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INFORMATION NEEDS, PARTICIPATION PREFERENCES AND
SATISFACTION WITH HEALTH CARE RELATIONSHIPS IN
CANCER PATIENTS: HOW THEY CHANGE OVER TIME

presented by

Dana Berry-Richardson

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INFORMATION NEEDS, PARTICIPATION PREFERENCES AND

SATISFACTION WITH HEALTH CARE RELATIONSHIPS IN

CANCER PATIENTS: HOW THEY CHANGE OVER TIME

By

Dana Berry–Richardson

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ABSTRACT

INFORMATION NEEDS, PARTICIPATION PREFERENCES AND SATISFACTION WITH HEALTH CARE RELATIONSHIPS IN CANCER PATIENTS: HOW THEY CHANGE OVER TIME

By

Dana Berry-Richardson

A great deal of attention has been focused on how individuals with cancer cope with their illness. Changing trends in care delivery, an aging population and greater successes in treatment have brought the cancer patient more and more into the primary care field. A lack of understanding exists, however, in how coping changes over the course of the illness and treatment trajectory. This study utilizes secondary data analysis from a larger, funded research grant, "Family Home Care for Cancer Patients", Dr. Barbara Given, R.N., Ph.D., principal investigator. The study, using a sample of 32 patients with varying cancer diagnoses, explored how patients' coping behaviors change over time. Information needs, satisfaction with health care relationships and preferences for participation in health care decision were measured at initial diagnosis of new or recurrent disease, and again at three six-month intervals. Findings suggest that time from diagnosis has an impact on patients' needs for information, demonstrating a decreasing need for information over time. In addition, gender and severity of illness influence the dependent variables, suggesting that women may wish to participate more in treatment decisions than do men, and that decreasing severity of symptoms may negatively impact patients' satisfaction with their health care providers. Individual needs of each patient need to be considered at each visit across the illness continuum as they shift in magnitude and content over time.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Introduction

Cancer is no longer a clinical problem encountered in the acute care setting alone. Individuals with cancer are being diagnosed and treated in an ever-increasing number of settings, including community hospitals, clinics, physician offices and even in the home setting. In 1992, an estimated 520,000 people were expected to die from cancer, approximately 1400 people a day. Of every 5 deaths in the U.S., one will be from cancer. In addition, 1,130,000 people were expected to be diagnosed with cancer in 1992 (ACS, 1992). With the escalating numbers of people diagnosed and living with cancer, it now qualifies as a chronic disease, and as such, enters the realm of primary care, with prevention, detection and ongoing management as priority issues.

The Clinical Nurse Specialist (CNS) in primary care encounters proof of this trend daily. Screening for cancer is an important function of primary care. Patients with cancer are being managed in ambulatory clinics and outreach programs (Hamric, 1992). More patients are being diagnosed and treated for cancer in tertiary care settings and then returning to the community primary care provider for symptom management, monitoring and follow up. The primary care CNS must be cognizant of the unique needs of cancer patients and their families.

Understanding how individuals experience and cope with cancer is critical for the CNS in primary care, and should include recognition of the entire cancer experience

1

across the disease trajectory. Unfortunately, until recently, there has been a lack of research and literature that examines how individuals manage with cancer beyond the initial diagnosis and treatment phase. The diagnosis of cancer has been recognized as a crisis (Lewandowski & Jones, 1988; Messerli, Garamendi & Romano, 1980) for both the client and his or her family. This period is often characterized by acute emotional turmoil, panic, denial and depression. Generally, this period resolves as clients gather information and begin to implement adaptive coping measures. However, as with other chronic illnesses, the process of living with cancer is rarely smooth, and crisis periods occur, often during periods of treatment transition and disease progression. The CNS must develop a working knowledge base of the phases of living with cancer, and understand how the client and family's needs may change during these phases (Lewandowski & Jones, 1988). Coping is not of interest in the diagnosis phase alone. It is instead, a vital ongoing process as the client undergoes and completes treatment, and learns to live with the illness. Literature exists that examines the initial crisis of diagnosis (Edlund & Sneed, 1989; Loveys & Klaich, 1991; O'Connor, Wicker, & Germino, 1990). A gap exists, though, in the area of long-term adjustment and coping. This is an area especially relevant for the primary care provider who is more likely to see the client in the later phase of the illness, during supportive care and follow-up management, than at initial diagnosis and during active treatment. There is a growing need to understand what the client experiences later in the disease and treatment trajectory, and how best to facilitate coping.

Three factors emerge as critical to the process of coping with cancer. First, the

gathering of information is clearly an essential task. Without information, the client cannot develop an understanding of the meaning or potential impact of the external event (the cancer diagnosis). Secondly, the development of a positive relationship with the health care team is essential. Without it, information cannot be successfully shared, questions asked or needs identified and met. Lastly, the client must be as much a part of the decision-making team as he or she wishes to be. Without this involvement, the client and family become "outsiders" and it is increasingly difficult for them to develop a clear understanding and personal meaning of the cancer's impact.

The primary care CNS is in a unique position to facilitate coping of the individual experiencing cancer. By fostering the above coping behaviors, the CNS assists the client to gather the essential components of cognitive appraisal, allowing each patient to establish a personal understanding and meaning for the illness. As educator, the CNS is able to meet information needs across the span of illness, both for the client and for the family. As client advocate, the CNS develops relationships with the client that are based upon trust, concern and respect. As clinician and advocate, the CNS operates at all times within a framework that recognizes the client as an active participant in treatment decisions. It is critical, though, to understand how the client's needs for information and participation change over the disease course, so that interventions may be tailored to meet those needs more effectively. Do clients need more information in the early stages of disease, or do they feel less informed later, when there may be less contact with the health care team? Does the client's desire to participate in decisions grow over time, as self-efficacy is gained, or does the client relinquish that control as he or she gains trust

that the health care provider will make an appropriate choice?

Statement of the Problem

Three behaviors have been identified as important to the process of clients' coping with cancer: information gathering, establishment of successful health care relationships and participation in health care decisions. These behaviors are used repeatedly in the cognitive appraisal process as it spans the phases of the cancer's course.

A gap in the literature exists to explore how these behaviors change over the course of time. Most research attention has focused on the initial diagnostic phase of illness. With more clients living longer, it has become imperative to examine coping over the entire continuum of illness, and to be able to intervene at each phase of illness to enhance individual and family coping.

The purpose of this study was to examine, by secondary analysis, how individuals' coping, as measured by information needs, satisfaction with relationships with health care providers and participation preferences, changes over time, as defined by months from diagnosis.

<u>Research Question</u>

This study attempted to answer the following research questions:

1. How do clients' information needs, participation preferences and satisfaction with health care relationships change over time?

2. Do the background demographic factors age, gender, education or income influence information needs, participation preferences and satisfaction with health care relationships over time?

3.   Is there a confounding effect of severity of illness on information needs, participation preferences and satisfaction with health care relationships over time?

Study Relevance

The results of this research will provide valuable insight to primary care providers who interact with individuals who are experiencing cancer. An individualized and wholistic approach to patient care is a hallmark of advanced nursing practice. Patients who have adequate information, are comfortable with their health care providers and feel a part of treatment decisions are likely to better define and meet their own needs, utilize resources, adhere to treatment regimens and find a satisfactory meaning for their illness experience. By gaining a better understanding of clients' coping over the course of illness, interventions aimed at facilitating information gathering, enhancing the health care relationship, and empowering patients to participate in treatment decisions to the extent they wish to will be identified. Intervention strategies may be better tailored to the phase of illness, allowing the CNS to provide care that is individualized and timely. This study yields information useful to the primary care and oncology fields alike.

Theoretical Framework

Moos (1977) developed a framework for examining how the individual copes with physical illness. A multifaceted process of adaptation occurs (see Appendix A for the original unmodified model) in which the patient establishes a personal meaning and understanding of the illness event (cognitive appraisal), and is then able to identify and utilize adaptive tasks and coping skills, and thus positively impact the outcome. The

ability to perceive and establish a satisfactory meaning of the illness event is influenced by three primary areas: the patient's background and personal factors, such as age, gender, previous experience with illness, and knowledge level; illness-related factors, such as potential for cure, invasiveness and discomfort of treatment and severity of illness symptoms; and physical and social environmental factors, such as social support and financial resources. The patient's ability to establish meaning, and then to select and utilize adaptive tasks and coping skills will, in turn, define the outcome of the illness crisis. The independent variable, time, is depicted as a feedback loop that will continually influence the process of cognitive appraisal (see Figure 1). Previous crisis outcomes will influence later ones; adaptive tasks will again be identified and previously proven effective coping skills exercised again.

Cognitive appraisal is worthy of further discussion here, for it places the three variables to be studied into context. Information seeking, establishment of positive relationships with health care providers and participation in treatment decisions are antecedents to patients' successful cognitive appraisal. Cognitive appraisal provides a "mediating" effect between the environmental stress (the illness) and the emotional response (Murray, 1964). It allows the individual and family to identify the stressor, look for resources available to allow coping, and then to form a perception of the extent of threat engendered. The process is an interactive one that requires input and understanding between the client, family and the health care team.

