the study?

(If agreeable, the name of the subject is given to the investigator and the staff member thanks them.)

(If the subject declines, the staff member thanks them for their time.)

**APPENDIX B**  
**LETTER TO SUBJECTS REQUESTING PERMISSION TO RELEASE NAMES**  
**(HOME CARE PATIENTS AND FAMILY MEMBERS)**

Name

Home Care Coordinator

Hospital Address

Winnipeg, Manitoba

Dear \_\_\_\_\_:

I am mailing you this letter on behalf of Margaret Kvern, a registered nurse and a Master of Nursing student at the Faculty of Nursing, University of Manitoba. She is interested in learning about the involvement patients and family members want to have in making decisions about patient care. She is also interested in what affects patients' and family members' choices about involvement in making these decisions.

I am writing to obtain your consent to give Margaret Kvern your name as a possible participant in the study. If you do not wish your name to be given to Margaret, please call my secretary at \_\_\_\_\_ by \_\_\_\_\_. If I do not hear from you, I will assume that it is alright to give Margaret your name. Margaret will then contact you by telephone and provide you with further information about the study.

Should you decide to participate, all the information you give will be kept strictly confidential.

No information about you or your family will be shared with health professionals caring for you.

The care you or your family member receive will not be affected by your decision to take part or not take part in this study.

Thank you for considering this request. If you have any questions about this research study,

Margaret can be reached at 235-3480.

Sincerely,

Name of Home Care Coordinator

**APPENDIX C****LETTER TO SUBJECTS REQUESTING PERMISSION TO RELEASE NAMES  
(TEACHING UNIT PATIENTS AND FAMILY MEMBERS)**

Name of Patient's Teaching Unit  
Teaching Unit Address

Dear \_\_\_\_\_:

This letter is being mailed to you on behalf of Margaret Kvern, a registered nurse and a Master of Nursing student at the Faculty of Nursing, University of Manitoba. She is interested in learning about the involvement patients and family members want to have in making decisions about patient care. She is also interested in what affects patients' and family members' choices about involvement in making these decisions.

Your consent is being sought to give Margaret Kvern your name as a possible participant in the study. If you do not wish your name to be given to Margaret, please call the clinic at \_\_\_\_\_ by \_\_\_\_\_. If we do not hear from you, we will assume that it is alright to give Margaret your name. Margaret will then contact you by telephone and provide you with further information about the study. You may choose to participate or not participate at any time.

Should you decide to participate, all the information you give will be kept strictly confidential. No information about you or your family will be shared with health professionals caring for you. The care you or your family member receive will not be affected by your decision to take part or not take part in this study.

Thank you for considering this request. If you have any questions about this research study,

Margaret can be reached at 235-3480.

Sincerely,

Name of Patient's Teaching Unit

**APPENDIX D****PATIENT CONSENT TO PARTICIPATE**

**Title: Symptom Distress, Functional Ability, Family Function, and Decision Making  
Preferences in Cancer Patients and Their Families**

I \_\_\_\_\_ agree to participate in the above titled research project. The purpose of this study is to understand the preferences patients and their family members have about making decisions about patient care. The study is being conducted by Margaret Kvern, R.N., B.N., a Master of Nursing student at the Faculty of Nursing, University of Manitoba. Her advisor is Dr. Linda Kristjanson from the Faculty of Nursing, University of Manitoba. This study has been approved by the Ethics Review Committee at the Faculty of Nursing, University of Manitoba.

I understand that my participation involves answering questions about my thinking, memory, and concentration abilities. I will also be asked questions about my age, education, marital status, etc. The rest of the questions will be asked while I am alone with the investigator. These questions will be about how I am managing with my illness and my involvement in my own care decisions. Answering these questions will take approximately 20 to 30 minutes. I will be asked some of these questions on the following day, and this will take approximately 10 minutes.

Arrangements for the second interview will be made with the investigator who will adjust to my time and energy.

My participation is voluntary and I may withdraw from the study at any time by simply telling the investigator. My decision to participate or not participate in the study will in no way affect the care I receive.

The information I provide will be confidential because names will not be included on the questionnaire. My name will not be used in any reports. Only grouped information will be reported. This grouped information may be published.