Moos (1977) defines essential adaptive tasks that must be dealt with by most clients experiencing physical illness:

1. Dealing with pain and incapacitation

2. Dealing with the health care environment and treatment procedures

3. Developing adequate relationships with professional staff

4. Preserving emotional balance

5. Preserving a satisfactory self-image

6. Preserving relationships with family and friends

7. Preparing for an uncertain future

Any number of coping skills enhance the client's ability to achieve the above tasks. Moos describes the following general areas of coping skills commonly used:

1. Denying or minimizing the seriousness of the threat

2. Seeking relevant information

3. Requesting reassurance and emotional support

4. Learning specific illness-related procedures

5. Setting concrete, limited goals

6. Rehearsing alternative outcomes

7. Finding a general purpose or meaning

For the purpose of this study, the model has been modified (see Figure 1) to more clearly depict the relationship between the independent variable (time) and the dependent variables (information needs, relationship satisfaction and participation preferences in health care decisions.) It is expected that the patient's needs will change over time, as the focus of care shifts from diagnosis, to treatment, to remission and survivorship or recurrence and advanced disease. Thus a feedback loop was added to the model to depict

the influence of time on the patient's needs. In addition, the CNS, within the framework of the health care system is in a position to assist the patient and family to meet those needs, so that patients and family have the tools they need for successful appraisal. The patient's ability to meet his or her needs over time will provide the essential ingredients for cognitive appraisal at each phase of the illness (see Figure 1).

Conceptual Definition of the Study Variables

The first dependent variable to be considered is information needs. Cognitive appraisal requires information. Without it, the individual is unable to define the threat engendered by the illness, to identify options for action or to mobilize support and coping measures. Information needs are defined as an expressed lack of adequate knowledge or information related to the cancer illness or its treatment.

The second dependent variable, relationship satisfaction, is defined as the patient's perception of the health care provider's degree of concern and caring for him or her as an individual. This is a distinct phenomenon from satisfaction with the medical treatment as a whole, a nebulous concept whose study is beyond the scope of this work. This concept is not represented as a distinct phenomenon from relationship dissatisfaction, but rather is thought to represent a continuum ranging from a complete lack of satisfaction (dissatisfaction) to high levels of satisfaction.

The third dependent variable, participation preferences, is defined as the extent to which the patient feels that he or she is an active participant in health care decisions and the treatment plan.

Figure 1: Modified Conceptual Model of Adaptation to Physical Illness (Moos, 1977).
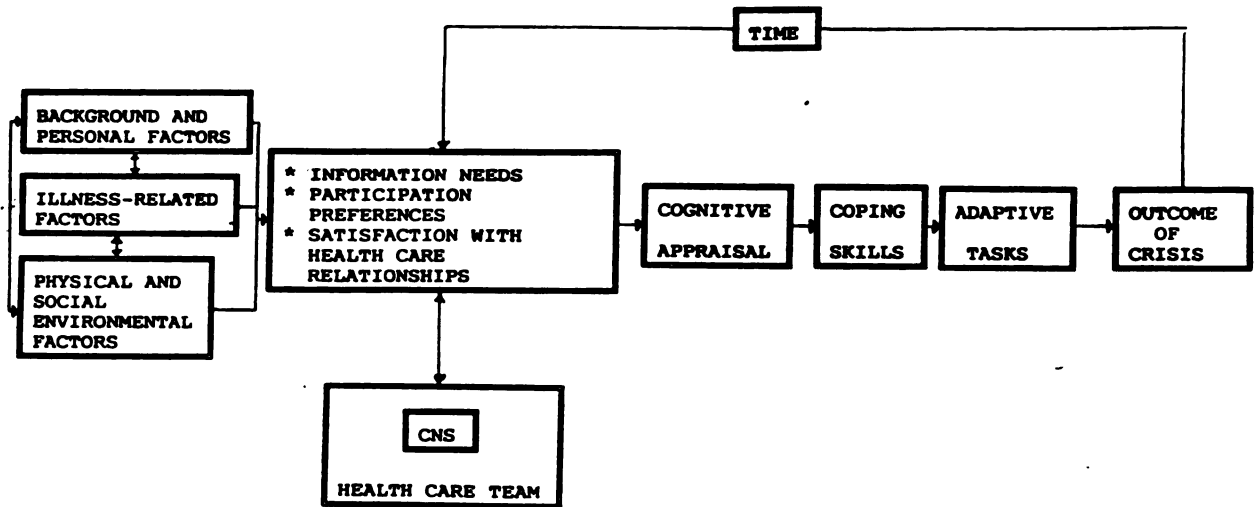
Time, the independent variable in this study, is defined as the amount of time (in months) from the initial diagnosis of cancer, or the diagnosis of new recurrence of disease. The dependent variables were measured at three intervals across the study: three, nine and fifteen months post diagnosis. These intervals were chosen so as to keep each time span between measurement equal, as well as to minimize a potential "Hawthorne" effect by measuring with the same instrument more often. Time is expected to produce changes in the three mediating variables influencing coping and cognitive appraisal: information needs, relationship satisfaction and participation preferences. As a result, it is anticipated that information needs, relationship satisfaction and participation factors will not remain static, but will also shift as time goes on. Current research has demonstrated that needs are high at the initial diagnostic phase of illness. There is limited information concerning cancer patients' needs later in the illness, but there is a growing belief that late stages in the illness are equally difficult, as patients are often completing treatment and may be receiving less support from family and the health care team.

While this study examines each of the dependent variables separately, there is evidence to suggest they are interrelated; patients who wish for more information tend to want to participate more (Cassileth et al., 1980). Patients who are satisfied with their relationships with the health care team are more likely to be comfortable asking questions and playing an active role in the decision-making process. Thus, the three dependent variables are expected to follow a similar pattern across the course of the study.

Moos's model depicts background personal, illness-related and environmental characteristics as influencing factors on the dependent variables. Age, gender, education,

10

illness and income, for example, may impact the individual's experience and coping needs. These factors were addressed in this study. A number of these characteristics were measured only once, as they were not likely to change significantly over the course of the study. The following background personal factors were measured at initial entry onto the study (at the screening interview): age, gender and education. Social and environmental factors examined at Wave I (three months post diagnosis) included marital status and income. The following illness–related factors were measured at three months only (Wave I): location of initial cancer, treatment modalities, presence of recurrence and involved sites of the cancer. Symptom experience was examined for its confounding effect across time, therefore it was measured at all three intervals (three, nine and fifteen months post diagnosis.)

The Role of the CNS

As depicted within the model, the CNS, within the framework of the health care system, is in a unique position to help the patient and family to identify and gather the essential tools for successful cognitive appraisal to take place, at any phase of illness. The CNS helps the patient to define individual information needs and meet them, using the learning style that works best for the individual. The CNS establishes a relationship with the entire family that fosters trust and respect. Within such a safe environment, it becomes possible for the CNS to continually evaluate the patient and family's satisfaction and address concerns before they become problems. And, finally, early within the relationship, the CNS assesses the patient's preference for participation in treatment decisions, and remains supportive of such preferences over the course of the illness. The

patient is accepted as an active part of the health care team.

In addition, the primary care CNS maintains a long-term relationship with the patient and family, that is not limited to one phase of illness (eg. the acute care phase). As a result, the CNS is able to impact repeatedly on the cognitive appraisal process, across the illness continuum. As information, relationship satisfaction and participation preference needs change, the CNS is uniquely suited to detect and meet new needs.

Critique of the Moos Framework

Moos's model has a number of strengths. It provides a simple framework for predicting how individuals will respond to physical illness, and ackowledges the mutifaceted process that is involved in coping with the stressors of being chronically ill. It successfully simplifies the process of adjustment to illness to a schema that demonstrates a linear process, incorporating the internal and external factors that impact individual coping.

However, the model is heavily based on the assumption that once cognitive appraisal occurs, there is a logical, linear flow to adaptive tasks and selection of coping skills. One might argue that information seeking, a coping skill, must be incorporated before cognitive appraisal can even occur.

The model requires modification to understand the role of the health care provider. Where do health care interventions fit in the model? In addition, the adaptive tasks and coping skills are not well described in Moos's work: instead they are simply listed in outline form. The argument may be made that every individual will have unique adaptive tasks to achieve, and highly individualized coping skills to utilize. The "grocery list" of

these factors in the model is not especially helpful.

Lastly, the role of the family in coping with illness is not depicted in the model, although Moos has discussed it more in his narrative work (1977). One is forced to relegate the family to the "Physical and Social Environmental Factors" section of the model, which makes it difficult to depict potential family intervention strategies.

However, Moos's model provides a springboard for further study of adaptation to chronic illness. The variables of this study are readily integrated into the model as antecedents to the cognitive appraisal approach to coping.

Review of the Literature

Progress has been made over the last decade in the oncology field. Cancers are being detected earlier and treated more successfully (Loescher, Clark, Atwood, Leigh & Lamb, 1990). This translates into more individuals experiencing cancer for longer periods of time. As a result, the health care field, and nursing in particular, is gaining interest in mediating factors in how these individuals experience and cope with their disease. In addition, focus has begun to shift to understanding adjustment across the entire cancer continuum, rather than just at the initial diagnostic phase (Adams, 1991).