Answering some questions may arouse sad feelings about the illness. Otherwise, there are no known risks involved in participating in the study. The study offers no direct benefit to me. However, the results may be helpful to health professionals caring for cancer patients and their families by giving them information about how to improve the care they give.

I understand that I can receive answers to any questions about the study at any time by contacting Margaret Kvern at 235-3480. Ms Kvern's advisor is Dr. Linda Kristjanson (235-3480) at the University of Manitoba.

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

Interviewer's  
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. Michael Harlos**  
Assistant Professor  
Department of Family Medicine  
Faculty of Medicine  
University of Manitoba

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

**Send to:** \_\_\_\_\_ **(Name)**

\_\_\_\_\_ **(Address)**

\_\_\_\_\_

**APPENDIX E****FAMILY MEMBER DISCLAIMER****Title: Symptom Distress, Functional Ability, Family Function, and Decision Making  
Preferences in Cancer Patients and Their Families**

I \_\_\_\_\_ agree to participate in the above titled research project.

The purpose of this study is to understand the preferences patients and their family members have about making decisions about patient care. The study is being conducted by Margaret Kvern, R.N., B.N., a Master of Nursing student at the Faculty of Nursing, University of Manitoba. Her advisor is Dr. Linda Kristjanson from the Faculty of Nursing, University of Manitoba. This study has been approved by the Ethics Review Committee at the Faculty of Nursing, University of Manitoba.

I understand that my participation involves answering questions about my age, education, marital status, etc. I will also be asked questions about my involvement in decision making and about the effects of the illness on my family - I will be asked these questions without my family member in the room. Answering these questions will take approximately 20 to 30 minutes. I will be asked some of these questions the following day, and this will take approximately five minutes. Arrangements for the second interview will be made with the investigator who will accommodate my schedule.

My participation is voluntary and I may withdraw from the study at any time by simply telling the investigator. My decision to participate or not participate in the study will in no way affect the care my family member receives.

The information I provide will be confidential because names will not be included on the questionnaire. My name will not be used in any reports. Only grouped information will be reported. This grouped information may be published.

Answering some questions may arouse sad feelings about the illness. Otherwise, there are no known risks involved in participating in the study. The study offers no direct benefit to me. However, the results may be helpful to health professionals caring for cancer patients and their families by giving them information about how to improve the care they give.

I understand that I can receive answers to any questions about the study at any time by contacting Margaret Kvern at 235-3480. Ms Kvern's advisor is Dr. Linda Kristjanson (235-3480) at the University of 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. Michael Harlos**  
Assistant Professor  
Department of Family Medicine  
Faculty of Medicine  
University of Manitoba

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

**Send to:** \_\_\_\_\_ **(Name)**

\_\_\_\_\_ **(Address)**

\_\_\_\_\_

## APPENDIX F

Subject No. \_\_

## FOLSTEIN MINI-MENTAL STATUS EXAMINATION

| Maximum<br>Score | Score |   |
|------------------|-------|---|
|                  |       | <b>Orientation</b>  |
| 5                | ( )   | What is the (year)(season)(date)(day)(month)?   |
| 5                | ( )   | Where are we<br>(country)(province)(city)(street/hospital)(street<br>number/hospital floor)?  |
|                  |       | <b>Registration</b>   |
| 3                | ( )   | Name 3 objects: 1 second to say each. Then ask the patient<br>all 3 after you have said them. Give 1 point for each correct<br>answer. Then repeat them until he/she learns all 3. Count<br>trials and record. Trials ____.   |
|                  |       | <b>Attention</b>  |
| 5                | ( )   | Serial 7's (count backwards from 100 by 7's). 1 point for<br>each correct. Stop after 5 answers. Alternately, spell<br>"world" backwards.   |
|                  |       | <b>Recall</b>   |
| 3                | ( )   | Ask for the 3 objects repeated above. Give 1 point for each<br>correct.   |
|                  |       | <b>Language</b>   |
| 9                | ( )   | Show a pencil and a watch. Ask patient to name them (2<br>points).<br>Repeat the following: "No ifs, andd, or buts" (1 point).<br>Follow a three-stage command: "Take a paper in your right<br>hand, fold it in half, and put it on the floor" (3 points).<br>Read and obey the following (show written item):<br>CLOSE YOUR EYES (1 point).<br>Write a sentence (1 point).<br>Copy a design (1 point). |