Cancer survivorship as a construct has been studied by a number of researchers (Dow, 1990, 1991; Loescher et al., Mullan, 1984; Quigley, 1989). In all their works, these authors demonstrated that cancer patients' needs do not go away after treatment has been completed. Instead, their needs change in scope and content. The focus of patients' anxieties and distress change, but is no less compelling. There has been gradual recognition that health care providers must better understand how these needs change as

the illness itself changes over time.

Cognitive Appraisal

Adjustment to cancer requires appraisal of the extent of threat engendered by the diagnosis, and the likely ongoing impact of the disease and treatment. Cognitive appraisal, as a mediating mechanism of coping, has been studied for decades within the disciplines of stress theory, grief, bereavement and loss theory, and crisis intervention theory. Lazarus (1974) described appraisal as the central factor in self-regulation, in which the individual views events and defines the likely degree of impact on personal well-being. Demands of the situation are defined and potential coping mechanisms explored, selected and put into use. Primary appraisal allows the individual to define the potential impact of the stressor as beneficial, irrelevant or harmful. How serious is the diagnosis? Will it impact the patient's way of life? What threat may it bring, to working, relationships, even to life? Secondary appraisal involves defining resources and strategies for dealing with the stressor event. During this stage, the patient searches for support mechanisms and strategies to deal with the often acute stress of the cancer illness. Family is often essential during this time. In addition, supportive and candid relationships with health care providers may become a source of support and critical information. The variables under study in this research are critical to both phases of cognitive appraisal. However, primary appraisal was the focus of this research. Moos's (1977) model includes coping mechanisms and adaptive tasks as an outcome of the initial appraisal of the crisis; however, they were not explored in this study.

Information Needs

Primary appraisal requires accurate information. The individual with cancer requires complete and comprehensive information in order to define the extent of threat inherent in the cancer illness. The health care team must be able to predict and meet information needs at the diagnostic, treatment, and adaptation phases of illness. Information is no less critical for secondary appraisal. The patient and his family will build an inventory of resources to utilize to cope with the threat of the illness. The health care provider must be able to facilitate identification of resources and coping strategies at all phases of the illness.

Literature exists that identifies the importance of meeting information needs at the initial diagnostic phase. Derdarian's work (1987, 1989) with recently diagnosed cancer patients yielded compelling support for Lazarus's (1974) theory that information seeking is a critical task of coping. Patients and family who had received an individualized, comprehensive information-providing intervention reported lower information needs, and higher satisfaction and coping scores than the control group who received routine, standardized written or verbal information. Sutherland et al. (1989) reported, in their work with recently diagnosed cancer patients undergoing treatment, an interesting lack of correlation between desire for information and desire for participation in treatment decisions. Patients actively sought information and were satisfied with the information provided but the 63% who scored highly on the information-seeking questionnaire preferred little or no involvement in decision-making. Cassileth, Zupkis, Sutton-Smith and March (1980) reported that patients who wanted detailed and complete information

15

about their disease tended to be white and younger, better educated and more recently diagnosed than those who preferred no information.

A gap exists in the literature that examines how information needs of clients and their families are altered by time from diagnosis and by change in health status. Adams (1991) discusses how information needs, and thus teaching strategies and content, may change across the diagnostic, treatment, rehabilitation and continuing care, survivorship, remission, recurrence and advanced disease phases of cancer care. The importance of an interdisciplinary approach to cancer education, and of involving the entire family is stressed. Loescher et al. (1990) examined physiological, psychological and socioeconomic problems encountered by cancer survivors. The need for information remained as poignant for these survivors as it seems to be for those newly diagnosed. Patients reported feelings of vulnerability, prompting frequent contact with the health care team for reassurance. In addition, patients reported that information from the health care provider assisted in dealing with physical changes and problem–solving, but did not mediate their sensation of personal vulnerability.

In summary, the paucity of literature examining the relationship between time from diagnosis and information needs further supports the significance of this study. In this era of cost constraints, it is critical that nurses who work with cancer patients and their families be able to provide information that is relevant, and with timing and methods that enhance its usefulness to clients and their families.

Relationship Satisfaction

The health care relationship, as a factor in client adjustment to illness warrants

careful scrutiny. While technology and sophistication in diagnostics and therapeutics have sky-rocketed in this decade, consumer satisfaction has not (Thorne & Robinson, 1988). Dissatisfaction is an expensive phenomenon that may be measured in terms of noncompliance and litigation.

Moos (1977) identifies the establishment of satisfactory relationships with the health care team as a critical adaptive task of adjusting to chronic illness. The health care environment does not always make such a task easy, with fragmented care, turn-over of health care providers, lack of clear information about the illness and treatment options, confusing jargon and clearly imbalanced control acting as impeding factors.

Satisfaction has been examined in relation to physician behaviors and cancer patients' perceived involvement in physician-patient interactions in the inpatient setting (Blanchard, Ruckdeschel, Fletcher & Blanchard, 1986). Patients uniformly reported high satisfaction with their oncologists (Mean = 8.56, on a 10 centimeter scale), with advancing age, poor prognosis and positive news offered by the oncologist correlated with higher satisfaction scores. In addition, patients who reported higher satisfaction perceived greater involvement and reported having had their needs better met than those who responded with lower satisfaction scores. An interesting finding was that discussion of the family's role in the patient's care was associated with lower patient satisfaction scores. As pointed out by the authors, this may have been a reflection of worsening disease and greater distress on the patient's part.

Satisfaction with the health care relationships does not remain static over the course of the disease and treatment trajectory. Thorne and Robinson (1988), in their study of

17

26 families of chronically ill children, have identified stages of the health care relationship in patients and families dealing with chronic illness. An initial *naive trusting* stage occurs early in the relationship, as the client and family approach the health care team with the assumption that there is a shared perspective of the client's needs. There is an expectation that the role of the family will be held paramount. The client and family gather information in this stage and wait in a passive mode for their needs to be anticipated and met. This stage gives way to dissatisfaction, as the client and family come to realize that their health care professionals may hold very different perspectives and goals from their own. This leads to the *disenchantment* phase, characterized by anger, frustration and fear. There is a perceived difficulty in obtaining information from the health care providers and a generalized perceived lack of accessibility. Thorne and Robinson describe the last phase as a *guarded alliance* in which a cooperative model of medical and family involvement develops. The client and family have greater understanding of the norms of the health care system and of effective ways to communicate with the team. They remain vigilant advocates and perceive both strengths and limitations of the health care providers. In addition, family may take steps to decrease the emotional distance of the provider, by accepting him or her as a human individual, rather than as the medical savior.

Understanding how relationships change over time will allow us to predict and anticipate the client's and family's needs. By addressing these issues, we, as health care professionals, may be able to enhance the quality of the care delivered, and in turn, the success of the outcomes. Further research is needed to document factors that improve and

18

diminish the quality of our relationships with clients and families, and how these factors are altered over time from the initial diagnosis.

Participation Preferences

The consumer movement in the health care arena has advocated shared decision making by patients and clinicians. There exists growing support for inclusion of the client and family as partners in the treatment planning team. Parsons (1951) was one of the early authors to address the responsibilities of the sick person: to be motivated to get well, to seek the expertise of a professional and to trust the doctor and comply with the medical regimen. In contrast, especially within the discipline of nursing, there has been recent advocacy of allowing the client final decision-making power, and tailoring treatment plans to the individual's unique needs and preferences. Success has been reported, for example, in the use of a client-centered model of drug choice with hypertensive patients, who were allowed to select and trial drugs. Enhanced control, compliance and subjective report of response to therapy were reported (Gullickson, 1993).

Limited research exists that examines how cancer patients' desire for participation in treatment decisions changes over the course of their illness. Preferences have been measured as dichotomous variables, and usually at single points in time (Blanchard, Labrecque, Ruckdeschel & Blanchard, 1988; Degner & Sloan, 1992). Cassileth, Zupkis, Sutton-Smith and March (1980) found that patients who desired to participate fully in treatment decisions were younger and better educated than those who did not. Degner and Sloan (1992) reported that three variables impact desire for participation in health care decisions: age, education and gender. Older patients preferred less involvement, and

more educated patients preferred greater participation. In addition, women were more likely to desire involvement in decisions than men. This latter finding was not supported by Blanchard et al.'s (1988) study, in which there existed no significant difference in preferences between the sexes.

Only one study was found that explored differences between participation preferences at different disease stages. Degner and Sloan (1992) reported that, contrary to expectations, patients who were more ill did not desire less control over their treatment decisions. Symptom distress and disease stage remained insignificant in predicting participation preferences. In that same study, age was the most important predictor of preferences for participating in decisions, followed by gender. These results contrasted strikingly in the same study, when compared against a control group of healthy cohorts. The control group reported preferring a significantly higher degree of participation than the cancer patients did. The authors speculated that the majority of cancer patients in the study were fairly recently diagnosed, and may have been psychologically vulnerable, thus preferring a passive role until they had the information they needed to more actively participate.

Studies are needed to more accurately understand the role of time and experience in mediating desire for participation. There is a shortage of research that demonstrates what degree of control and participation clients and their families prefer. In addition, it has yet to be established that clients who wish a great deal of information will, in turn, use it to participate in treatment decisions. There is a need for further controlled, longitudinal studies to examine the patient outcomes of shared participation models.