\_\_\_\_ = TOTAL SCORE

ASSESS level of consciousness along a continuum:

---

Alert   Drowsy   Stupor   Coma

## APPENDIX G

## PATIENT DEMOGRAPHIC DATA FORM

Subject No. \_\_

1. Marital status: Married/Common-law \_\_\_  
 Divorced/Separated \_\_\_  
 Never married \_\_\_  
 Widowed \_\_\_
2. Age: 18 - 29 years \_\_\_ 40 - 49 years \_\_\_ 60 - 69 years \_\_\_  
 30 - 39 years \_\_\_ 50 - 59 years \_\_\_ 70 years + \_\_\_
3. Sex: male \_\_\_ female \_\_\_
4. Education: grade 8 or less \_\_\_ some college \_\_\_  
 some high school \_\_\_ college degree \_\_\_  
 high school diploma \_\_\_ graduate degree \_\_\_
5. Occupation: clerical \_\_\_ retired \_\_\_ homemaker \_\_\_  
 labourer \_\_\_ management \_\_\_ other \_\_\_  
 retail \_\_\_ professional \_\_\_
6. Family Income: below \$10,000/year \_\_\_  
 \$11,000 - \$20,000/year \_\_\_  
 \$21,000 - \$30,000/year \_\_\_  
 \$31,000 - \$40,000/year \_\_\_  
 \$41,000 - \$50,000/year \_\_\_  
 \$51,000 - \$60,000/year \_\_\_  
 over \$60,000/year \_\_\_
7. Ethnic Background: European \_\_\_ Aboriginal peoples \_\_\_  
 British Isles \_\_\_ Asian \_\_\_  
 French \_\_\_ Others \_\_\_
8. Religion: Catholic \_\_\_ Protestant \_\_\_ Jewish \_\_\_  
 Other \_\_\_ None \_\_\_
9. Patient's Diagnosis (Primary): \_\_\_\_\_
10. Date of Diagnosis (month, year): \_\_\_\_\_

## APPENDIX H

## FAMILY MEMBER DEMOGRAPHIC DATA FORM

Subject No. \_\_

1. **Marital Status:** Married/Common-law \_\_  
 Divorced/Separated \_\_  
 Never married \_\_  
 Widowed \_\_
2. **Age:** 18 - 29 years \_\_      40 - 49 years \_\_      60 - 69 years \_\_  
 30 -39 years \_\_      50 - 59 years \_\_      70 years + \_\_
3. **Sex:** male \_\_      female \_\_
4. **Education:** grade 8 or less \_\_      some college \_\_  
 some high school \_\_      college degree \_\_  
 high school diploma \_\_      graduate degree \_\_
5. **Occupation:** clerical \_\_      retired \_\_      homemaker \_\_  
 labourer \_\_      management \_\_      other \_\_  
 retail \_\_      professional \_\_
6. **Relationship to Patient:** spouse \_\_      daughter \_\_  
 son \_\_      sibling \_\_  
 other \_\_
7. **Family Income:** below \$10,000/year \_\_  
 \$11,000 - \$20,000/year \_\_  
 \$21,000 - \$30,000/year \_\_  
 \$31,000 - \$40,000/year \_\_  
 \$41,000 - \$50,000/year \_\_  
 \$51,000 - \$60,000/year \_\_  
 over \$60,000/year \_\_
8. **Ethnic Background:** European \_\_      Aboriginal peoples \_\_  
 British Isles \_\_      Asian \_\_  
 French \_\_      Others \_\_
9. **Religion:** Catholic \_\_      Protestant \_\_      Jewish \_\_  
 Other \_\_      None \_\_

APPENDIX I

CONTROL PREFERENCES SCALE (CPS)

A. PATIENT/  
PHYSICIAN  
DIMENSION

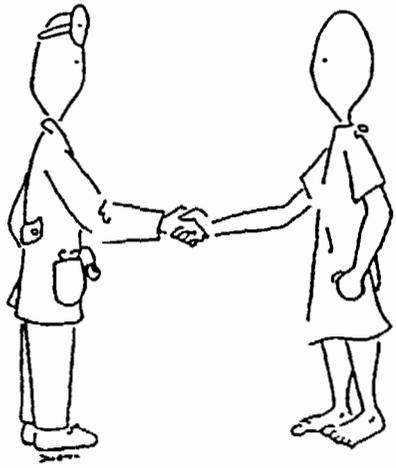
Active Role

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

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

Collaborative Role

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



Passive Role

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

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

**APPENDIX J****CONTROL PREFERENCES SCALE-FAMILY (CPS-F)  
-PATIENT-****ACTIVE**

- A. I prefer to make the final decision about which treatment I will receive.
- B. I prefer to make the final decision about my treatment after seriously considering my family member's opinion.

**COLLABORATIVE**

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

**PASSIVE**

- D. I prefer that my family member makes the final decision about which treatment will be used, but seriously considers my opinion.
- E. I prefer to leave all decisions regarding my treatment to my family member.

**APPENDIX K****CONTROL PREFERENCES SCALE - FAMILY (CPS-F)  
-FAMILY MEMBER-****ACTIVE**

- A. I prefer to make the final decision about which treatment my ill family member\* will receive.
- B. I prefer to make the final decision about my ill family member's treatment after seriously considering his/her opinion.

**COLLABORATIVE**

- C. I prefer that my ill family member and I share the responsibility for deciding which treatment is best for him/her.

**PASSIVE**

- D. I prefer that my ill family member makes the final decision about which treatment will be used, but seriously considers my opinion.
- E. I prefer to leave all decisions regarding my ill family member's care to him/her.

\* ill family member = patient-subject

## APPENDIX L

Subject No. \_\_

## FAMILY ASSESSMENT DEVICE GENERAL FUNCTIONING SUB-SCALE (FAD-GFS)

**Instructions:** This questionnaire contains a number of statements about families. Please read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family. For each statement there are four possible responses. Please answer each statement as honestly as you can.

1. Planning family activities is difficult because we misunderstand each other.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
2. In times of crisis we can turn to each other for support.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
3. We cannot talk to each other about the sadness we feel.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
4. Individuals are accepted for what they are.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
5. We avoid discussing our fears and concerns.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
6. We can express feelings to each other.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
7. There are lots of bad feelings in the family.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
8. We feel accepted for what we are.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
9. Making decisions is a problem for our family.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
10. We are able to make decisions about how to solve problems.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
11. We don't get along well together.  
 Strongly Agree     Agree     Disagree     Strongly Disagree
12. We confide in each other.  
 Strongly Agree     Agree     Disagree     Strongly Disagree

## APPENDIX M

Subject No. \_\_

## SYMPTOM DISTRESS SCALE (SDS)

**Instructions:** I have thirteen cards to show you. Each card has five statements. Think about what each statement says, and tell me (or point to, or circle if doing SDS independently) the statement that best says how you have been feeling over the past two to three days. The statements are numbered from one to five, with number one indicating no problems and number five indicating the most amount of problems. Numbers two, three, and four indicate that you feel somewhere in between the two extremes.

| SYMPTOM                  | DEGREE OF DISTRESS                             |   |  |  |   |
|--------------------------|--|---|--|--|---|
| 1. Nausea<br>(frequency) | 1<br>I seldom feel<br>nausea at all            | 2<br>I am nauseous<br>once in a while                             | 3<br>I am often<br>nauseous  | 4<br>I am usually<br>nauseous                            | 5<br>I suffer from<br>nausea<br>almost<br>continually                         |
| 2. Nausea<br>(intensity) | 1<br>When I have<br>nausea, it is<br>very mild | 2<br>When I have<br>nausea, it is<br>mildly<br>distressing        | 3<br>When I have<br>nausea, I feel<br>pretty sick                              | 4<br>When I have<br>nausea, I feel<br>very sick          | 5<br>When I have<br>nausea, I am<br>as sick as I<br>could possibly<br>be      |
| 3. Appetite              | 1<br>I have my<br>normal<br>appetite           | 2<br>My appetite is<br>usually, but not<br>always,<br>pretty good | 3<br>I don't really<br>enjoy my<br>food like I<br>used to                      | 4<br>I have to force<br>myself to eat<br>my food         | 5<br>I cannot<br>stand the<br>thought of<br>food                              |
| 4. Insomnia              | 1<br>I sleep as well<br>as I always<br>have    | 2<br>I have<br>occasional<br>spells of<br>sleeplessness           | 3<br>I frequently<br>have trouble<br>getting to<br>sleep and<br>staying asleep | 4<br>I have difficulty<br>sleeping almost<br>every night | 5<br>It is almost<br>impossible<br>for me to get<br>a decent<br>night's sleep |
| 5. Pain<br>(frequency)   | 1<br>I almost never<br>have pain               | 2<br>I have pain<br>once in a while                               | 3<br>I frequently<br>have pain<br>several<br>times a week                      | 4<br>I am usually<br>in some degree<br>of pain           | 5<br>I am in some<br>degree of<br>pain almost<br>continually                  |