In summary, there is a shortage of convincing, empirical data that describe how individuals cope with cancer. Most studies focus on the initial diagnostic and treatment phases of illness. There is a clear lack of longitudinal research that explores the cancer experience over time. In addition, there are few studies that examine the health care provider's role in facilitating the coping process over the entire disease and treatment course. Further study is needed in these areas, as well as in exploring the impact of enhanced coping on clinical outcomes.

Methods

This study was a secondary analysis of data from "Family Homecare For Cancer Patients", (Given & Given, 1988). The sample consisted of 32 individuals with cancer (out of an original total of 121 at the study onset) who completed questionnaires at all five measurement intervals of the study. Data were compiled from self–administered questionnaires completed by patients at three of the five intervals: three months post diagnosis (Wave I), nine months post diagnosis (Wave III) amd fifteen months post diagnosis (Wave V).

The following hypotheses were addressed:

1. There will be a significant main effect for time on all three of the dependent variables over time.

2. There will be a significant effect on the means of all three dependent variables over time related to the factors of age, gender, education and income.

3.   There will not be a significant effect on the means of the three dependent variables over time by the severity of the patient's illness at each wave.

Sample

Given and Given's original study (1988) used a non-probability convenience method. For further information regarding specific aims of the original study, see Appendix B. The sample for the present study was comprised of 32 individuals (male and female) with new cancer or new recurrence of disease who had completed the questionnaires at all three of the measurement intervals (three, nine and fifteen months post-diagnosis.) All were English-speaking, with solid tumors, leukemia or hodgkins lymphomas; between the ages of 20 and 90, with an active caregiver who was also willing to participate in the study. All patients required some assistance with activities of daily living. All subjects indicated consent to participate by completing an informed consent form (see Appendix C).

Data Collection Procedures

Subjects completed questionnaires that were mailed to them in return addressed, stamped envelopes. Data was compiled from questionnaires completed by patients three, nine and fifteen months post diagnosis.

Operational Definitions

The dependent variables were operationalized as follows from the Treatment-related Demands of Illness Inventory (Woods, Haberman & Packard, 1984, 1987):

(1)   Information needs are the patient's perceived need for more information about the disease and treatment than is already possessed. Patients were

asked, for example, to what extent they have wanted more facts about treatment, or wanted to know why they were asked to do something in particular for treatment. This variable is addressed in items 7 and 11 of the Treatment-Related Demands of Illness Inventory.

(2) Relationship satisfaction is the patient's perception that the health care provider does not care for him or her as an individual. Patients were asked to what extent their health care providers have been insensitive to their preferences, acted as if their opinions were unimportant or not shown concern for them as individuals. This variable is addressed in items 1, 2, 3, 5, 6 and 14 of the Treatment-Related Demands of Illness Inventory.

(3) Participation preferences are the patient's perception that he or she has not been included enough in treatment decisions. Patients were asked to what extent they have felt rushed to make hasty decisions, wanted to be more assertive in the decision-making process or wanted to question decisions but been unable to. This variable is measured in items 4, 8, 9, 10 and 12 of the Treatment-Related Demands of Illness Inventory.

Time, the independent variable, is defined as the number of months from diagnosis of new or recurrent disease, to be expressed by wave number: Wave I was three months post diagnosis; Wave III was nine months post diagnosis; Wave V was fifteen months post diagnosis.

Background factor definitions of age and gender are self-explanatory. Education and income was defined categorically (see Table 1).

23

Severity of illness was measured by the patient's perceived symptom experience. Patients indicated whether their experience with a number of given symptoms was mild, moderate or severe. If a given symptom was not experienced at all, the patient left it blank.

<u>Instrumentation</u>

The instrument used was the Treatment Issues subscale of the Demands of Illness Inventory (DOII), by Woods, Haberman and Packard, (1984, 1987). The DOII measures demands commonly experienced by patients and family members dealing with chronic illness, including the challenges of managing treatment regimens and side effects, maintaining family functioning, managing symptoms, maintaining body image and seeking causal explanations for illness (Haberman, Woods & Packard, 1990).

The scale uses a 5-item likert format, based on two stem sentences (see Appendix D). Three items (questions 13, 15 and 16) were eliminated for this study after psychometric testing revealed that they measured global satisfaction with medical care, a construct that is beyond the scope of this study. Therefore, only thirteen items will be included.

The DOII has been used with a number of chronic illnesses including diabetes, breast cancer, and fibrocystic breast disease in the Family Impact Study (FIS) (Haberman, Woods & Packard, 1990). The instrument was also utilized in the Family Functioning during Chronic Illness study (FFCI), a secondary project by the same authors. In this study women with breast cancer and diabetes were compared. The instrument is scored on both the number of illness demands as well as their intensity. Following the FFCI

Haberman, Woods and Packard (1990) reported alpha coefficients of 0.89 for the number scoring, and 0.92 for the intensity.

Factor analysis of the instrument by Given and Given (1988) revealed four "subconcepts" within the Treatment Issues subscale: information needs, satisfaction with medical treatment, participation, and relationship satisfaction. As mentioned above, satisfaction with medical treatment will not be considered in this study. Alpha coefficients for the remaining three concepts are: Information Needs: 0.73; Relationship Satisfaction: 0.84; Participation Preferences 0.82.

Construct validity was established by Haberman, Woods and Packard (1990) using extensive literature review. In addition, contrasted groups method was used with three distinct illnesses (diabetes, fibrocystic breast disease and breast cancer) and supported the validity of the instrument. The authors also compared the instrument with other standardized instruments used in the Family Impact Study and concluded that the instrument contained significant measures of coping (Haberman, Woods & Packard, 1990). No further validity testing was carried out by Given and Given (1988).

Scoring

The DOII is scored for number and intensity of demands. Items are scored on a five point likert scale ranging from 0 indicating "not at all' to 4 indicating "extremely". There are two stem statements in the modified Treatment Issues subscale; "At times some of my health care providers have...", and "As I've experienced my illness situation, I've...". The higher the DOII score, the more demands (or needs) exist. Thus, for example, a high "satisfaction" score, actually indicates a high degree of dissatisfaction. The frequency

of occurrence score is the number of items in the subscale rated 1 or greater. The intensity score is the summative score on each of the variable item groups (eg. information needs). Frequency scores will not be used for this study. Only mean intensity scores will be used in the analysis (range 0 to 4).

Symptom severity was scored 0 to 4. If the patient did not experience a given symptom at all, the response was left blank, and a "0" was scored. If the symptom was experienced, the patient was asked to rate it as mild, moderate or severe, and number scores were assigned to each response (1 for mild; 2 for moderate; 3 for severe.) This allowed calculation of mean symptom experience at each of the measurement intervals.

Data Analysis

The research design was exploratory, using secondary analysis of data from a longitudinal field study. No external manipulation of the independent variable (time from diagnosis) was feasible, and there was no randomization or control group. Exploratory studies are characterized by detailed analysis of a concept or construct. In addition, exploratory research implies that there is a lack of knowledge about the topic, and therefore limited research upon which to build (Brink & Wood, 1988).

Descriptive statistics were utilized to define the demographics of the sample: frequency distributions and percentages were collated for background data such as gender, marital status and diagnosis. Ranges, means and standard deviations were identified for interval and ratio measures, such as age. Education and income were measured categorically and were represented by frequency tables. The following tests were utilized to address each hypothesis:

1.	Hypothesis # 1 : Mean intensity scores of the 32 subjects were calculated for the three dependent variables and compared at waves I, III and V. Three repeated measures analysis of variance were used to determine the significance of the difference in the three means.

2.	Hypothesis # 2: One-way repeated measures analysis of variance was used to determine the effect of the factors gender, age, education and income on the three dependent variables.

3.	Hypothesis # 3: One way repeated measures analysis of variance was used to determine the confounding effect of symptom experience on the three dependent variables over time.

Repeated measures one-way ANOVA was used to examine the significance of the difference in the means, because three means were to be compared, thus eliminating the paired t-test method as an option. While change scores might have yielded more accurate information about individual trends across the three time intervals, it was determined to be beyond the scope of this study.

Because the sample size was so small, only two cells were built for the factors to be used in the ANOVA for hypothesis # 2, to avoid having any empty cells. Frequency tables were studied for each of the four factors and the median score was used to break the sample into two categories (see Table 9).

Assumptions of the Study

Assumptions of the study include the following:

1.	Caregiver education may be used as a proxy measure of patients' education

level.

2.   There was no significant change in the factors age, gender, education and income over the course of the three measurement intervals, thus allowing a single measure of these at the study onset to suffice.

3.   Marital status showed so little variation that it may be eliminated as an important background factor influencing the dependent variables.

Limitations of the Study

Limitations of this study included the following:

1.   The study design used secondary analysis, thus limiting the ability to gather precisely the data desired.

2.   The sample size is very small, thus limiting the ability to generalize the results. In addition, only patients with cancer were included in the data set, therefore limiting the researcher's ability to infer conclusions to other chronic illnesses.