|                        |   |   |  |   |   |
|------------------------|---|---|--|---|---|
| 6. Pain<br>(intensity) | 1<br>When I do<br>have pain, it is<br>very mild       | 2<br>When I do<br>have pain, it is<br>mildly<br>distressing           | 3<br>The pain I<br>do have is<br>usually<br>fairly intense   | 4<br>The pain I have<br>is usually<br>very intense  | 5<br>The pain I<br>have is<br>almost<br>unbearable  |
| 7. Fatigue             | 1<br>I am usually<br>not tired at all                 | 2<br>I am<br>occasionally<br>rather tired                             | 3<br>There are<br>frequently<br>periods when<br>I am<br>quite tired  | 4<br>I am usually<br>very tired   | 5<br>Most of the<br>time I feel<br>exhausted  |
| 8. Bowel               | 1<br>I have my<br>normal<br>pattern                   | 2<br>My bowel<br>pattern<br>occasionally<br>causes me<br>some concern | 3<br>I frequently<br>have discomfort<br>from my<br>present<br>bowel pattern  | 4<br>I am usually<br>in discomfort<br>because of<br>my present<br>bowel pattern                             | 5<br>My present<br>bowel pattern<br>has changed<br>drastically<br>from what<br>was normal<br>for me |
| 9. Concen-<br>tration  | 1<br>I have my<br>normal<br>ability to<br>concentrate | 2<br>I occasionally<br>have trouble<br>concentrating                  | 3<br>I often have<br>trouble<br>concentrating  | 4<br>I usually<br>have at least<br>some<br>difficulty<br>concentrating                                      | 5<br>I just can't<br>seem to<br>concentrate<br>at all   |
| 10. Appear-<br>ance    | 1<br>My<br>appearance<br>has basically<br>not changed | 2<br>My<br>appearance<br>has gotten<br>a little worse                 | 3<br>My<br>appearance<br>is definitely<br>worse than<br>it used to be,<br>but I am not<br>greatly<br>concerned<br>about it | 4<br>My<br>appearance<br>is definitely<br>worse than<br>it used to be,<br>and I am<br>concerned<br>about it | 5<br>My<br>appearance<br>has changed<br>drastically<br>from what<br>it was                          |
| 11. Breathing          | 1<br>I usually<br>breathe<br>normally                 | 2<br>I<br>occasionally<br>have trouble<br>breathing                   | 3<br>I often have<br>trouble<br>breathing  | 4<br>I can hardly<br>ever breathe<br>as easily as<br>I want   | 5<br>I almost<br>always have<br>severe trouble<br>with my<br>breathing                              |

|                    |   |  |  |   |  |
|--------------------|---|--|--|---|--|
| <b>12. Outlook</b> | <b>1</b><br>I am not<br>fearful<br>or worried | <b>2</b><br>I am a little<br>worried<br>about things | <b>3</b><br>I am quite<br>worried,<br>but unafraid | <b>4</b><br>I am worried<br>and a little<br>frightened<br>about things      | <b>5</b><br>I am worried<br>and scared<br>about things           |
| <b>13. Cough</b>   | <b>1</b><br>I seldom<br>cough                 | <b>2</b><br>I have an<br>occasional<br>cough         | <b>3</b><br>I often<br>cough                       | <b>4</b><br>I often<br>cough and<br>occasionally<br>have severe<br>coughing | <b>5</b><br>I often have<br>persistent<br>and severe<br>coughing |

## APPENDIX N

Subject No. \_\_

**KATZ INDEX OF ACTIVITIES OF DAILY LIVING (KATZ INDEX)**

**Instructions:** For each area of functioning, check the description that applies (the word “assistance” means supervision, direction, or personal assistance).