3.   The statistical method used (repeated measures analysis of variance) by utilizing group means, lost valuable information about individual scores. However, this sacrifice was deemed necessary, as calculating individual change scores was beyond the scope of this project.

4.   There was a degree of selection bias in the sampling method. By utilizing only those subjects who remained on study at wave V, the researcher may have introduced an unexplored "difference" into the sample. Those subjects who remained may possess different characteristics from those who

28

dropped which may have impacted the dependent variables as well.

Protection of Human Subjects

Protection of the rights of human subjects was maintained by using identification codes only during all data analysis. Only aggregate data was utilized. No individual's name was ever available to the researcher during the study. Approval from the University Committee on Research Involving Human Subjects (UCHRIS) for this research study was received.

Findings

The sample to be described consisted of 32 patients who returned all three self-administered questionnaires (SAB's). Of the original 51 patients involved at the study outset, 42 returned the three month (Wave I) SAB, 36 returned the nine month (Wave III) SAB and 35 returned the fifteen month (Wave V) SAB.

Mean age of the sample was 58.9 years (S.D. = 14.56). Exactly half the sample was female, and half was male. Almost all of the subjects were married (90.6%). Patients' average annual household income was $37,714 (S.D. = 17,500). Of the sample, 17 (53%) had completed high school, while 3 (9.4%) had completed college. The most common diagnosis was colon cancer, followed by lung cancer. All patients were undergoing treatment at the study outset, the majority receiving chemotherapy. Table 1 summarizes the demographic characteristics of the sample. Table 2 illustrates disease and treatment characteristics of the sample.

Table 1.

Sociodemographic characteristics of the sample

Characteristics	n	%
Age		
20–30	2	6.2
31–40	2	6.2
41–50	4	12.5
51–60	7	21.9
61–70	8	25.0
71–80	8	25.0
81 +	1	3.1
Gender		
Male	16	50.0
Female	16	50.0
Marital Status		
Married	29	90.6
Single	1	3.1
Divorced	1	3.1
Widowed	1	3.1
Highest Grade Completed		
Grade school	1	3.1
Some high school	3	9.4
High school	17	53.1
Some college	8	25.0
College	3	9.4
Patient Household Income		
<$20,000	4	12.5
$20,000–$35,000	10	31.2
$35,001–$50,000	7	21.8
$50,001–$65,000	4	12.5
$65,001–$75,000	3	9.4
Missing	4	12.5

Table 2

Disease and treatment characteristics of the sample

Characteristic	n	%
Diagnosis (Primary cancer site)		
Breast	5	15.6
Colon	10	31.3
Gastrointestinal	1	3.1
Gynecological	1	3.1
Lung	7	21.9
Lymphoma	4	12.5
Leukemia	1	3.1
Brain	1	3.1
Hodgkin's	1	3.1
Other	1	3.1
Current Treatment		
Hormonal modalities	1	3.1
Chemotherapy	24	75.0
Radiation therapy	4	12.5
Surgery	8	25.0
Oral chemotherapy	3	9.4
Other	3	9.4
Diagnosed Recurrence		
Yes	6	18.8
No	26	81.3

Analysis of Research Questions

Question # 1. How do clients' information needs, participation preferences and satisfaction with health care relationships change over time?

Information Needs over Time

Information needs diminished over time (see Table 3), with the largest drop between Wave I and Wave III (three and nine months post diagnosis). Standard deviations were

large at all three waves. Individual responses ranged from 0, indicating patients eperienced no problem with unmet information needs at all, to 4, indicating patients were extremely bothered by unmet information needs. Repeated measure analysis of variance (ANOVA) revealed the difference in the means to be significant ($p \leq .05$), with an F score of 4.49 and significance of 0.016 (see Table 4).

Table 3

Mean Information Needs over Time

	Wave I	Wave III	Wave V
Mean (Range 0 – 4)	1.50	1.05	.90
Standard deviation	1.27	1.13	1.14

Table 4

Repeated Measures ANOVA: The effect of time on information needs

Variation	S.S.	D.F.	M.S.	F.	Sig.
Within–subject	37.87	54	.70		
Time	6.29	2	3.15	4.49	.016

Participation Preferences over Time

Like information needs, participation preference scores dropped off at each wave, indicating subjects felt less excluded from decision making at each wave. The largest drop was between three months (Wave I) and nine months (Wave III), however scores were uniformly low, with relatively small standard deviations (see Table 5). ANOVA

demonstrated the difference between the means to be less than significant (see Table 6).

Table 5

Mean participation preferences over time

	Wave I	Wave III	Wave V
Mean (Range 0 – 4)	0.55	0.20	0.19
Standard deviation	0.83	0.39	0.45

Table 6

Repeated measures ANOVA: The effect of time on participation preferences

Variation	S.S.	D.F.	M.S.	F.	Sig.
Within–subject	8.81	54	0.16		
Time	.81	2	0.41	2.49	.093

Relationship Satisfaction over Time

Relationship satisfaction scores did not follow the same pattern as the previous two variables. The group mean score dropped at nine months (Wave III), and then climbed to its highest level at fifteen months (Wave V) (see Table 7). However, the means were again uniformly low (the highest individual mean score for relationship satisfaction was 1.67, on the 0 to 4 scale). F score failed to achieve significance at the .05 level (see table 8).

Table 7

Mean relationship satisfaction over time

	Wave I	Wave III	Wave V
Mean (Range 0 – 4)	0.12	0.05	0.17
Standard deviation	0.24	0.12	0.38

Table 8

Repeated measures ANOVA: The effect of time on relationship satisfaction

Variation	S.S.	D.F.	M.S.	F.	Sig.
Within–subjects	2.43	54	0.05		
Time	0.24	2	0.12	2.72	.075

Question # 2.   Do the background demographic factors age, gender, income and education influence the dependent variables over time?

Following an analysis of the characteristics of the sample, and review of the literature to select factors that may confound the relationship between the dependent variables and time, four factors were selected. The sample was divided into two groups for each factor. Age was divided into those younger than 60, and those older. Division of gender is self explanatory. Income groups were defined as less than or equal to $32,500, and greater than or equal to $37,500. Education was grouped by "completed high school or less", or "some college or more". Means and standard deviations were computed for each group on the three dependent variables at the three waves (see Table 9).

34

Table 9

Mean dependent variable scores by age, gender, income and education

	Wave I	Wave III	Wave V
Information Needs			
< 60	1.96	1.36	1.20
≥ 60	1.09	0.79	0.62
Male	1.23	1.03	0.69
Female	1.77	1.06	1.13
≤ $32,500	1.31	0.93	0.96
≥ $37,500	1.69	1.08	0.86
High school or <	1.31	0.97	0.77
Some college or >	1.94	1.18	1.14
Participation Preferences			
< 60	0.63	0.16	0.25
≥ 60	0.34	0.19	0.08
Male	0.28	0.24	0.05
Female	0.67	0.11	0.28
≤ $32,500	0.28	0.23	0.07
≥ $37,500	0.57	0.14	0.26
High school or <	0.44	0.18	0.05
Some college or >	0.56	0.14	0.26
Relationship Satisfaction			
< 60	0.13	0.10	0.22
≥ 60	0.11	0.02	0.13
Male	0.14	0.03	0.08
Female	0.10	0.07	0.27
≤ $32,500	0.14	0.02	0.11
≥ $37,500	0.14	0.10	0.27
High school or <	0.10	0.03	0.13
Some college or >	0.17	0.09	0.26

ANOVA's were computed for each dependent variable by the four factors (see Table 10). Interaction effects between the factors were not examined.

Table 10

ANOVA: The effects of age, gender, income and education on the dependent variables

	S.S.	D.F.	M.S.	F.	Sig.
Information Needs by age:					
Within cells	37.72	52	0.73		
Time	6.36	2	3.18	4.39	0.17
Age by time	0.15	2	0.08	0.10	0.90
by gender:					
Within cells	35.83	52	0.69		
Time	6.29	2	3.15	4.57	0.01
Gender by time	2.04	2	1.02	1.48	0.23
by income:					
Within cells	35.43	46	0.77		
Time	5.83	2	2.91	3.78	.030
Income by time	0.35	2	0.17	0.23	.799
by education:					
Within cells	36.98	52	0.71		
Time	7.15	2	3.57	5.03	.010
Education by time	0.90	2	0.45	0.63	.535
Participation Preferences by age:					
Within cells	5.90	52	0.11		
Time	0.74	2	0.37	3.26	.046
Age by time	0.64	2	0.32	2.84	.068

36

Table 10 Cont'd

by gender:

Within cells	5.70	52	0.11		
Time	0.66	2	0.33	3.03	.057
Gender by time	0.84	2	0.42	3.84	.028

by income:

Within cells	5.96	46	0.13		
Time	0.68	2	0.34	2.64	.082
Income by time	0.44	2	0.22	1.71	.193

by education:

Within cells	6.11	52	0.12		
Time	0.70	2	0.35	2.97	.060
Education by time	0.43	2	0.22	1.84	.169

Relationship Satisfaction
by age:

Within cells	2.38	52	0.05		
Time	0.25	2	0.12	2.72	.076
Age by time	0.05	2	0.02	0.52	.600

by gender:

Within cells	2.24	52	0.04		
Time	0.24	2	0.12	2.83	.068
Gender by time	0.19	2	0.09	2.17	.124

by income:

Within cells	2.27	46	0.05		
Time	0.28	2	0.14	2.86	.068
Income by time	0.13	2	0.07	1.32	.277

by education:

Within cells	2.38	52	0.05		
Time	0.28	2	0.14	3.07	.055
Education by time	0.05	2	0.03	0.57	.567

Question # 3. Is there a confounding effect for severity of illness on the dependent variables over time?