**Bathing (sponge bath, tub bath, or shower):**

\_\_\_\_\_  
 Receives no assistance  
 (gets in and out of tub  
 by self if tub is usual  
 means of bathing)

\_\_\_\_\_  
 Receives assistance in  
 bathing only one part of  
 the body (eg. legs)

\_\_\_\_\_  
 Receives assistance in  
 bathing more than one  
 part of the body (or  
 not able to bathe self  
 at all)

**Dressing (gets clothes from closet/drawer, including underclothes, outer garments, and using fasteners):**

\_\_\_\_\_  
 Gets clothes and gets  
 completely dressed  
 without assistance

\_\_\_\_\_  
 Gets clothes and gets  
 dressed without  
 assistance except for  
 assistance in tying  
 shoes

\_\_\_\_\_  
 Receives assistance in  
 getting clothes or in  
 getting dressed, or  
 stays partly or  
 completely undressed

**Toileting (going to the “toilet room” for bowel and urine elimination, cleaning self after elimination, and arranging clothes):**

\_\_\_\_\_  
 Goes to “toilet room”,  
 cleans self, and arranges  
 clothes without assistance  
 (may use object for support  
 such as a cane and may  
 manage night bedpan/  
 commode, emptying it  
 in the morning)

\_\_\_\_\_  
 Receives assistance in  
 going to “toilet room”  
 or in cleaning self or in  
 arranging clothes after  
 elimination or in use  
 of night bedpan/commode

\_\_\_\_\_  
 Doesn't go to room  
 termed “toilet” for  
 the elimination  
 process

**Transfer:**

\_\_\_\_\_ **Moves in and out of bed as well as in and out of chair without assistance (may use object for support such as a cane)**

\_\_\_\_\_ **Moves in and out of bed or chair with assistance**

\_\_\_\_\_ **Doesn't get out of bed**

**Continence:**

\_\_\_\_\_ **Controls urination and bowel movement completely by self**

\_\_\_\_\_ **Has occasional "accidents"**

\_\_\_\_\_ **Supervision helps keep urine and bowel control, catheter is used, or is incontinent**

**Feeding:**

\_\_\_\_\_ **Feeds self without assistance**

\_\_\_\_\_ **Feeds self except for getting assistance in cutting meat or buttering bread**

\_\_\_\_\_ **Receives assistance in feeding or is fed partly or completely using tubes or intravenous fluids**

**APPENDIX O**

Subject No. \_\_

**FIVE INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADL)**

**Instructions:** Answer each of the statements by placing an "X" beside the statement that best describes your ability to accomplish the stated tasks. Answer the statements in terms of your ability to perform the task over the past two to three days.

1. Can you get to places out of walking distance...  
 Without help (can travel alone on buses, taxis, or drive your own car)  
 With some help (need someone to help you or go with you when traveling), or unable to travel unless emergency arrangements are made for a specialized vehicle like an ambulance
  
2. Can you go shopping for groceries or clothes (assuming you have transportation)...  
 Without help (taking care of all shopping needs yourself, assuming you had transportation)  
 With some help (need someone to go with you on all shopping trips), or completely unable to do any shopping
  
3. Can you prepare you own meals...  
 Without help (plan and cook full meals yourself)  
 With some help (can prepare some things but unable to cook full meals yourself), or completely unable to prepare any meals
  
4. Can you do your housework...  
 Without help (can scrub floors, etc.)  
 With some help (can do light housework but need help with heavy work), or completely unable to do any housework
  
5. Can you handle your own money...  
 Without help (write cheques, pay bills, etc.)  
 With some help (manage day-to-day buying but need help with managing your cheque book and paying your bills), or completely unable to handle money

**APPENDIX P**

Subject No. \_\_

**DECISION MAKING INVOLVEMENT QUESTION**

**Instructions:** Answer the question by placing an "X" beside the response that best describes your ill family member's involvement in decision making. Answer the question in terms of decision making involvement over the past two to three days.

**To what extent is your ill family member involved in treatment/care decision making?**  
(eg. medication changes, being cared for at home or at the hospital)

Not at all        —  
Somewhat       —  
Quite a bit     —  
Totally         —

**Comments:**

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