To examine the potentially confounding effect of the severity of patients' symptoms on the dependent variables over time, mean symptom severity scores at each wave are reported, along with standard deviations (Table 11). The range of symptom severity scores was 0 to 3, with 0 indicating the symptom was not experienced at all, 1 indicating severity was "mild", 2 indicating severity was "moderate", and 3 indicating severity was "severe". Mean severity of symptoms diminished at each wave, an unexpected finding, with the largest drop between waves I and III. Repeated measure ANOVAs are reported for the influence of symptom severity on each dependent variable at each wave (see Table 12). The only dependent variable significantly affected by symptom severity was relationship satisfaction ($p \leq .05$), and this was apparent only at the nine and fifteen month post diagnosis measurement intervals (Waves III and V).

Table 11

Mean symptom severity at each wave

	Wave I	Wave III	Wave V
Mean (Range 0 – 3)	0.56	0.43	0.37
Standard deviation	0.34	0.43	0.34

Table 12

Repeated measures ANOVA: The effect of symptom severity on the dependent variables.

	S.S.	D.F.	M.S.	F.	Sig.
Information Needs:					
Within–residual	32.91	48	0.69		
Time	2.25	2	1.12	1.64	.205
Symptom Severity					
Wave I	0.36	2	0.18	0.26	.773
Wave III	3.17	2	1.58	2.31	.110
Wave V	3.79	2	1.89	2.76	.073
Participation Preferences:					
Within–residual	8.25	48	0.17		
Time	0.03	2	0.02	0.10	.909
Symptom Severity					
Wave I	0.26	2	0.13	0.76	.474
Wave III	0.22	2	0.11	0.65	.527
Wave V	0.16	2	0.08	0.46	.637
Relationship Satisfaction:					
Within (residual)	8.25	48	0.03		
Time	0.01	2	0.01	0.17	.845
Symptom Severity					
Wave I	0.04	2	0.02	0.51	.603
Wave III	0.30	2	0.15	4.26	.020*
Wave V	0.74	2	0.37	10.64	.000*

Discussion

The limited size of this sample is problematic, limiting the researcher's ability to infer the results to the larger population. However, these findings will provide beginning conclusions upon which to build further research in the area of coping with cancer over

the course of the disease. The sample proved to be small, and fairly homogenous. Variation in age, marital status, education and income was very limited. Information on the patient's race is not available, and might be a worthy factor to include in further studies. In addition, type of cancer and type of treatment might provide further insight into the coping variables. For example, one might wonder if patients receiving chemotherapy perceived higher information needs than those receiving hormonal therapy. Because the sample size in this study was so limited, these factors were not examined independently.

The findings of this study revealed that information needs taper off over time, with the largest drop occurring between three and nine months post–diagnosis (Waves I and III.) These results suggest that patients feel least informed at the early diagnostic and treatment phase of their illness, but that as time goes on, they feel more informed. Scores, however, were low for most patients (the highest group mean, at three months (Wave I), was 1.50, on a 0 to 4 scale.) ANOVA revealed a significant relationship between time and information needs. The alpha coefficient was fairly high (alpha = .71), indicating satisfactory reliability for this subscale.

These data support the hypothesis that information needs are directly affected by time from diagnosis. This is an important finding, for it indicates that one may anticipate and predict that patient's information needs will be most acute early in the diagnostic phase of illness and will diminish over time. This is supported by a majority of the literature on information needs.

Participation preferences, like information needs, dropped between three months

(Wave I) and nine months (Wave III), and then climbed very slightly at fifteen months (Wave V). Standard deviations were slightly smaller than those of the information need means, indicating slightly less variance in responses. ANOVA failed to detect a significant relationship between time and participation preferences (F = 2.49, Significance = .093). Scores were uniformly low, and varied little across time, indicating that few patients felt they weren't able to participate enough. This may indicate that participation preference as a trait is less determined by external events than by psychological make-up and socialization by one's culture. Reliability analysis of this subscale revealed satisfactory reliability (alpha = .82). These findings do not support the hypothesis that time will have a direct effect on participation preferences over time.

Relationship satisfaction mean scores were the lowest of all three dependent variables (group means of .05 to .17, on the 0 to 4 scale), indicating a high level of satisfaction. This may be due to the rather universal phenomenon of patients' reluctance to admit to dissatisfaction with their health care providers. In addition, the alpha coefficient was very low (alpha = .28), indicating poor reliability of this subscale. Group means dipped at nine months (Wave III) and then climbed to their highest level at fifteen months (Wave V), indicating patients were most satisfied at nine months and least at fifteen months. This may be due to diminished contact with health care providers at this stage of the disease, as treatment is likely to have been completed fifteen months post diagnosis.

ANOVA failed to detect a significant relationship between time and relationship satisfaction, thus hypothesis # 1 is not supported.

Only one dependent variable, participation preferences, appeared to be significantly

influenced by a background factor, gender (see tables 9 and 10). The male group mean score at three months was lower then the female mean, indicating that women felt less a part of the decision making process than did men. Both means dropped at nine months. However the male group mean continued to drop off at fifteen months, while the female group mean climbed again. This suggests that while men feel increasingly involved in treatment decisions over time, women perceive higher participation needs, indicating they feel more excluded from decision making early in the disease process, and again at later stages. This supported the work of Degner and Sloan (1992), who found in their study that women with cancer prefer more control in treatment decisions than do men.

Although there were no other statistically significant relationships between the dependent variables and the four demographic factors, the data reveals a number of nonsignificant trends that provide implications for further study. Mean group scores for those under sixty years of age were consistently higher than those of older individuals on all three dependent variables, supporting the findings of previous researchers who found that younger individuals tend to want more information, more participation, and tend to express lower satisfaction scores than older individuals (Degner & Sloan, 1992; Cassileth et al., 1980; Blanchard et al., 1986).

Although a statistically significant relationship was not identified, education also appears to influence the dependent variables. The group means of those with some college education were consistently higher than those with high school education or less, indicating higher information needs, a desire for more participation, and higher dissatisfaction with the health care relationship.

Severity of illness was a concern for this study in that it is difficult to extricate from time as an independent variable. The conceptual model, in addition, represents illness–related factors as important influences on the coping process, and, potentially, on the dependent variables (see Figure 1). Thus symptom severity was considered at each of the three waves, and ANOVA's were computed to evaluate the potential for a confounding effect. The trend in symptom severity was unexpected, and remains difficult to explain. With the high rate of attrition due to morbidity and mortality, it was surprising that, on the average, patients reported lower symptom severity at each wave. In addition, mean severity scores were comparatively low at all three waves (less than 1, on a 0 to 3 scale), indicating patients generally felt their symptoms to be mild.

Only one dependent variable was significantly influenced by the severity of symptoms. The relationship between symptom severity and relationship satisfaction was significant, although only at nine and fifteen months (Waves III and V). It is possible that at initial diagnosis, other factors are more important in predicting satisfaction, but that as symptoms diminish, patients have less contact with the health care setting, producing dissatisfaction with their providers. As mentioned earlier, conclusions are somewhat limited by the poor reliability of the relationship satisfaction subscale.

In summary, three statistically significant relationships are suggested by these findings. First, time may predict cancer patients' needs for information. Patients report feeling more informed as time passes from diagnosis. Secondly, gender may predict patients' participation preferences. Women report higher needs than men both early and late in the disease trajectory, indicating they feel more excluded from decision making

than do men. Lastly, the severity of the patient's illness may predict his or her satisfaction with the health care provider. As symptom severity diminishes over time, satisfaction also decreases.

The data from this study, then, fails to predict several of the relationships that are depicted by the modified version of Moos's (1977) conceptual framework (see Figure 1). It does successfully conceptualize the impact of time on information needs, but not on the other two dependent variables. Figure 2 illustrates the relationships that were established as statistically significant by this study. It is possible that a more effective way to use Moos's model would be to establish and test separate scales for each of the dependent variables. In addition, more extensive demographic data collection might allow the researcher to more thoroughly examine the role of environmental background factors in predicting the dependent variables. However, Moos's model is useful in examining the antecedents to coping and how they change over time. It suggests future direction of study that may illuminate specific factors that better predict participation preferences and relationship satisfaction than does time, such as cultural and social characteristics. Although statistical analysis failed to confirm significant relationships in other areas, several additional trends in the data are worthy of note. In general, women reported higher needs in all three of the dependent variables; they perceived higher unmet information needs, felt more excluded from decision making, and were less satisfied with health care relationships.

Figure 2. Moos's model (1977) (revised): Significant relationships confirmed by this study

Dashed Lines = Statistically
              Significant
              Relationships
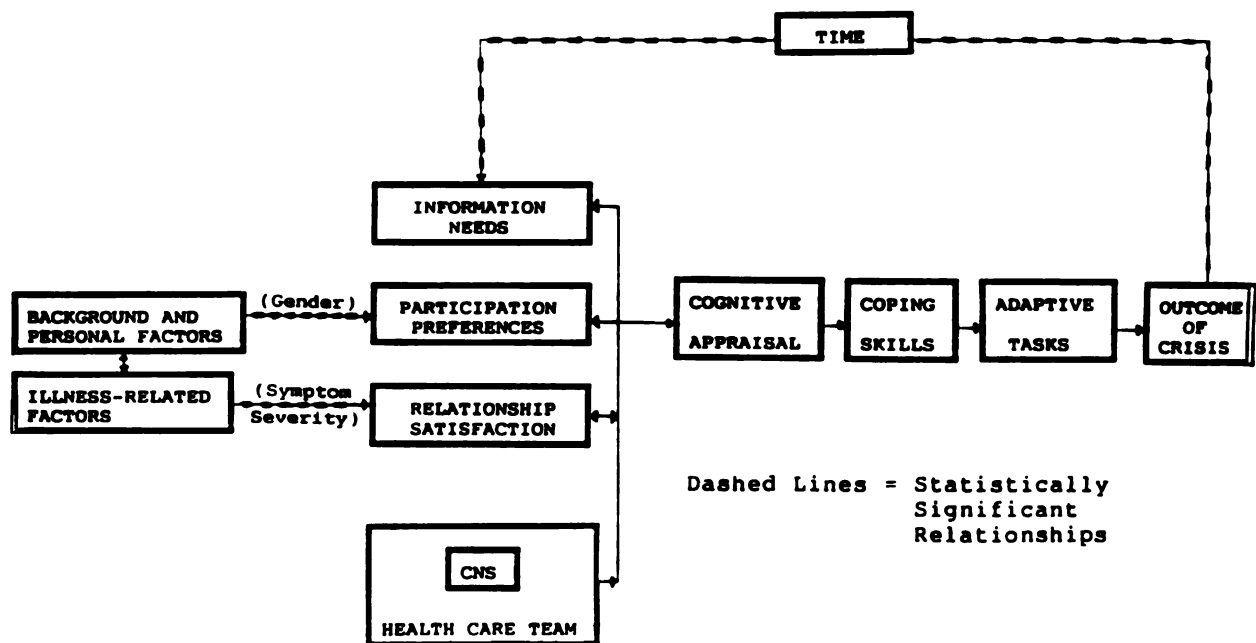
Women also demonstrated higher variability patterns across each time interval than men; men's needs tended to drop at each wave, whereas women's responses dipped and climbed again. Younger patients tended to report higher needs than did their older counterparts, a finding that supports Degner and Sloan's study (1992). In addition, the more highly educated patients generally reported higher needs than those who were less educated.

Implications for Advanced Practice Nursing

This research has a number of implications for the CNS in the primary care setting. Primary care should serve four critical functions (Parker, 1975). First, it serves as an "entry point" for the client into the health care system, from which screening and referrals are initiated. Secondly, primary care provides the client and family with a full range of comprehensive services to maintain health and wellness, and manage common illnesses so as to minimize disability. Third, primary care offers supportive, long-term relationships for clients and families with providers, which are critical during health care transitions and times of acute illness. Lastly, primary care provides coordination and long-term management of available health care services across the life-span and across the health-illness continuum.

The role of the primary care CNS, then, should be to facilitate the above functions. Individuals experiencing the threat or actuality of cancer have a multitude of needs that this professional is uniquely qualified to meet. The CNS functions within the clinician role to provide screening, assessment and physical management to the individual with cancer. Within the educator role, the CNS provides the patient and family with the information and skills they need to maintain self-care and to operate successfully within

the health care setting. As client advocate, the CNS establishes relationships with the client and family that are built upon mutual trust and respect, and that recognize the right to self-determination every individual possesses.

It is not enough to understand the needs of the patient with cancer only at the initial diagnostic phase of illness. Cancer has become a chronic disease, due to medical advances, and patients often deal with the stress of the disease for many years or even over the remainder of their life span. Helping individuals with cancer and their families to cope with the disease across the illness trajectory is increasingly important, as, more and more, long-term survival becomes a reality.

This research explored the issue of how patients cope with cancer over time, with the goal of identifying areas in which the CNS can play an important role in fostering coping. Three behaviors were identified as important antecedents to individual coping from literature review and application of the theoretical framework: seeking information, establishing satisfactory relationships with the health care provider, and participating in treatment decisions. Understanding how patients' needs change in these three areas over time will provide beginning intervention strategies for the CNS.

The findings suggest that the magnitude of patients' information needs is influenced by time from diagnosis. Patients report needing the most information at the early diagnostic phase of the illness, although it must be recognized that reported information needs were very low even at the three month measure. While information needs diminish over time, they do not cease. The CNS can use these findings in practice. Offering the individual and family the opportunity to identify their questions, especially during the

traumatic diagnostic and early treatment phase of illness is critical. Maintaining contact with the patient, even if he or she is being treated in the acute care setting, will help to provide a source of continuity, support and information.

There existed a fair amount of variability in the means of all three dependent variables across the three time intervals. This finding suggests that the CNS cannot assume that individuals who have few needs early in the disease trajectory will continue to experience few needs as time goes on. Needs assessment should be carried out at every visit with the patient, and as the need for office visits decreases over time, assessment and contact should be maintained, perhaps by such other means as letters and telephone calls.

While this study failed to identify a significant relationship between participation preferences and time, it is still useful to note that patients seemed to feel most excluded from the decision-making process early in the illness, indicating that it is especially critical to include the patient at this stage as an active member of the decision-making team. In addition, women, more than men, appear to feel left out of decisions later on in the illness. The CNS can reinforce the patient's right to be an informed decision-maker at all stages of the disease, not only by providing information, but also by assisting with values clarification, identifying individual goals, and reinforcing patients' esteem and confidence as they deal with the often intimidating health care environment.

This research failed to establish a significant interaction between satisfaction with health care relationships and time. However a nonsignificant trend may still be noted across the three waves. Satisfaction appeared to be highest during the "mid-phase" of

illness (nine months post diagnosis). This may be because the patient has already lived through the highly stressful initial diagnostic phase, and has either acclimated to or just completed treatment. It is likely that patients in this stage are still receiving regular follow-up with the health care provider, a factor that may improve patients' satisfaction. As speculated earlier, satisfaction may diminish as contact with the provider tapers off. This has ramifications for the CNS; although patients may be physically stable and even recovering, contact with the health care team remains important to them. The CNS can remain a dependable link with the patient and family, by maintaining follow-up visits and phone calls with the patient and family. In addition, the CNS can prepare the patient and family for the expected ambivalence they may feel as they receive less frequent monitoring over time. Identifying and helping patients to access other resources available in the community may provide additional support.

Severity of the patient's symptoms significantly impacts satisfaction with the health care relationship, especially later in the disease trajectory. This is an especially interesting finding in this group, who described their symptoms as less severe as time went on. This may support the above speculation that patients are less satisfied with their provider as their contact with him or her diminishes. This supports the work of Hydzik (1990) who has described a "conversational isolationism" experienced by cancer survivors, in which they are reluctant to talk about the fears and anxieties of living with cancer because they believe others (including their health care providers) want to "move on". Thus they may have unmet needs that they are not expressing, and, as a result, feel less satisfied with their provider. Patients may also be very fearful of recurrence as time goes

on, and be counting on the health care professional to reassure them. The CNS can assist by helping patients in this phase to take on some self-monitoring tasks to detect early signs of recurrence. This will enhance self-efficacy and decrease the patient's dependence on the provider. The researcher's ability to further interpret these findings is somewhat limited by the fact that this sample did not experience the expected escalating severity of illness, making it difficult to predict how patients' needs change as they become sicker.

Moos's model provides a useful framework for understanding the multitude of factors that impact the coping process. Further work will refine it further. The longitudinal, one-way depiction of coping is limiting, and fails to depict the typical "pendulum" swing of coping, as individual are repeatedly stressed and then able to rally during the normal course of chronic disease.

Implications For Further Research

This study was limited by a small, homogenous sample, and by a subscale with questionable reliability. Future research warrants larger sample size and random design to limit the potential for participation bias.

Time proved to be a difficult variable to isolate. This study was unable to clearly separate the impact of time from other background factors influencing information needs, particpation preferences and satisfaction with health care relationships. Additional measures of severity of illness, as well as of background factors and how they may be altered over time from diagnosis, might yield more clarity and confidence to conclusions that may be drawn using time as the independent variable.

The Treatment-related Demands of Illness Inventory may be most valuable when

used in conjunction with other instruments to further refine its reliability. Its use as a single instrument broken down further into subscales proved to be problematic. With only two items measuring information needs, the sample size required to be truly confident of the results would be quite large. The instrument is too short to effectively measure three isolated concepts; items should be added for each of the concepts to be measured. Further use of this instrument, especially with other diseases will also enhance its usefulness.

The measurement intervals in this study, in retrospect, may also have been problematic. A number of patients may have completed their treatment by the fifteen month measure. Thus treatment related issues may have been less pressing. Information needs may well have remained high, however the instument used measures only those related to treatment. Thus information needs related to other issues may still exist. Future studies might benefit from limiting measurement intervals to closer to diagnosis, so as to capture only those needs related to treatment. Another option would be to alter the instrument so as to capture needs related to issues other than treatment, such as self care, detecting recurrence, monitoring symptoms and reentering the work force.

Satisfaction remained a somewhat muddy concept in this study, especially in maintaining clear definitions. The Treatment-related Demands of Illness Inventory subscale, because it it negatively worded, appears to measure relationship dissatisfaction. An option for future research, rather that to place the concept onto a continuum, might be to alter the wording of the instrument so as to capture patients' degree of satisfaction. This might also yield interesting information on the phenomenon of subjects' reluctance

to express negative feelings about their providers. Would uniformly high satisfaction scores result?

Questions to be addressed by further research include: what is the interaction between information needs, satisfaction and participation warrants further study? Do patients who feel their information needs are met feel more satisfied? And do they participate more? How do these variables impact clinical outcomes? In addition, further research may reveal how the content of patients' information needs change over time. It has been suggested in the cancer survivorship literature that patients need more information about reentering the work force, about insurance and legal issues as time goes on, and less about the daily physical demands of the illness. Further research is needed to pinpoint how these needs change and when.

In addition, the influence of background factors on information needs, satisfaction, and participation should be explored more carefully and the interaction between them examined. For example, do younger women desire more information than older women? Examining the role of particular cancer diagnoses in predicting information needs and participation preferences might provide useful information as well. Larger sample size and random design will strengthen the conclusions that may be drawn, by allowing comparison with healthy cohorts.

<center>Summary</center>

This study has addressed how information needs, relationship satisfaction, and participation preferences, as antecedents to coping, change over time. Trends over a fifteen month period post diagnosis of new or recurrent disease were examined. The

effects of background demographic factors on these antecedents were considered, as well as the potentially confounding effect of severity of patient symptoms.

The significance of the findings are limited by the sample size and sampling method. However ramifications for the CNS in primary care are identified. Strategies for improving the effectiveness of patient teaching, for enhancing the health care relationship with the client and family, and for maximizing the patient's role as an active participant in treatment decisions have been discussed. Further longitudinal research, using random sampling techniques and yielding more diverse samples of subjects will allow greater confidence in interpretation and generalization to the larger target population.

APPENDICES

Appendix A

Conceptual Model of Adaptation to Physical Illnesss, Moos (1977).
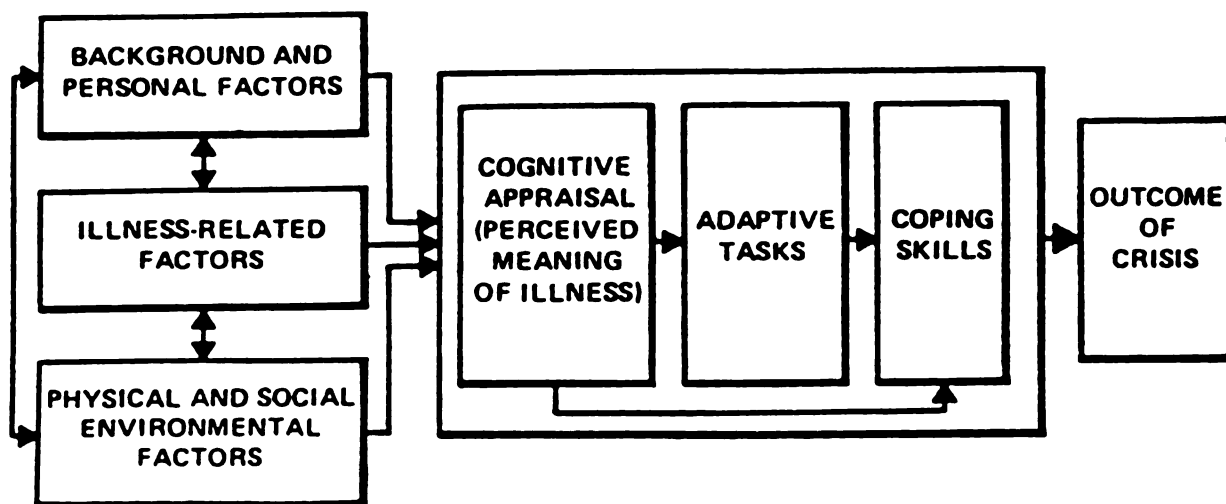
Appendix B

Aims of "Family Homecare for Cancer – A Community Based Model", grant # NR01915

1. To describe over seven observation periods caregivers' and patients' physical and mental health states.

2. To describe over seven observation periods caregivers' and patients' and others' involvement in tasks of caregiving and symptom management.

3. To describe over seven observation periods the formal assistances utilized and social supports available to caregivers of patients with cancer.

4. To determine how the physical and mental health states of newly diagnosed and patients with recurrence/metastases, and work/social roles influence caregivers' mental health states and their physical and mental health outcomes and reactions to caregiving.

5. To determine how the levels and stability of caregiver involvement in tasks and symptom management interacts with caregivers' mental health states leading to caregivers' outcomes and reactions to caregiving.

6. To determine the conditions (patient physical health, caregiver mental health, caregiver involvement and caregiver work/social roles) under which formal assistance and social support may modify caregiver outcomes.

7. To determine the interaction among conditions (i.e. patient physical, mental health states, and caregiver mental health states) under which levels of caregiver involvement, formal assistance and support are related to caregiver outcomes and reactions to caregiving.

CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which cancer affects the individual with cancer. Over the next 18 months, individuals will be asked to complete a questionnaire about your health status and symptoms. Each questionnaire will take approximately 20 minutes to complete. If you are willing to participate in the study, please read and sign the following statement.

1. I have freely consented to take part in a study of caregivers conducted by the College of Nursing and Department of Family Practice, College of Human Medicine, Michigan State University.

2. The study has been described to me and I understand what my participation will involve.

3. I understand that participation in this study is voluntary.

4. I understand that I can withdraw from the study at any time after originally agreeing to participate, and that withdrawal from the study will not affect the regular health care that I receive.

5. I understand that the results of the study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that, within these restrictions, results of the study will be made available upon request.

6. I understand that no immediate benefits will result from taking part in this study, but am aware that my responses may add to the understanding of health care professionals.

I, _____, state that I understand what is required of me as a participant and agree to take part in this study.

Signed _____ Date_____

Appendix D

INSTRUMENT

DEMANDS OF ILLNESS INVENTORY

Below is a list of events and thoughts that some individuals with cancer experience when facing a health problem like cancer. Please read each item carefully and indicate the extent to which you have experienced the following problem in relation to your cancer or treatment during the last three months.

0= NOT AT ALL
1= A LITTLE
2= MODERATELY
3= QUITE A BIT
4= EXTREMELY

At times, some of my health care providers have:

1. been insensitive to my preference for treatment. 0 1 2 3 4 __ 64

2. acted as if my opinions were unimportant. 0 1 2 3 4 __ 65

3. made decisions without my best interests in mind. 0 1 2 3 4 __ 66

4. not told me the truth about changes in my health. 0 1 2 3 4 __ 67

5. not shown concern for me as a person. 0 1 2 3 4 __ 68

6. not thoroughly explained my health status to me. 0 1 2 3 4 __ 69

As I've experienced my illness situation, I've:

7. wanted more facts about the treatments. 0 1 2 3 4 __ 70

8. had questions that I wanted to ask but just couldn't 0 1 2 3 4 __ 71

9. felt rushed to make a hasty treatment decision 0 1 2 3 4 __ 72

10. wanted to be more assertive about the direction my treatment should take. 0 1 2 3 4 __ 73

11. wanted to be told the reason why, when asked to do something for treatment. 0 1 2 3 4 __ 74

12. realized I was initially unclear about the treatment
    I would receive.   0 1 2 3 4
                                                                       $\overline{75}$

13. been dissatisfied with the progress of my treatment. 0 1 2 3 4
                                                                       $\overline{76}$

14. been dissatisfied with my medical care.   0 1 2 3 4
                                                                       $\overline{77}$

15. felt my illness was incorrectly managed.   0 1 2 3 4
                                                                       $\overline{78}$

16. worried my illness may be incorrectly managed in
    the future.   0 1 2 3 4
                                                                       $\overline{79}$

Appendix E

U.C.R.H.I.S. Approval

MICHIGAN STATE
U N I V E R S I T Y

August 23, 1993

TO: Dana Berry-Richardson
       2549 Cinnamon Ridge
       Howell, MI 48843

RE: IRB #: 93-364
       TITLE: INFORMATION NEEDS, PARTICIPATION PREFERENCES AND
               SATISFACTION WITH HEALTH CARE RELATIONSHIPS: HOW THEY
               CHANGE OVER THE COURSE OF ILLNESS
       REVISION REQUESTED: N/A
       CATEGORY: 1-E
       APPROVAL DATE: August 23, 1993

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

Renewal: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the enclosed form to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

Revisions: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the enclosed form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable. the year, please outline the proposed revisions in a letter to the Committee.

Problems/
Changes: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517) 355-2180 or FAX (517) 336-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

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